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Rehabilitation of Ventilator-Dependent Subjects with Lung Diseases*

The Concept and Initial Experience

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Sixteen ventilator-dependent patients were enrolled in an in-patient pulmonary rehabilitation (PR) program in a university medical center with the goals of achieving independent self-care, mobility and discharge home. Ten patients had chronic obstructive pulmonary disease and six had restrictive respiratory disorders. PR by a multidisciplinary team consisted of five phases: 1) stabilization; 2) evaluation; 3) rehabilitation planning including motivation by allowing speech and mobility; 4) rehabilitation training encouraging independent performance of activities of daily living (ADL); and 5) discharge planning with training of patients and families in home respiratory care techniques. A key aspect of the program is improving independence early in the program through the use of mobile ventilators. Periods of weaning from ventilatory support for two or more hours per day were of great importance in improving patient mobility and independence in ADL. Twelve patients were discharged home; except for two individuals who were severely limited by neuromuscular disease, all patients were largely independent in ADL in the home. This preliminary report demonstrates the feasibility of training ventilator-dependent persons to be independent and to participate in their own care in the home.

Over the past two decades, the application of advanced technology to the care of patients with respiratory disease has improved survival in acute respiratory failure.[1] However, a considerable number of patients treated for exacerbations of chronic lung disease fail to be weaned from mechanical ventilation, even after prolonged attempts. These persons are often placed on general medical floors of acute care hospitals for prolonged periods of time or are transferred to chronic care facilities. Their world is limited to the area described by the radius of their ventilator tubing. They rarely leave the confines of their hospital room, never go outside the institution, become dependent upon hospital staff for their care, and virtually cease social and recreational activities. The social and economic loss to society is compounded by the financial drain of chronic institutional care.

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We have established a unit for the rehabilitation of ventilator-dependent patients in the belief that if we could successfully apply the principles of musculoskeletal and pulmonary rehabilitation[2-5] to this group of patients, it should be possible for them to become more responsible for their own care, more mobile and more functional in activities of daily living (ADL). Ideally, many of these persons could be discharged to their homes, and in addition to improving the quality of their lives, the cost of their care could be markedly reduced. This report provides an overview of our methods and summarizes the results in our first 16 consecutive discharges, with a minimum of one year of follow-up.

Methods

In January, 1981, an inpatient unit devoted to the rehabilitation of ventilator-dependent persons and called the Respiratory Care Center (RCC), opened at University Hospital, Boston, MA. The unit is located on a floor dedicated to the rehabilitation of patients with neurologic and musculoskeletal conditions. This floor is equipped with wheelchair roll-in showers and bathrooms, a physical therapy exercise room, a recreation room, an occupational therapy training facility with a kitchen and video-tape replay facilities; its corridors are equipped with hand rails. In addition to having the expected complement of physical and occupational therapists, social workers, respiratory therapists and psychologists, all nurses are specially trained and experienced in the discipline of rehabilitation.

The RCC is co-directed by a pulmonary physician and a respiratory nurse specialist. A psychiatrist acts in a liaison role with patients and the staff. Physicians specializing in rehabilitation medicine, clinical nutrition and otolaryngology are consulted on most patients. In-service training provides for interchange of expertise in respiratory care and rehabilitation among the members of the team.

Patient Intake

Patients referred to the unit are screened by the unit co-directors after a family visit to the RCC allows the nurse and social worker to assess the family. A physical and occupational therapy evaluation devised by RCC personnel is completed by the staff of the referring hospital. Once all evaluations are complete, the RCC team meets to review the patient's potential for successfully meeting the goals of the RCC and decides on the suitability of the patient for admission to the

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unit. Criteria for admission are a stable medical condition not requiring intensive medical and nursing care, the absence of conditions other than lung disease that limit life expectancy to less than five years, a physically and psychologically supportive family willing to aid in home care, and patient willingness to participate in the program.

Patients admitted to the RCC proceed through five phases of the rehabilitation program: stabilization, evaluation, rehabilitation planning, rehabilitation training and discharge.

Stabilization

Following transfer to the RCC, the patient's preadmission schedule is re-created as closely as possible to allow the patient to gain confidence in the staff and to adjust to the new environment. A system of primary care nursing enhances the development of rapport with RCC staff. The primary nurse acts as a patient advocate in weekly team meetings held to discuss patient progress and rehabilitation plans and takes the main responsibility for coordinating patient interactions with other team members.

Adjustments are made on mechanical ventilator settings to achieve adequate ventilation ($PaCO_2$ of 50-55 mm Hg) and oxygenation (PaO_2 >60 mm Hg at rest and during activity). The rate of ventilator-delivered breaths is set at 8 or more per minute to improve patient comfort and decrease energy expenditure for breathing, thereby allowing increased ability to perform nonrespiratory activities.

Evaluation

RCC staff and consultants perform baseline evaluations during this phase to allow planning of an individualized rehabilitation program for the patient and subsequent assessment of patient improvement. RCC team members assess upper and lower extremity strength and endurance, ADL performance, social and home situation and leisure time interests. Necessary medical consultations, tests and procedures are performed during this period so that they will not interfere with the rehabilitation process which follows. Neuropsychological test results and psychiatric consultation aid the staff in planning the best methods of teaching patients the skills and knowledge necessary for home care. Behavior modification techniques are developed to meet the needs of each individual.

Rehabilitation Planning

The patient and family are engaged by the staff and together they set long-range goals, including discharge home. From these long-range goals, short-term goals are developed by the patient and staff. Motivation of the patient is an important part of this phase and is aided by realistic, readily-achievable, short-term goals and providing staff feedback to the patient as goals are successfully accomplished. Motivation is further enhanced by allowing the patient to speak and be mobile. Speech is allowed by partially deflating the tracheostomy cuff and simultaneously increasing the tidal volume delivered by the mechanical ventilator so that the patient may talk during ventilator-delivered inspirations.[6] Mobility is provided as early as possible through the use of mobile ventilators.

We use the term "mobile ventilators" to refer to small mechanical ventilators mounted on motorized wheelchairs; these units are self-contained, self-powered, and include sufficient oxygen and suction equipment to allow mobility for up to three hours. The most appropriate mobile ventilator for each patient is chosen, depending on the individual's pulmonary mechanics and oxygen requirements. The LP-3 and LP-4 (Life Products Co, Boulder, Colorado), IC-2 (Bio-Med Devices, Stamford, Connecticut), and a sophisticated, custom-designed prototype ventilator have been successfully mounted on motorized wheelchairs in several different configurations.

The battery powered LP-3 and LP-4 units have generally proved adequate for patients with restrictive pulmonary disorders (*eg*, neuromuscular disease, kyphoscoliosis), but have not always proven satisfactory for patients with chronic obstructive pulmonary disease (COPD) who require supplemental oxygen, long expiratory times and a variable respiratory rate. The gas-powered Bio-Med machine was chosen because of its small size, versatility and ability to ventilate patients with airways obstruction.

Figure 1 shows one of our mobile ventilators incorporating the Bio-Med ventilator, oxygen blender (Medical Products Division, 3M Corp, St Paul, MN), four tanks of compressed air, two tanks of oxygen, and battery powered suction machine (Laerdal Safety Labs, Baywood Park, CA) mounted behind the seat of a motorized wheelchair (Everest and Jennings, Camarillo, CA). Moving the wheelchair batteries forward counterbalances the weight of the gas tanks. The tank carrier tilts backward to facilitate cylinder changes. Custom made high pressure tubing connects the gas tanks in parallel; tanks are connected in pairs with one pressure gauge and regulator for each pair to simplify the apparatus. Although mobile ventilators are an important part of the inpatient rehabilitation program, they are infrequently required at home because some patient mobility without ventilator support has been attained by most patients.

Other important goals of the rehabilitation planning phase are to reduce patient anxiety and allow individuals to control their dyspnea. Anxiety about the RCC environment, personnel and program are allayed by staff reassurance. Specific relaxation techniques, including imagery and audio tapes, are often employed. Patients are taught the factors likely to precipitate dyspneic episodes, how to recognize such situations early, how to treat the underlying factors by themselves, and finally, how to prevent dyspnea. For example, because of the importance of retained tracheobronchial secretions as a cause of increased airways obstruction, patients are taught how to recognize a buildup of secretions prior to the onset of dyspnea and how to suction themselves.

Throughout the rehabilitation process, patients and families are

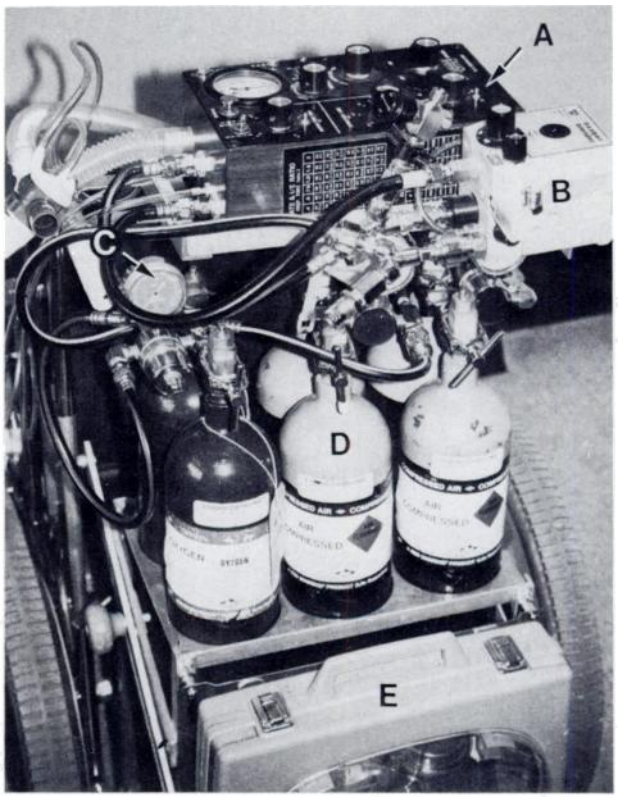

FIGURE 1. Mobile ventilator. A Bio-Med IC-2 ventilator mounted on a motorized Everest and Jennings wheelchair is used to increase patient mobility and thereby motivation. A—ventilator; B—oxygen blender; C—pressure regulator; D—compressed gas tanks; E—portable suction unit (see text for details).

taught respiratory anatomy and physiology, are informed about the patient's lung disease and are taught the techniques necessary for self-care. A set of comprehensive patient learning objectives guides the staff in providing patient education.

Weaning

Complete weaning from ventilatory support is not the primary goal of rehabilitation, but one of the major lessons of this program has been the great utility to patients for periods as short as two hours off the ventilator for mobility and independence in ADL. Weaning is attempted on all ventilator-dependent persons, once they have regained sufficient strength and endurance (as judged by ability to transfer independently from bed to chair, sit in a chair for most of the day, wash independently at the bedside and walk at least 100 feet with ventilatory support), and have an adequate nutritional state (*ie*, gain of most of the weight lost during hospitalization prior to RCC admission and sufficient oral caloric intake to maintain weight stability). Patients are removed from all ventilatory support for increasing periods of time with appropriate increase in inspired O_2 concentration; the technique of weaning by decreasing the rate of intermittent mandatory ventilation is not used. Patients are taught to return promptly to mechanical ventilation when they become dyspneic or fatigued. The weaning process is monitored by arterial blood gases and clinical parameters (pulse, blood pressure, respiratory rate, tidal volume, diaphoresis, skin color, fatigue, and subjective assessment of work of breathing). Weaning is terminated if there is respiratory acidosis (Po_2 <7.30), hypoxia (Po_2 <50) or significant change in other monitored parameters. Once patients can be without mechanical ventilation for more than one to two hours, they begin to perform activities, such as eating, washing, dressing, toileting or walking, with progressively increasing metabolic requirements. Thus, the purpose of weaning is focused not on permanently removing the patient from the ventilator, but on improving the patient's capacity for independent ADL, mobility and leisure time activities.

Rehabilitation Training

Retraining the patient to perform ADL independently is accomplished by nurses, physical therapists and occupational therapists. Each team member is guided by written general protocols. Physical therapists concentrate on improving lower extremity strength and endurance, while occupational therapists stress energy conservation and concentrate on upper extremity activities such as washing and dressing. Patients walk early in the program while receiving oxygen and mechanical ventilation, or inspirations from a manual resuscitator. Most patients are able to progress to the point where they tolerate exercise on a stationary bicycle (Fig 2). ADL such as washing and using the toilet are performed in the bathroom, with continued mechanical assistance to ventilation. With improved mobility, speech and endurance, patients are encouraged to increase their recreational and social activities in the hospital.

Discharge Planning

During the discharge planning phase, patients and families are taught the skills required for independent home care, such as suctioning, tracheostomy care, the use of supplemental oxygen, chest physical therapy and ventilator care. Home support services including homemakers, home health aids, visiting nurses, and respiratory therapists are integrated into discharge planning to allow a smooth transition to the home. The simplest, least costly method of providing ventilatory support in the home is chosen, based upon each patient's lung disease, oxygen and ventilatory requirements. Oxygen, ventilators, and other respiratory equipment are provided and maintained in the home by an independent respiratory home care company chosen on the basis of well-defined criteria for routine and emergency services provided by respiratory therapists and equipment support. A visit to the patient's home is made by RCC personnel prior to discharge and appropriate modifications are arranged. Prior to final discharge, patients spend one or more half days and then an overnight visit at home to practice techniques learned in the hospital. Follow-up care is provided by RCC pulmonary physicians and respiratory nurse specialist through home and office visits. Our approach to making a smooth transition from hospital to home for these patients has been reviewed.[7]

Discharge Status

Patients are characterized according to the number of hours of free time from mechanical ventilation and independence in ADL. The latter is graded on a 4-point scale: maximal (independently performing personal care and ambulation), moderate (requiring aid only for selected activities such as meal preparation and showering), minimal (requiring assistance to organize materials for personal care and to travel away from the bedside) or none (requiring complete or almost complete assistance from others in all aspects of care).

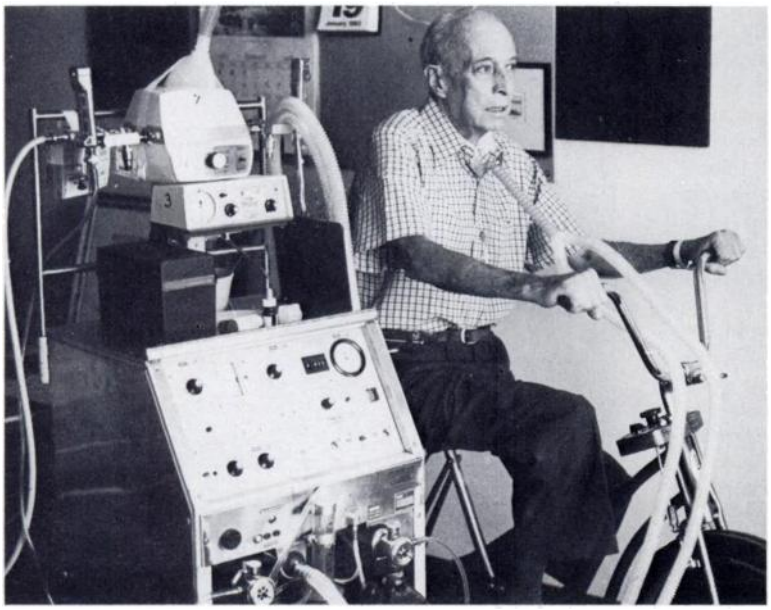

FIGURE 2. Ventilator-dependent patient with COPD exercising on a stationary bicycle as part of the rehabilitation program.

Table 1—*Characteristics of Patients Admitted for Rehabilitation*

Patients	Age/Sex	Diagnosis	Consecutive Acute-Care Days Prior to Admission	Rehabilitation Period (days)
Group 1—COPD				
1	60 M	Emphysema	287	219
2	56 F	Emphysema, asthma	98	119
3	54 M	Emphysema	180	99
4	54 M	Bullous emphysema	65	155
5	71 M	Emphysema	56	158
6	61 M	Emphysema	79	57
7	59 F	Emphysema	386	126
8	64 F	Emphysema	170	157
9	64 F	Emphysema	117	118
10	55 F	Emphysema	38	124
Mean, group 1	60		148	133
Group 2—Restrictive Disorders				
11A	33 F	Limb girdle dystrophy	0	51
11B*	34		0	66
12	58 M	Polio	111	182
13	61 M	Kyphoscoliosis	150	70
14A	61 F	Thoracoplasty	31	14
14B*	62		14	34
15	66 M	Polio, unilateral diaphragm paralysis	35	93
16	47 F	Limb girdle dystrophy	0	41
Mean, group 2	53		43	69

*Patients 11B and 14B were admitted on two occasions separated by 180 and 220 days respectively.

Results

Patient Characteristics

Sixteen ventilator-dependent patients (Table 1) were discharged from the RCC from its inception in January 1981, through November, 1982; two patients were admitted twice during this period. The patients were divided into two groups based upon the nature of their pulmonary disease: group 1 with COPD, and group 2 with restrictive disorders.

The ten patients in group 1 had been hospitalized in other acute care settings for an average of 148 days prior to admission to the rehabilitation program. Several patients (patients 4, 9, 10) had repeated lengthy hospitalizations for respiratory failure during the 6-12 months before becoming ventilator-dependent; this is not reflected in the number of consecutive days of acute hospital care just prior to rehabilitation. The predomi-

Table 2—*Outcome of Rehabilitation in Ventilator-Dependent Patients*

Patient	Independence in Activities of Daily Living*	Location after Discharge	Time Off Ventilator (hrs/day)	Ventilator Type†	Home Follow-up (months)‡
Group 1—COPD					
1	Minimal	Expired	0	E	—
2	Moderate	Home	8	E	28.5
3	None	Chronic hospital	1	E	—
4	Maximal	Home	12	E	18.5
5	Minimal	Expired	1	E	—
6	None	Expired	0	E	—
7	Moderate	Home	8	E	18
8	Moderate	Home	2	M, L	17.5
9	Maximal	Home	14	E	12
10	Moderate	Home	8	E	12.5
Group 2—Restrictive Diseases					
11A	None	Long-term care facility§	13	PN	6
11B	None	Long-term care facility§	0	PN, PW	13
12	None	Home	0	E, L	12
13	Maximal	Home	15	L	25.5
14A	Maximal	Home	24	None	7
14B	Maximal	Home	13	L	12.5
15	Maximal	Home	14	L	15
16	Moderate	Home	3	PN	14

*Maximal—performs own self-care.
Moderate—performs own personal care except for showering, meal preparation.
Minimal—can wash, dress and eat at bedside once materials are set up. Cannot travel alone away from bedside.
None—needs complete assistance with almost all personal care.
†M = Bennett MA-1; E = Emerson IMV; PN = Pneumobelt; L = LP-3 or LP-4 (Life Products Co.); PW = Pulmo-wrap (J.H. Emerson).
‡Length of time followed-up at home (as of November 1, 1983). All patients discharged home are still alive, except for patient 12 who died at home 12 months after discharge.
§Patient returned to long-term care facility where she had previously resided.

nant lung disease in group 1 patients was emphysema; the mean age was 60 years and their mean stay in the RCC was 133 days. On admission to the RCC, all patients in group 1 had hypercapnia while receiving mechanical ventilation and required supplemental oxygen administration. Ventilatory support had been instituted for progressive respiratory acidosis in all patients.

The mean age of the six patients in group 2 was 53 years, similar to that of group 1. These patients averaged only 43 consecutive acute-care days prior to admission, less than one-third the number experienced by group 1 discharges; their mean rehabilitation period was 69 days or about half the mean duration of group 1 subjects. Their restrictive disorders were all due to neuro-musculo-skeletal chest wall defects.

Outcome

Outcome data are summarized in Table 2 and will be discussed under several headings. Outcome was not related to arterial blood gas levels, alveolar-arterial oxygen gradient or cardiac disease (cor pulmonale, left-sided heart failure or arrhythmias). Outcome was not related to patient or family psychosocial information obtained prior to RCC admission.

Weaning: None of group 1 patients was able to be weaned totally from ventilatory support. However, all patients who were successfully rehabilitated and discharged home had some free time (2 to 14 hours per day) from the ventilator. During periods of spontaneous ventilation, all patients required oxygen via nasal prongs and most were able to speak with fenestrated tracheostomy tubes. Mobility and independence were greatly enhanced by ventilator-free time, which allowed trips outside the home to go shopping, to the hairdresser (patient 2), restaurants, to attend college-level courses (patient 12), and to visit neighbors (patient 9) and family (patient 10). Group 2 patients had more success in weaning; one patient was totally weaned from the ventilator and four others were weaned for 13 or more hours each day.

Functional outcome: The ability of patients to be independent in ADL such as eating, washing, dressing, toileting, suctioning and performing tracheostomy care at the time of discharge from the RCC varied (Table 2). Four patients with COPD were minimally independent or totally dependent in ADL. These patients were limited in ADL performance by extreme dyspnea despite mechanical ventilation; severe anxiety demonstrated by all patients was considered to be secondary to their dyspnea. Two patients (patients 11 and 12) with neurologic disorders were unable to be independent in ADL due to extremely limited neuromuscular function. However, both of these patients moved about extensively with the use of mobile ventilators; one individual (patient 12) carried on a business from his home and enrolled in a college calculus course, but required attendants to perform all his personal care.

Location after discharge: Eleven patients were discharged to their own home; one additional individual (patient 11) with limb girdle dystrophy was discharged to the long-term care facility where she had resided for five years prior to hospitalization. One person (patient 3) who was not successful in achieving the rehabilitation goals was electively transferred to a chronic care hospital. Although this patient's wife expressed a desire to aid in rehabilitation prior to RCC admission, she never visited the patient in the RCC and was suspected of being an alcoholic only after the patient was admitted to the RCC. Only one man with COPD was discharged home. Our impression is that men are less successful in accepting ventilator and physical dependence and loss of social role as provider for the family than women. The men who have not been discharged were unwilling to have their wives and others aid in their home care.

Three COPD patients expired suddenly in the hospital of uncertain causes. Analysis of the patients who died (patients 1, 5, 6) revealed that all had extreme degrees of dyspnea, were men, were unable to wean from the ventilator for even brief periods, and were unsuccessful in meeting the general goals of the rehabilitation program; death occurred only after it had become clear to patients and staff that patient independence and transfer to their homes was not feasible. None of the patients who died had demonstrated unstable cardiac rhythms in the 48 hours prior to death. Ventilator disconnection and malfunction were not causes of death in these patients. One individual (patient 1, described below) decided not to be resuscitated; it was elected not to treat gradually increasing hypercapnia ($PaCO_2 > 90$) and respiratory acidosis. Patient 5 was monitored in the coronary care unit for two days after becoming pulseless for 15 seconds following suctioning for excessive, noninfected tracheobronchial secretions. Spontaneous return of a pulse was followed by multifocal atrial tachycardia with a heart rate of 120 per minute which resolved spontaneously. No further arrhythmia was noted during monitoring; there was no evidence of acute myocardial infarction. The patient returned to the rehabilitation unit and 24 hours later was found to be unresponsive, cyanotic and without a pulse. Resuscitative efforts were unsuccessful. Patient 6 was afebrile, but developed cellulitis of the foot treated with intravenous antibiotics 24 hours prior to being found unresponsive. Resuscitative efforts were unsuccessful. Although continuous cardiac monitoring might have led to different outcomes in patients 5 and 6, these patients were not felt to be unstable prior to

death and were no more ill than other individuals cared for in the RCC. Episodes of tracheobronchitis and mild congestive heart failure in patients who are otherwise hemodynamically stable are often treated successfully in the RCC and do not require the facilities of an intensive care unit.

All patients discharged from the RCC have been followed-up at home for at least one year (Table 2). Although many patients were treated at home for minor respiratory infections, each of the COPD patients discharged after initial rehabilitation has required at least one readmission to the hospital for exacerbation of the pulmonary disease and many have been readmitted for management of nonrespiratory disorders. Two patients with restrictive disorders (patients 11 and 14) have required readmission for increasing respiratory failure requiring additional ventilatory support.

Costs: Third party payers (Blue Cross, Medicaid, Medicare, and private insurance companies) accepted the concept of home care for ventilator-dependent persons and funded most outpatient care. The monthly rental of volume ventilators, oxygen blenders, routine preventive and emergency maintenance, services of respiratory nurse/therapists for both routine and emergency home visits, and rental of a manual resuscitator and air compressor were covered. The amount of oxygen used is variable, but in most cases is fairly high due to the use of the mechanical ventilator. We routinely teach our patients to use and clean nondisposable ventilator tubing and suction catheters. However, because of the burden of outpatient care, many families find cleaning suction catheters a very time-consuming chore and choose to utilize disposable catheters. Some patients do not require home health aides due to the presence and support of family members who are available most of the day. Other individuals with more limited function and working families require home health aides for one-two hours each day. Similarly, the need for visiting nurses varies from weekly to monthly. None of our patients with COPD required daily nursing care.

Case studies: A review of the first two patients with COPD and the first patient with neuromuscular disease admitted to the RCC highlights both the successful and unsuccessful outcomes of individuals discharged from the unit.

Patient 1 was the first patient admitted to the RCC on January 6, 1981. This 60-year-old man was transferred from a large urban teaching hospital in the greater Boston area where he had been admitted over nine months earlier for increasing dyspnea, fatigue and weight loss due to an exacerbation of his COPD. He could not be weaned from mechanical ventilation following surgery on June 1 for a perforated sigmoid diverticulum and was transferred to a general medical floor on August 1, where weaning attempts continued. His course was complicated by a necrotizing Gram-negative pneumonia and by pulmonary emboli treated with an inferior vena caval umbrella. Before admission to the RCC his activity was limited to moving from the bed to a chair once daily to allow his sheets to be changed; this activity required premedication with morphine to control what the staff felt was undue anxiety. The patient did not eat because food had "no taste" and he was being fed via gastrostomy tube. The patient's wife was very caring and devoted, but overly anxious. She assumed responsibility for a large portion of his personal care when she visited from 2 to 8 PM daily.

Before transfer, a contract was developed between the patient and the RCC team outlining the expectations and responsibilities of each party. After rehabilitation, the patient fed himself, sat in a chair all day without premedication, and intermittently performed his own tracheostomy care, suctioning and bathing at bedside. Although his anxiety level was markedly reduced, he was unable to progress further due to dyspnea. The family members became quite adept at caring for the patient including ventilator care, suctioning and other aspects of daily living. The patient, however, felt that home care would place an undue burden on his wife and a 40-year-old son living at home, and would require extensive aid from other home care professionals. He and his wife, with the support of the RCC staff, finally decided that the physical and emotional stress of home care would be extreme and should not be undertaken. The patient gradually deteriorated after home care was felt to be impossible, and after the patient decided not to be resuscitated. Toward the end of the hospital stay, the patient and family accepted death as an alternative to institutionalization.

Patient 2, a 61-year-old woman with COPD, was admitted to the RCC on March 16, 1981. She was transferred from a community hospital where she had been admitted three months before with an upper respiratory tract infection leading to respiratory failure requiring mechanical ventilation. Her course had been complicated by a long-standing seizure disorder and a myocardial infarction with hypotension. She could not be weaned from the ventilator, but was able to wash at the bedside and feed herself prior to transfer. During rehabilitation, the patient's strength and endurance improved so that she was able to wash in the bathroom, dress, use the toilet and perform her own tracheostomy care and suctioning independently and on her own initiative. She took frequent walks in the hall and exercised on a stationary bicycle Once her strength and endurance were improved, weaning was initiated, using short periods off the ventilator with oxygen supplementation. She progressed to periods of up to six hours off the ventilator. Since discharge she has

maintained her independence in her home and often travels from her home to the hairdresser and goes for walks in her neighborhood. She does light housekeeping, vacuum cleaning and light meal preparation. Home health aid is provided through the local visiting nurse association for about one hour daily to help the patient cook dinner for her family, clean equipment and perform chest physical therapy. She has been readmitted for seizures and bronchospasm requiring treatment with steroids, but has otherwise done very well at home since her initial RCC discharge 20 months ago.

Patient 12, a 58-year-old man with quadriplegia resulting from polio at a young age, was transferred to the RCC from a Veterans Administration hospital where he had been a patient for almost four months. He presented initially to that hospital with bilateral pneumonia and respiratory failure necessitating mechanical ventilation with a volume ventilator from which he could not be weaned. Prior to hospitalization, he ran his own business from his home and was mobile using a motorized wheelchair and a specially equipped van, but required a chest cuirass for nocturnal respiratory assistance. During rehabilitation in the RCC, he regained the limited muscle strength he had had prior to hospitalization. He was again able to sit all day and use the controls on his motorized wheelchair, which was adapted to carry an LP-4 ventilator. Despite improvements in strength, endurance and nutrition, he was unable to wean from the ventilator for more than 20-30 minutes at a time. Speech utilizing this ventilator and partial deflation of the cuff on his tracheostomy tube was excellent and allowed him to carry on his business over the telephone from his home. His wife was taught suctioning and ventilator care, but she died of a myocardial infarction while in a restaurant with her husband one week after the patient's hospital discharge. The patient was then readmitted for one week to enable him to hire 24-hour-a-day personal care attendants. He trained these persons to perform his personal and respiratory care at home, and he enrolled in college and took courses at night while using his mobile ventilator. He died suddenly at home one year after his RCC discharge. Permission for postmortem examination was denied.

Discussion

Our experience indicates that not only can ventilator-dependent persons be discharged from the hospital and cared for in their homes, but also that these individuals can be mobile, functional, and retain a good deal of independence. Although it is well known that patients with neuromuscular and chest wall diseases can successfully receive ventilatory support in the home,[8] there has been mixed success in the home care of ventilator-dependent persons with COPD. Sivak et al[8] reported sending four patients with amyotrophic lateral sclerosis and six patients with other restrictive disorders home on mechanical ventilators, but suggested that COPD is a "relative contraindication" to home care.[9] Dull and Sadoul[10] in France retrospectively reviewed the records of seven patients with COPD sent home on ventilator treatment and suggested that their quality of life was not improved. Although mechanical ventilation resulted in decreased respiratory acidosis, there was no reduction in hospitalization after initiating home care. Another French group reported that ventilator-dependent patients with restrictive disorders managed at home had significantly higher survival rates and a better quality of life than persons with obstructive disease.[11] Although home ventilation in COPD patients was felt to probably provide a lower mortality and improved life, the course of the underlying disease was not altered.[12] Fischer and Prentice[13] recently reviewed 29 selected patients (14 with obstructive lung disease) discharged on mechanical ventilators and found a reduction in hospitalization requirements after home care was begun. Feldman and Tuteur[14] reported a single patient with bronchiectasis discharged on home mechanical ventilation.

Our results indicate that six of ten selected ventilator-dependent patients with COPD and all eight with restrictive disorders were able to be discharged home. Two factors, lack of family support, and severe dyspnea which limited activities and which was not improved by adjustment of ventilator settings, were associated with failure to discharge several of our patients.

Other investigators have not commented extensively on the level of independence or activities of daily living performed by patients receiving mechanical ventilation. Many patients with neuromuscular disorders have maintained some mobility, function and independence despite ventilator dependence, probably because the medical community has long recognized the need to provide not only medical care but also an overall rehabilitation program for such individuals. While pulmonary rehabilitation has become an accepted practice for ambulatory patients with COPD,[4] the principles of rehabilitation have not generally been applied to ventilator-dependent persons with COPD. In the 22 ventilator-dependent patients with COPD receiving home care, reported in the English language, patient functional ability and independence have not been reported extensively. No comment was made on the function of the seven patients reported by Dull and Sadoul.[10] A patient with bronchiectasis reported by Feldman and Tuteur[14] was able to write letters and watch TV, but required 24-hour-a-day private-duty nurses, probably to perform respiratory care such as suctioning and ventilator monitoring.

Fisher and Prentice reported the activity status of only six of their 14 patients with COPD; one patient was confined to bed, two were housebound, one was occasionally able to travel outside the house, and two were "independent during the day."[13] None of these reported programs focused on rehabilitation, and their primary goal was the reduction of the direct costs of medical care. Our program was begun with the dual goal of rehabilitation and home care, a goal achieved by the majority of our patients despite their continued need for ventilatory assistance. We believe that the psychologic benefit to the patient and family living together at home and the feelings of independence in patients who have some control over their lives argue strongly in favor of such a program.

The ability of patients to perform their own care greatly affects the cost of outpatient care. In some patients reported by Sivak et al,[8] Feldman and Tuteur,[14] and Banaszak et al,[15] monthly home care costs were $5,000 to $12,000 because of the requirements for skilled medical personnel, such as nurses on a daily basis. Although we have not yet analyzed the indirect costs of home care including the family's participation, many of our patients (Nos 2, 4, 7, 13 and 16) had working spouses and thus the indirect costs of home care probably do not substantially influence the cost-benefit ratio of home care. It is important to emphasize that many of our patients are self-sufficient, a goal of our rehabilitation program. The type of ventilator required by the patient is a second important factor in the cost of home care. Large, volume ventilators used in acute care hospitals are very expensive, but may be required to adequately ventilate patients with severe obstructive or interstitial lung disease. Small, portable ventilators are less costly. The amount of oxygen required and the mechanism by which oxygen is delivered can escalate home care costs. Our results are in general agreement with those of other investigators[8,13-16] who have documented a reduction in direct costs with home care as compared to hospital care.

In conclusion, this preliminary communication has demonstrated the feasibility of a rehabilitation program to discharge home ventilator-dependent persons with obstructive and restrictive lung disorders to lead functional, independent lives. We are planning a more detailed analysis of the physical function, ADL performance, and psychologic status of patients before and after this form of pulmonary rehabilitation and an estimate of cost/effectiveness. Because of the high personnel costs of our in-hospital unit, and the experience necessary to make the program run efficiently, we suggest that similar programs only be instituted in referral institutions until the techniques of care can be further refined and standardized and more in-depth cost analyses are available. At present, the long-term prognosis for our patients is not clear. Nevertheless, we believe that the rehabilitation program described here provides ventilator-dependent persons with a hopeful alternative for an improved quality of life at home compared to continued institutional care.

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