Clinical considerations in the implementation of home care ventilation: observations in 24 patients[1]

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The assessment and management of 24 patients with compromized respiratory systems, in our experience, suggest that the physiological support delivered by mechanical ventilation can improve the clinical status of such patients. Clinical observations of recurrent respiratory failure, progressive deterioration in exercise tolerance, and/or symptoms of alveolar hypoventilation due to hypercarbia and hypoxemia were sufficient to warrant clinical trials of assisted mechanical ventilation. Long-term management goals included supportive care for patients with progressive neuromuscular diseases and rehabilitation in patients with restrictive chest wall disease or diaphragmatic paralysis.

Index terms: Lungs, ventilation • Respiratory failure
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The feasibility of assisted mechanical ventilation in the home for the treatment of chronic respiratory insufficiency has been reported,[1–7] and the specific physiological benefits of long-term ventilatory assistance have also been documented.[8–12] In spite of such documentation, the literature continues to provide various clinical approaches to the treatment of respiratory insufficiency. We present our experience with 24 patients who were considered for home care ventilation; 21 of these patients were managed at home with mechanical assistance. Our purpose is to outline the clinical evaluation that supported the decision to begin mechanical ventilation and to review the process of evaluation. The sociological, financial, and psychological aspects are discussed elsewhere.[13,14]

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Patients

Diagnosis and symptoms of patients with chronic respiratory insufficiency are listed in *Table 1.* All patients were in the hospital at the time home care ventilation was considered and 16 patients, 3 of whom were referred from other hospitals, had developed respiratory failure and were supported by mechanical ventilation. Eight patients had been studied for symptoms of respiratory insufficiency (dyspnea at rest, retained secretions, orthopnea, and hypersomnolence) before the respiratory failure developed. Of this latter group, 5 patients chose to accept assisted mechanical ventilation.

Methods

Patients in Group I had respiratory muscle fatigue (respiratory rate, >35/min, alternation between chest wall muscle and abdominal muscle movement, 3–5 times/min prior to the institution of mechanical ventilation.[15] Mechanical ventilation was instituted with volume cycled ventilators at periods of 5–7 days. Weaning was instituted with gradually increasing time periods during which patients would be spontaneously breathing (T-piece). The ultimate goal was to require complete ventilatory support only at night.

Patients in Group II developed respiratory failure from respiratory muscle weakness and increased work of breathing due to retention of secretions. Mechanical ventilation was instituted with volume-cycled ventilators, and T-piece weaning was instituted as in Group I. The goal of weaning, however, was to allow the patients some freedom from mechanical ventilation during the day. When patients felt fatigued or when the respiratory rate exceeded 30/min, mechanical ventilation was reinstituted.

Only one patient with chronic obstructive lung disease (Group III) was considered for home care. After numerous attempts to wean the patient from mechanical ventilation during two months hospitalization, home care was decided upon because the patient and family desired that the terminally ill patient not remain hospitalized until his death. The goal was to fully support the patient's minute ventilation to relieve symptoms of dyspnea.

Group IV patients had symptoms of alveolar hypoventilation.[16] All patients had arterial carbon dioxide levels greater than 50 mm Hg, and patients 15, 16, and 18 had abnormal responses to carbon dioxide with the non-rebreathing technique described by Read.[17] Patients 17, 18, and 19 developed respiratory failure before consideration of long-term support and were initially supported by volume-cycled ventilation. All patients in this group, with the exception of patient 18, were assisted with oscillating beds. When the clinical trial with an oscillating bed was instituted, an arterial cannula was placed in the radial artery to obtain arterial blood gas samples while the bed was in motion. Usually, a head-down position of 10° and a foot-down position of 15°–25° were tried.[17] A decrease in arterial pCO_2 of 5 mm Hg or more was considered adequate. The arterial cannula was then removed and a one-week clinical trial at the appropriate settings was instituted.

Patients in Group V required mechanical ventilation because of weakness of the respiratory muscles (patients 21 and 22) or diaphragmatic paralysis after reoperation for a heart valve prosthesis replacement (patients 23 and 24).

With the exception of patients who were assisted with oscillating beds, family members and in some instances the patients themselves were instructed in tracheostomy care, airway suction technique, and ventilator care and maintenance. This instruction was done by a home care therapist and usually required 20–30 hours of instruction per patient situation. Tracheostomy changes are done by patients 1 and 18, by family members of patients 7, 13, 23, and 24, and by respiratory therapy personnel in the outpatient department in all other patients in Groups I and V. Tracheostomy changes in Group II patients and patient 21 are done in the home by physicians or by a registered nurse or respiratory therapist.

Chest physical therapy and tracheobronchial suctioning was taught to patients and family members when appropriate. As expected, the frequency of such therapy varied with the amount of secretions. Broad spectrum antibiotics were necessary only with a change in the quality of secretions, an unusual increase, or an upper respiratory tract infection. No patient showed clinical evidence of pneumonia during the period of observation.

All patients and immediate family members underwent psychological study to determine motives in desiring home care, to identify underlying conflicts, and to evaluate coping mechanisms. Interviews were conducted by a primary intensive care unit nurse, home care social worker,

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Table 1. Diagnosis and symptoms of patients with chronic respiratory insufficiency

Pt	Age	Sex	Diagnosis	Home care	Symptoms
Group I—Restrictive chest wall defects					
1	61	F	Thoracoplasty	17 yr	Hypersomnolence, recurrent respiratory failure
2	42	F	Kyphoscoliosis	4 yr	Hypersomnolence, fatigue, recurrent respiratory failure
3	43	F	Thoracoplasty	1 yr	Fatigue, decreased exercise tolerance, respiratory failure
4	53	M	Kyphoscoliosis	1 yr	Fatigue, decreased exercise tolerance, edema, respiratory failure
5	72	F	Kyphoscoliosis	1 yr	Fatigue, hypersomnolence, respiratory failure
6	56	F	Kyphoscoliosis	1 yr	Fatigue, decreased exercise tolerance (bed-confined due to dyspnea on exertion)
Group II—Motoneuron disease					
7	61	M	ALS	4 yr	Fatigue, hypersomnolence, edema
8	72	M	ALS	. . .	Fatigue, progressive limb weakness, respiratory failure
9	69	M	ALS	. . .	Fatigue, insomnia, respiratory failure
10	71	M	ALS	2 yr	Fatigue, weakness of upper extremities, retention of secretions, respiratory failure
11	70	M	ALS	1 yr	Fatigue, dyspnea on exertion, respiratory failure
12	64	M	ALS	2 yr	Weakness of upper extremities, dyspnea on exertion, retained secretions, respiratory failure
13	64	M	ALS	6 mo	Fatigue, weight loss, insomnia, dyspnea on exertion, retained secretions
Group III—Chronic obstructive lung disease					
14	81	M	Chronic obstructive lung disease	1 mo	Retained secretions, decreased exercise tolerance, respiratory failure
Group IV—Disorders of control of ventilation					
15	51	M	Olivopontine cerebellar degeneration	1 yr	Hypersomnolence, fatigue
16	66	F	Primary alveolar hypoventilation Diabetes mellitus	3 yr	Hypersomnolence, fatigue, apnea (60 seconds), bradycardia
17	51	M	Polio, age 19	2 yr	Paraparesis, hypersomnolence, retained secretions, respiratory failure
18	57	F	Vocal cord paralysis Primary alveolar hypoventilation	2 yr	Hoarseness, recurrent respiratory failure after tracheostomy
19	57	M	Shy-Drager syndrome Parkinsonism	3 mo	Aspiration pneumonia, retained secretions
20	28	F	Brain stem glioma	. . .	Brain stem glioma 9 years prior, respiratory failure, disturbed sleep, morning headaches
Group V—Miscellaneous					
21	26	F	Multiple sclerosis Diaphragmatic paralysis	2 yr	Retained secretions, hypersomnolence, respiratory failure
22	67	F	Peripheral neuropathy	2 mo	Weakness, respiratory failure
23	72	F	Diaphragmatic paralysis after mitral valve replacement	6 mo	Recurrent respiratory failure after mitral valve replacement
24	54	F	Diaphragmatic paralysis after aortic valve replacement	6 mo	Recurrent respiratory failure after aortic valve replacement

ALS = amyotrophic lateral sclerosis.

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Table 2. Results of long-term ventilation

Pt	Diagnosis	Equipment	Outcome
Group I—Restrictive chest wall defects			
1	Thoracoplasty	Bird Mark VII. Shiley tracheostomy; nighttime ventilation only	Reversal of symptoms; able to return to work as part-time cashier; weaning attempts resulted in recurrence of symptoms in one week
2	Kyphoscoliosis	LP-4*; Shiley tracheostomy; nighttime ventilation and as necessary when fatigued	Reversal of symptoms; weaning attempt resulted in recurrence of symptoms in 2 weeks; exercise level—housework, driving
3	Thoracoplasty	MA-1; Shiley tracheostomy; oxygen, 2 L daytime; 28% nighttime ventilation and as necessary when fatigued	Reversal of symptoms; weaning not attempted; exercise level—light housework (died after 12 months)
4	Kyphoscoliosis	PVV† portable volume ventilator; Shiley tracheostomy; nighttime ventilation only	Reversal of symptoms; exercise level—ambulatory, rides public transportation unattended to Clinic visits
5	Kyphoscoliosis	PVV† portable volume ventilator; Shiley tracheostomy; oxygen 2 L, 28% nighttime; nighttime ventilation and additional 4 hours daily	Reversal of symptoms; exercise level—ambulates with minimal assistance because of osteoarthritis in knees and ankles
6	Kyphoscoliosis	LP-4*; Shiley tracheostomy; oxygen 2 L daytime, 25% nighttime; nighttime ventilation only	Reversal of symptoms; exercise level—ambulatory, light housework
7	ALS	PVV†; Shiley tracheostomy	Ambulatory for 18 months with nighttime ventilation; now ventilator-dependent and quadraparetic
8	ALS	MA-I; Shiley tracheostomy; 28% oxygen	Ambulatory with assistance; died before hospital discharge
9	ALS	Kamen-Wilkinson; 28% oxygen; feeding gastrostomy	Family refused home care ventilation; patient died in hospital
10	ALS	PVV† Kamen-Wilkinson tracheostomy; feeding gastrostomy	Ventilator-dependent but ambulatory with assistance for 12 months; now quadraparetic
11	ALS	PVV†; Kamen-Wilkinson tracheostomy	Ambulatory with nighttime ventilation only for 12 months; died after 15 months of home care
12	ALS	PVV†; Kamen-Wilkinson tracheostomy	Ambulatory with nighttime ventilation for 15 months; now requires additional 4–6 hours daytime ventilation; ambulates with assistance
13	ALS	LP-4*; Kamen-Wilkinson tracheostomy; feeding gastrostomy	16–18 hours of ventilation required daily; ambulates with assistance
Group III—Chronic obstructive lung disease			
14	Chronic obstructive lung disease	LP-4*; Shiley tracheostomy 28% oxygen	Ambulatory with assistance; died at home after one month
Group IV—Disorders of control of ventilation			
15	Olivopontine cerebellar degeneration	Oscillating bed at night and hours of rest	Increased alertness; died from primary disease after 15 months
16	Primary alveolar hypoventilation Diabetes mellitus	Oscillating bed at night only	Reversal of all symptoms; no longer insulin-dependent
17	Polio, age 19	Oscillating bed at night only	Reversal of symptoms; unable to sleep without oscillating bed
18	Vocal cord paralysis Primary alveolar hypoventilation	PVV†; at night only	Reversal of symptoms; increased exercise tolerance
19	Shy-Drager syndrome Parkinsonism	Oscillating bed at night and hours of rest	Increased level of alertness; died after 6 months of home care
20	Brain stem glioma	Oscillating bed	Patient refused assisted ventilation
Group V—Miscellaneous			
21	Multiple sclerosis	LP-4*; Shiley tracheostomy	Ventilator-dependent
22	Peripheral neuropathy	Bennett PR-2; Shiley tracheostomy	Ventilator-dependent for only 2 months; now completely recovered
23	Diaphragmatic paralysis	LP-4*; Shiley tracheostomy; nighttime ventilation only	Ambulatory; able to perform light housework
24	Diaphragmatic paralysis	LP-4*; Shiley tracheostomy; nighttime ventilation only	Ambulatory; marked improvement in exercise tolerance, self-sufficient

* Volume ventilator (Life Products, Boulder, Colorado).
† Portable volume ventilator (Life Care Services, Boulder, Colorado).

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home care respiratory therapist, psychiatrist, and intensive care unit physician. These interviewers conferred to objectively assess the suitability of long-term ventilatory support, particularly as an alternative in patients with terminal illness.

Assessment of patient's and family's ability to afford home care was made by the social worker through interviews with the family, durable medical equipment suppliers, Medicare/Medicaid, and other insurance representatives.

Results

Patients in Group I who underwent long-term ventilation (restrictive chest wall defects) had a marked improvement in exercise tolerance and reversal of symptoms of alveolar hypoventilation (*Table 2*). Digoxin and diuretic therapy were discontinued in all patients before hospital discharge. Patients 1, 2, 4, and 6 require only nighttime ventilation and are completely ambulatory and function independently during the day. Patient 3 died at home of undetermined causes after 12 months of home care, and patient 5 has not returned to independent ambulatory status because of osteoarthritis in hips and knees. Subjectively, all patients experienced definite improvement in their sense of well-being. Attempts to gradually reduce nighttime ventilation resulted in return of symptoms in patients 1 and 2.

Patients in Group II (motoneuron disease) experienced reversal of symptoms of alveolar hypoventilation and relief of symptoms of airway and chest congestion due to retention of secretions. All patients who accepted home care remained ambulatory for an average of 18 months after respiratory failure developed. Patients 7, 12, and 13 required only nighttime ventilation and periodic afternoon ventilation for the first year of home care. Patient 8 died before hospital discharge, and the family of patient 9 refused home care. Patient 11 died at home while recuperating from surgery for a bowel obstruction due to adhesions. Patient 12 recovered completely from surgery for a similar problem after 18 months of home care. Although all patients readily accepted assisted ventilation, those with progressive motor neuron disease did not fully realize the implications of the disease and its prognosis until ambulation was no longer possible.

Only one patient with chronic obstructive lung disease (Group III) was considered for home care ventilation. After hospital discharge, he lived in his son's home with his daughter-in-law providing custodial care. His death after one month of home care appeared to be secondary to a cerebral vascular accident.

Patients in Group IV (disorders of control of ventilation) had reversal of symptoms when assisted ventilation was instituted. Patient 18 no longer experienced recurrent respiratory failure, and patient 19, who had been ventilator-dependent since an episode of aspiration pneumonia, was able to be completely weaned from volume-cycled ventilation. Patients 15 and 19 died from progressive deterioration due to the primary disease, and patient 20 refused further study after initial demonstration that an oscillating bed could lower arterial pCO_2 and increase arterial pO_2.

Patients 21 and 22 in Group V were completely dependent upon mechanical ventilation at the time of hospital discharge. Patient 22 noted movement in her shoulders after two months of home care, and six weeks subsequent to rehospitalization for further study, she recovered completely from her peripheral neuropathy and no longer required mechanical ventilation. Patients 23 and 24 had become ventilator-dependent after open heart surgery because of diaphragmatic paralysis. Institution of nighttime ventilation resulted in less respiratory muscle fatigue and improved exercise tolerance to the point that each patient became completely ambulatory during the day and was able to perform light housework without difficulty.

Discussion

Our experience in assessment and management of 24 patients with compromised respiratory mechanics, although anecdotal, suggests that physiological support of ventilation can benefit patients who suffer from chronic respiratory insufficiency. Patients with the disorders we have listed often present to the clinician without the availability of serial pulmonary function evaluation documenting progressive deterioration. Consequently, clinical symptomatology of decreased exercise tolerance, hypersomnolence and fatigue, and signs of respiratory muscle fatigue rather than laboratory evaluation are the only indicators of when to add assisted mechanical ventilation to the clinical regimen of respiratory care.

The clinical rationale for assisted ventilation varied somewhat between groups. Patients in Group I (restrictive chest wall disease) were supported to prevent hypoxemia and hypercarbia during sleep and to allow the respiratory muscles

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to rest for a period of time each day through controlled ventilation.[19–22] The rationale in Group II patients was similar, but the purpose of assisted ventilation was to allow the respiratory muscles to rest between periods of activity so that patients could ambulate without support of respiration. In contrast, the goal in Group I was mainly rehabilitation. In the one patient in Group III with chronic obstructive lung disease, maintenance rather than long-term support was the goal. Complete mechanical assistance allowed him to be comfortable at home. All patients in Group IV had symptoms and arterial blood gases that suggested alveolar hypoventilation. The goal again was to prevent hypoxemia and hypercarbia during the hours of rest.[23–25] Two patients in Group V required total support of mechanical ventilation. However, the goal in two patients with diaphragmatic paralysis was providing rest for the accessory muscles of respiration at night and preventing severe hypoxemia, particularly during REM sleep.[26,27]

Clinical observation in the posthospital discharge period was equally important as clinical observation in deciding upon long-term ventilation because pulmonary function studies and exercise testing were difficult or impossible to obtain in patients with tracheostomies. The patient's subjective assessment of exercise tolerance, absence of fatigue, and psychological well-being were considered adequate indicators of the effects of long-term assisted ventilation.

During the past four years, our observations of the patients in this series have enabled us to establish a home care ventilation program and to make certain technical, financial, and psychological recommendations.

From a technical standpoint, we have used either oscillating beds or volume-cycled ventilators to assist respiration. Early in our experience we attempted to use oscillating beds for a patient with diaphragmatic paralysis and two patients with motor neuron disease. Clinical trials in these three situations were unsuccessful, suggesting that oscillating beds may be most useful for patients with abnormal control of ventilation rather than compromised respiratory mechanics. However, positive pressure ventilation is particularly successful in patients with compromised mechanics. We recommend either the LP-4 ventilator (Life Products, Boulder, Colorado) or the PVV portable volume ventilator (Life Care Services, Boulder, Colorado) because of their portability (27 pounds each) and ease of operation. Although we had no difficulties with tracheostomy tubes, we learned that health care agencies in our area would not change cuffed tracheostomy tubes. Therefore, patients or family members were taught this procedure in a few select cases; otherwise, patients returned for outpatient care. In cases of total ventilator dependence, a physician or our home care therapist or registered nurse changed the tubes in the home.

Because of Medicare and other health care insurance, none of our patients or their families encountered financial problems. However, in most cases, Medicare coverage alone would have been inadequate. Medicare is 18 months behind schedule and claims clerks are unfamiliar with the types of durable medical equipment required for home care ventilation. Monthly rental fees vary from 5% to 15% of the purchase price of an item. A national supplier (Life Care Services, Boulder, Colorado) suggested 5% is a fair fee, but local suppliers quoted 10% or more. Thus, the difference between Medicare coverage and actual cost was covered by additional insurance. Respiratory therapy services were not covered by third party payers except when performed by registered nurses. Services related to ventilatory management were unavailable through local home health care agencies.

Psychological study of patients and families was particularly useful in helping individuals make decisions about accepting home ventilator care. Identification of previously existing family conflicts was useful in separating them from those specific to home care ventilation. Success of home care ventilation could be predicted from knowledge of individual and group coping mechanisms. In studying patients and families at home, we often found that those who were most positive vocally about home care ventilation were least likely to provide consistent assistance. Analysis revealed that these individuals displayed outward concern but inward inability to accept the reality of the patient's illness. Historically, these members had difficulty coping with stressful situations before the patient's illness.

We believe that if a patient and his family are willing to accept responsibility for home care, the physician should provide the necessary technological and psychological support.

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