Long-term management of the ventilator-dependent patient

Preparation for home care[1]

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The care of the ventilator-dependent patient should be classified as custodial or rehabilitative. The goals of custodial care range from patient comfort to emotional stabilization of patient and family domestic situations. The goals of rehabilitative care range from patient self-sufficiency to complete weaning from mechanical ventilation. Patient evaluation for home care should be done by a home care team consisting of the patients' physicians, intensive care unit nurses, home respiratory therapists, social workers, physical and occupational therapists, and dietitians. Essential factors required for successful home care ventilation include motivated patients and families, suitable home facilities, and the absence of other medical conditions which will preclude long-term survival.

Index terms: Home care services • Respiration, artificial

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Failure of the respiratory system can be due to failure of the lung parenchyma or of the respiratory muscles.[1] The symptoms of failure of the lung parenchyma are due to hypoxemia and range from acute tachypnea to chronic dyspnea at rest. The symptoms of failure of the respiratory muscles are due to hypercarbia and associated hypoxemia due to alveolar hypoventilation and range from an acute respiratory arrest to dyspnea, somnolence, and edema (i.e., cor pulmonale). The pathophysiology of respiratory failure has been reviewed.[2,3] It is sufficient to say, however, that when respiratory failure ensues, the clinician must decide whether to reverse the process by institution of therapies which reverse hypoxemia and correct hypercarbia. The

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Table 1. Goals of custodial care

—To make the patient comfortable in the intensive care unit
—To discharge the patient from the intensive care unit
—To make the patient comfortable outside of the intensive care unit
—To help the family accept the permanence of the debilitation
—To achieve self-sufficiency for the family so that they may provide adequate care at home which will guarantee maximum physical comfort
—To emotionally stabilize a patient's entire domestic situation

decision to institute mechanical ventilation implies that the responsible disease process is either acute and reversible or chronic and irreversible. Thus, even before institution of mechanical ventilation, the clinician must be aware of the expected benefits of such therapeutic intervention.[4]

Therapeutic intervention is based on the disease causing respiratory failure (fibrosis, pneumonia, ventilation/perfusion inequality from retained secretions, bronchospasm or emphysema, and pulmonary edema of cardiac or noncardiac origin) and consists of adding supplemental oxygen, mechanical ventilation, and end expiratory pressure to reverse the parenchyma shunt and prevent atelectasis. These latter measures are usually instituted when deterioration of the respiratory status of a patient is acute. If there are no underlying chronic diseases, treatment and reversal of the cause of the respiratory failure will be followed by weaning of the patient from mechanical ventilation. Because one seldom believes that a patient will become ventilator-dependent, home care is not of any concern, especially since no device exists which can adequately assume the function of the lung parenchyma.

Failure of the respiratory muscles can occur from a decreased drive to breathe, stiffness of the chest wall (decreased compliance of the chest wall), weakness, and/or fatigue of the muscles. Therapeutic intervention is usually mechanical or is at least designed to lessen the work of breathing in the latter two situations. Although mechanical ventilation is usually instituted in an acute situation, patients who have an underlying chronic disease might also become ventilator-dependent. Logically, such patients are more likely to qualify for long-term ventilation as the ventilator can substitute for the function of the respiratory muscles.

Table 2. Goals of rehabilitative care

—To allow the patient to participate in his or her own care
—To wean the patient from the ventilator for a period during the day
—To wean the patient from the ventilator for a whole day
—To wean the patient from the ventilator for the whole day and to allow the patient to be freely mobile outside of the home
—To achieve daytime weaning, subsequently allowing the patient to be employed full time
—To completely wean the patient so he or she can return to previous daily employment or routines

Patient classification

Patients who become ventilator-dependent require either custodial or rehabilitative care.[5] Custodial care implies that a patient is irreversibly ventilator-dependent. The underlying disease process may be an acute event as in the case of quadriplegia from trauma or a chronic debilitating condition such as motor neuron disease. Rehabilitative care implies that the patient can be weaned completely or at least partially from mechanical ventilation. Custodial care encompasses goals ranging from patient comfort and hospital discharge to emotional stabilization of a family's domestic situation (*Table 1*). Rehabilitative care ranges from patient participation in self-care to complete weaning from mechanical ventilation (*Table 2*).

Patient presentation and equipment selection

Since October 1977, 39 patients have been evaluated for home care at the Cleveland Clinic. Of this number, 35 were discharged on some type of assisted ventilation. None had failure of the lung parenchyma as the sole cause of respiratory failure. *Table 3* lists the causes of respiratory muscle failure and the patient population. In light of this experience, decisions to discharge patients on home care ventilation were analyzed; rarely were the physiological measurements sufficient enough to document progressive debilitation and identify a key time to begin home care ventilation.

Table 3. Home care patients in the Cleveland Clinic Home Care Ventilation Program (October 1977–August 1984)

Defect	No. of patients	Classification	Equipment
Altered drive to breathe			
Olivopontine cerebellar degeneration	1	Custodial care	OB
Idiopathic alveolar hypoventilation	3	Rehabilitative care	2 OB, 1 PVV
Chest wall defects			
Old thoracoplasty	2	Rehabilitative care	2 vol vent
Kyphoscoliosis	7	Rehabilitative care	7 LP-4
Respiratory muscle failure			
Hyperinflation			
Chronic obstructive pulmonary disease	2	Custodial care	2 LP-4
Neuromuscular disease			
Olivopontine cerebellar degeneration	2	Custodial care	2 OB
Amyotrophic lateral sclerosis	7	Custodial care	2 PVV, 5 LP-4
Multiple sclerosis	2	Custodial care	2 LP-4
Chronic Guillain-Barré syndrome	1	Custodial care	1 PR-2
Old polio	1	Rehabilitative care	1 OB
Diaphragmatic dysfunction			
Postsurgical diaphragmatic dysfunction	5	Rehabilitative care	2 LP-4, 3 OB
Adult-onset acid maltase deficiency	1	Rehabilitative care	1 LP-4
Charcot-Marie-Tooth disease	1	Custodial care	1 OB

LP-4 = volume ventilator (Life Care), *OB* = oscillating bed, *PR-2* = Bennett PR-2 pressure cycled ventilator, *PVV* = portable volume ventilator, and *vol vent* = volume cycled ventilator.

In the "altered drive to breathe" group, 2 patients presented with hypersomnolence with resting hypercarbia; 1, with obesity hypoventilation syndrome, presented with cor pulmonale and respiratory failure; and 1 presented with recurrent respiratory failure. Their responses to inhaled carbon dioxide were tested after clinical stabilization and were significantly blunted.[6] Three of the 4 patients were able to reverse their clinical symptomatology with the use of oscillating beds during sleep and rest.[7,8] The fourth patient who also had vocal cord paralysis elected to receive night ventilation with a portable volume-cycled ventilator since she required a tracheostomy. Long-term ventilation was used to prevent hypoxemia and hypercarbia during sleep and rest.[9] All patients were able to resume all activities of daily living. One returned to full-time employment as a secretary.

With one exception, the patients with chest wall defects presented with recurrent respiratory failure. All had signs of cor pulmonale which reversed with night ventilation. These observations have been previously reported.[10–12] This group was classified as rehabilitative. The shortest period of survival was one year, and the longest period was 19 years. The physiological defect was respiratory muscle fatigue due to increased effort to breathe with a stiff chest wall. The treatment rationale was designed to rest these muscles to allow them to function more effectively during the day when the patient pursued daily activities. Volume cycled ventilators were used to achieve night ventilation. All patients had tracheostomies in place when home care was chosen. The portable machines have allowed these patients to travel on extended trips.

The patients in the "respiratory muscle fatigue" category presented with respiratory failure and could not be weaned completely from mechanical ventilation without signs of tachypnea and decreased inspiratory forces.[13] Of the 21 patients in this category, only 8 were able to achieve satisfactory rehabilitation; the remainder received only custodial care. Two patients with neuromuscular disease recovered satisfactory function (1 with chronic Guillain-Barré syndrome recovered completely and 1 with old polio no longer required night ventilation with an oscillating bed).

The patients with diaphragmatic muscle dysfunction are a particularly interesting group regardless of etiology. Their symptomatology was due to fatigue of the accessory muscles of respi-

ration. Initially, these patients complained of dyspnea on exertion followed by disturbed sleep, then hypersomnolence, and cor pulmonale.[14,15] Patients who experienced phrenic nerve injury following surgery usually had difficulty when being weaned from mechanical ventilation[16]; initially, these patients had stiff lungs from long-standing mitral valve disease, had tracheostomies in place, and recovered within 16 months. Three additional postsurgical patients experienced bilateral diaphragmatic paralysis after coronary bypass surgery. Their lungs were compliant enough for night ventilation with oscillating beds. One patient with adult-onset acid maltase deficiency and diaphragmatic paralysis selected a portable volume ventilator for more mobility since the potential for reversibility was relatively small in this case.[17] The patient with Charcot-Marie-Tooth disease did not want a tracheostomy and ventilated well with an oscillating bed.

The selection of equipment for these patients was based on the need to provide assistance in whole or in part to the respiratory muscles. For the patient who required custodial care, an efficient, durable, portable volume cycled ventilator was selected. A tracheostomy was performed to allow for ease of clearance of secretions from the tracheobronchial tree. Furthermore, all of the patients had or had had chronic debilitating disease which eventually resulted in complete ventilator dependency. Initially, if a patient could spend some time off the ventilator, a fenestrated Shiley tracheostomy tube was used. Once complete dependency resulted, a Bivona foamed cuffed tracheostomy tube was used. These latter tubes decreased the incidence of aspiration of oral secretions and have provided effective seals of the trachea without much tracheal dilatation over long periods of time. Equipment selection for the rehabilitative group depended upon five factors:

1. The reversibility of the underlying disease,
2. The stiffness of the chest wall,
3. The compliance of the lungs,
4. The type of support that the patient was receiving at the time that home care was elected, and
5. The patient's desire for mobility.

Patient selection and discharge planning

The selection of a patient for home care should not be decided by the physician or the patient only. The processes of living and dying should be discussed openly with the patient and family so that the patient can freely decide whether to live with the handicap of impaired ventilation. In addition, the patient should not be afflicted with any other organic disease which would shorten survival or impair mental function. Consequently, metastatic cancer, debilitating cardiovascular disease, liver failure, renal failure, progressive pulmonary fibrosis, and Alzheimer's disease should be contraindications to home mechanical ventilation.

With a patient classification and goals in mind, one must consider the true benefit of long-term ventilation: an alternative to long-term institutional care and an improved quality of life. Providing home care is a societal issue, but the care of the patient is an individual responsibility. A proper physiological evaluation to determine appropriate equipment should be accompanied by a proper psychological evaluation to determine how a patient and his or her family cope with stress. The medical community must help a patient decide for or against an alternative health care. Home care is not for everyone.[18] When a patient and his or her family decide on home care, the care becomes the responsibility of the family. A family cannot decide after home care has begun that the situation will be too stressful. This is the reason for careful screening of the patient and family to determine if home care is possible. It is the responsibility of the home care team to inform a patient and family about all the positive and negative aspects of home care; it is not their responsibility to assume the care of the patient.

The evaluation of a patient should be done on an individual basis by a group of persons who are knowledgeable in respiratory care. If the activity within an institution increases to a point where more than two patients per year are involved with home care, a home care team should be assembled and consist of the attending physician, a pulmonary physician, a home care respiratory therapist, the patient's primary nurse in the intensive care unit, a psychiatrist, and a social worker. The primary physician and pulmonary physician should determine the patient's classification and whether or not there are any contraindications for home care ventilation. A home care respiratory therapist can help assess the suitability of the home care environment for equipment (e.g., locate electrical outlets, ascertain subse-

quent patient maneuverability within the home, and decide if the facilities are adequate in order to maintain the equipment in a clean condition) before the patient is discharged. The patient's primary nurse in the intensive care unit should develop home nursing care plans for the patient who will receive custodial care and assist physical therapists in developing rehabilitation goals for those patients who are able to achieve a higher level of self care and independence. Because of the personal stresses that home care can produce, a psychiatrist should provide insight into previously existing family conflicts and identify the mechanisms the patient and family have used to cope with stress prior to the patient's illness.[18,19] A social worker who can process claim forms as well as deal with families experiencing the stress brought on by the chronic illness of one member is an invaluable asset to the home care team. The social worker should also be easily accessible to those in the family who are concerned about the financial aspects of home care.

Conclusion

The essential factors required for successful home care ventilation include motivated patients and families, suitable home facilities, and the absence of other medical conditions which will preclude long-term survival. When these conditions are met, appropriate classification of patients will assist discharge planners in establishing long-term expectations and goals for patients and families. Perhaps, such classification will also assist third-party payers in the establishment of equitable payment schedules for durable medical equipment and ancillary services to assist the patient and family in their endeavors to achieve satisfactory, self-sufficient home care.

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