

HOME MECHANICAL VENTILATION OF PEDIATRIC PATIENTS



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Introduction

The last 5 to 10 yr have brought unprecedented emphasis on home care for chronically ill children, including ventilator-dependent children. Several factors have contributed to this shift from hospital to home-based care.

1. Advances in medical knowledge and technology have contributed to improved survival rates among critically ill children.
2. A strong movement exists to minimize health care costs and to expedite the transition from hospital to home. In many cases, the direct cost of home care is approximately 50% that of hospital care.
3. Medical equipment has been designed to accommodate home care needs.
4. The psychologic and developmental advantages of home care for chronically ill children are now recognized.

The prime indication for the use of home mechanical ventilation is chronic alveolar hypoventilation with associated respiratory failure as indicated by hypoxemia and hypercapnea. Chronic alveolar hypoventilation may occur in children with airway or parenchymal disease or in children with normal lungs. In the latter instance, central nervous system dysfunction or peripheral abnormalities such as chest wall deformity or neuromuscular disease may be the etiology of hypoventilation.

Safe and effective home care for ventilator-dependent children requires the following:

1. A thoroughly trained pediatric pulmonary team committed to the program in home ventilator care.
2. Proper patient selection.
3. Thorough family preparation.

The Health Care Team

Home care planning for the ventilator-dependent child should be implemented by a multidisciplinary team composed of the following:

1. Pediatric pulmonologists and other physician subspecialists when indicated.
2. Pediatric pulmonary nurse specialist.
3. Social worker.
4. Respiratory therapist.

In addition, the following professionals may be necessary on an *ad hoc* basis for many patients: physical therapist, occupational therapist, speech therapist, registered dietician, psychologist.

Team members must be expert in assessing and planning for the needs of chronically ill children, including medical management, long-term ventilator management, and psychosocial management. Team members must be aware of local community resources within the patient's home area and be able to establish effective collaboration with these resources.

Services provided by the program must include the following:

1. An individual responsible for coordinating all team planning efforts and facilitating communication (the "hospital-based care manager").
2. Pediatric pulmonologists familiar with each patient available on a 24-h basis.
3. Interpretation of diagnostic tests such as spirometry, pulse oximetry, end-tidal carbon dioxide monitoring.
4. Referral to a local, reliable durable medical equipment company (for ventilators, monitors, oxygen source, etc.) and to a home health care agency (for nursing, occupational therapy, physical therapy, speech therapy). The medical equipment company must have 24-h emergency equipment support service.
5. Instruction of parents, home care nurses, and all other caretakers in all aspects of home care.
6. Assistance of the family in securing funding for home care.

Patient Selection

In most cases, patient evaluation at a tertiary care center will be necessary in order to establish that the appropriate criteria for the consideration of Home Ventilation have been met. Referral will allow further patient assessment, choice of appropriate equipment, teaching of the parents and, most important, the establishment of communication between the community physician responsible for the primary care of the child and the home ventilation support team. Ideally, the community physician would be a pediatric pulmonologist familiar with chronic respiratory failure in children, but a pediatrician knowledgeable in pulmonology and willing to assume the necessary responsibilities could be an alternative.

Children who are being considered for home mechanical ventilation must fulfill the following physical criteria.

1. Cardiopulmonary stability, as indicated by clinical status and repeated monitoring of arterial partial pressure of oxygen and carbon dioxide.
 2. Positive trend in weight gain and growth curve.
 3. Stamina for periods of play while ventilated.
 4. Freedom from frequent respiratory infection and fever.
- In addition, a number of other elements should be present.

1. The child and family should be ascertained to be suitable candidates for the program as evidenced by awareness of the potential stresses of long-term home care and commitment to implement the program. Counseling regarding identification of family strengths, weaknesses, and resources is recommended to assure smooth transition from hospital-based to home-based care.
2. The home must have safe electrical, plumbing, and heating systems and a telephone. Adequate space must be available.
3. Adequate support to the family must be available in the form of home nurses, home-maker aides and/or family and friends.
4. Funding for home care must be available.

Family Preparation

Prior to discharge from the hospital, all primary home caregivers (parents, volunteers, and home nurses) should participate in a hospital-based education program developed specifically for the needs of each individual patient. Elements of this program should include the following:

1. Training in appropriate cardiopulmonary resuscitation.
2. Instruction in use, maintenance, and trouble-shooting of the equipment to be used in the home.
3. Instruction in the comprehensive home care plan for the child including respiratory care, tracheostomy care, skin care, bowel and bladder elimination, positioning, and ventilation.
4. Instruction regarding family responsibility for physical, speech, and occupational therapies.

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5. Discussion of the long-term psychologic impact of home care of chronically ill children.

The instruction should include didactic classroom sessions and bedside nursing care experiences; each caregiver should be expected to perform adequate demonstrations of each critical skill on several separate occasions prior to discharge.

Conclusion

Although the stresses of caring for chronically ill, technologically dependent children are numerous, this stress must be assessed in relation to that imposed by prolonged confinement in an intensive care unit. Home care may not be the most beneficial choice for a family, and it is imperative that alternatives such as extended care facilities and independent living centers be considered.

This statement was developed by an ad hoc committee of the Scientific Assembly on Pediatrics. The paper was prepared by:

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