Long-term management of the ventilator patient in the home[1]

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The author reviews 30 years of experience with home care of ventilator-dependent patients at Rancho Los Amigos Medical Center, involving 313 individuals. Diagnoses and equipment needs are reviewed and the required training of care givers in the home is emphasized. Follow-up by the physician and availability of resource people are critical to the success of the program. Emergency access to equipment vendors and medical professionals must be provided. In selected cases, home management is preferable to long-term hospitalization on both social and economic grounds.

Index terms: Home care services • Respiration, artificial

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The 1950s marked a period of rapid development in respirator technology. Spurred on by the unprecedented number of polio patients with respiratory paralysis, the March of Dimes helped to establish polio respirator centers, not only supplying respirators but also encouraging their development. Many survivors remained dependent on assisted ventilation full or part time, resulting in a need for home care programs.[1] Thousands of survivors live at home today and lead full, productive lives despite their need for mechanical respiration. With the development of effective polio vaccines, however, the epidemics abated, and with them the need for specialized and experienced home care teams. While patients with neuromuscular respiratory failure were occasionally managed at home,[2,3] the demand for skilled teams, along with appropriate respirators and support equipment, no longer developed as widely as it had

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during the outbreak of the epidemics. This paper reviews the experience with home care for respirator-dependent patients during the past two decades at Rancho Los Amigos Medical Center (RLAMC), emphasizing the requirements for a successful transition from the hospital to the home.

Materials and methods

The RLAMC patients reviewed in this paper include 180 individuals who require part- or full-time respirator support and who are living at home. These patients include 102 with respiratory polio, 29 with spinal cord injuries (14 children), 21 with muscular dystrophy, 7 with spinal muscular atrophy, and 21 with respiratory impairment due to a variety of other neuromuscular and skeletal diseases. A follow-up of 29 patients with restrictive or obstructive respiratory disease requiring respirators at home was previously reported.[4]

Results

Of the 29 patients from RLAMC reported previously,[4] the 14 with chronic airway obstruction were hospitalized five times as long (96 versus 19 days) as the 15 patients with restrictive disease following their initial discharge on the home respirator. At the time of the earlier report, hospitalization had been reduced by 36% in those with obstruction and 73% in those with restricted breathing; the average follow-up period was 29 months in the former group and 34 months in the latter. Of the 14 patients with obstructive lung disease, 6 were living as of 1979, whereas only 1 survived to 1984, and has since died. Of the 15 patients with restricted breathing, 11 were alive in 1979 and 6 (40%) survived to 1984.

Of the 114 former polio patients,[5] 52 required a tracheostomy late in their course; in 26 cases, this was because previously used negative-pressure ventilators were no longer effective, while in the other 26, respiratory failure developed following chest wall or pulmonary complications.

Of the 102 polio survivors who require respiratory assistance at home, 11 use tanks or rocking beds for their primary ventilators. Many use "mouth-positive" pressure to assist them while they are off their primary ventilator. Two of the 29 spinal cord injured patients are using external respirators; 1 uses a tank and 1 a pneumobelt. The group with muscular dystrophy who live at home includes 21 on ventilators; all of these use positive-pressure respirators by tracheostomy. One 37-year-old man with delayed-onset respiratory failure lives at home, attends college, and works as a teaching assistant, despite his need for a respirator. The average age of these muscular dystrophy patients is 28 years (range, 21–37). The ratio of time spent at home versus the hospital for 7 of these young men is 30:1 (average months). Complete data are not available for the others. The remainder of the 180 are ventilated through tracheostomy tubes, usually cuffed.

Of the 21 patients in the miscellaneous group, 5 are kyphoscoliotic, 4 have amyotrophic lateral sclerosis, 1 has obstructive sleep apnea, 1 has chronic airway obstruction, 1 has residuals of tuberculosis, and the remaining 9 have chronic neurological deficits.

Discussion

Five recent papers[4,6–9] reported on a total of 106 patients on home respirator care, most of whom (87%) had restrictive respiratory problems. In the series by Splaingard et al,[7] 47 respirator-dependent patients with neuromuscular disease spent an average of 26 months at home; and Sivak et al[6] have reported on 3 patients with restrictive chest wall disease who have been at home for 17 to 183 months. Four of their patients had amyotrophic lateral sclerosis, but survived for 11–38 months (average, 18) on home respirator care.

While experience with home respirators now spans half a century, it has been limited in large part to the centers where polio patients received their initial care, since the termination of the epidemics following the success of the vaccines meant that most patients became sequestered near these same centers. Polio patients generally felt insecure with health professionals, many of whom seemed to regard them as relics. In addition, the experienced teams who had originally organized the home care programs in the 1950s had dispersed. Since then, papers on home respirator care have occasionally appeared in the literature,[2,3] usually involving only a small number of cases. However, such reports have increased sharply in the past five years,[4,6–10] as technology has resulted in increasing numbers of patients who survive respiratory failure but remain respirator-dependent. As a result, home

care programs have necessarily increased, and with them, the recognition of allied health teams as an essential component of a successful transition from the hospital to the home.

Education of the family and other individuals involved in caring for the patient at home is of primary importance. At RLAMC, this is the responsibility of the liaison nurse. Other members of the home care team include a respiratory therapist, the primary care nurse on the respiratory service, a social worker, and the primary physician as well as a physical therapist, occupational therapist, and dietitian. The role of the family is second only to that of the patient. Both patient and family must accept the plan and become actively involved if it is to succeed; indeed, the desire of both patient and home care givers to make the transition is the primary factor in the success or failure of the team effort. If the patient does not have a family, this may complicate discharge planning but need not eliminate home care as an option. Many respirator-dependent patients with restrictive respiratory disease live at home with a trained attendant, as polio patients have done for decades. In some states, federal funds are available to hire a nurse when the need is clearly documented, which still costs considerably less than inpatient care. Although I have found that some government agencies are slow to reimburse home care providers, this problem should work itself out once it becomes apparent that the savings can be enormous.

Equipment needs are determined for each patient during discharge planning. Most are discharged on positive-pressure ventilation via a tracheostomy, although occasionally a patient with stable neuromuscular disease is released on a negative-pressure cuirass ventilator, pneumobelt, or rocking bed. An LP/PVV respirator is satisfactory for most patients with a tracheostomy, unless it is desirable (and possible) for the patient to breathe on his or her own. In patients with chronic airway obstruction and partial paralysis, when "demand" capability is called for, an LP-4 is usually prescribed. A back-up respirator is required if the patient has less than four hours tolerance off equipment at optimal respiratory function, since it may take four hours for the vendor to deliver a replacement. I do not use a cuffed tracheostomy tube in most cases. Although this means a certain amount of air leakage, it can generally be compensated for by increasing the volume; an additional increase is usually required at night or in patients with increased airway resistance caused by bronchial edema or mucus. The appropriate rate and volume are determined while the patient is hospitalized, using capnographic and oximetric analysis. Uncuffed tubes also have the advantage of permitting the patient to talk. On occasion, however, a cuff may be necessary to prevent aspiration during meals, or rarely, to provide adequate ventilation in a patient with marked airway resistance or decreased pulmonary compliance.

The vendor is a critical member of the home care team, and one should not wait until the last minute to introduce him or her into the discharge planning program. He or she must be provided with detailed information regarding equipment and supply needs, including ventilation settings, tracheostomy tubes, suction catheters and equipment, gloves, and dressings. A detailed checklist is prepared for both patient and care givers to ensure that all teaching needs have been met before discharge. After discharge, they must have access to someone who knows the patient's home care needs 24 hours a day; this may be the liaison nurse, physician, or ward nurse. The vendor must also be available 24 hours a day to replace equipment if necessary. The success of the home care program hinges on the reliability and availability of resource people, which is most critical in the first few days and weeks after discharge. Visits by the liaison nurse in the early post-discharge phase are important to identify present and potential problems during the transition from hospital to home.

Increasing attention has been given in recent years to home ventilation for young men with X-linked muscular dystrophy.[10,11] At RLAMC, a clinic has been developed to facilitate the transition of muscular dystrophy patients from the pediatric department to the adult pulmonary service. The patient and his family are seen at regular intervals and vital capacity and CO_2 levels are measured. I assess CO_2 by the rebreathing technique described by Hackney et al,[12] which reduces the number of arterial sticks needed. The clinic visits also offer an opportunity to discuss management options, with the goals of (*a*) providing elective intervention rather than allowing the disease to progress to the crisis stage and (*b*) supporting the patient and his family as they reach a decision regarding ventilation and long-term home management. This often poses a stressful ethical dilemma for the family, especially

if the patient is not competent to participate fully in the discussion.

The question of the "quality of life" for ventilator-dependent patients has often been raised, usually by those with little or no direct experience with their long-term care. I see this problem most frequently with parents of a muscular dystrophy patient who is approaching respiratory decompensation. However, I have found that these young men adapt to a respirator and wheelchair more readily than most older patients. At RLAMC, a short film has been put together featuring interviews with several respirator-dependent muscular dystrophy patients, which portrays the positive side of life on a respirator. While no effort is made to "sell" the respirator as an option, my experience with these patients has convinced me of its worth. As Norman Cousins has put it, "the kind of life lived by a patient under conditions of vigorous response to a challenge is infinitely preferable to a crunching desperate winding-down."[13]

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