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Long-Term Mechanical Ventilation

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INTRODUCTION

For most patients, mechanical ventilation is a short-term therapy used to support gas exchange until an acute cause of respiratory failure resolves. As the management of critically ill patients has advanced, more patients are surviving their acute illness but certain percentages are left with continued ventilator dependence. Although the group of patients requiring prolonged mechanical ventilation (PMV) is less than 10% of all patients requiring mechanical ventilation, they consume up to 40% of intensive care unit (ICU) patient days and Medicare ranks them first in charges per patient.[1,2] Moreover, the number of these patients has increased substantially over the years with one review estimating a 190% increase in the incidence of tracheostomy for PMV from 1993 to 2002.[3] There are also children born with neurologic disorders and adults with progressive disorders that require lifelong ventilator support.

EPIDEMIOLOGY

Over the last two decades the prevalence of long-term ventilation has risen dramatically. The often cited ventilator weaning trials of the early and mid-1990s consistently demonstrated that approximately 10% of patients in ICUs were not able to be liberated from ventilators within 14 days.[4] This inevitably leads to growing numbers of patients requiring prolonged ventilation. Nevertheless, in the early 1990s there were few options for ventilator-dependent individuals and some would reside in acute care hospitals indefinitely. This was not an ideal situation for anyone involved. Patients were forced to live away from family, in settings that were not designed with creature comforts in mind. Hospitals lost money as insurers began to cap reimbursement based on diagnosis-related groups. Despite these pressures, there are

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ample data demonstrating increases in the incidence of mechanical ventilation, PMV, and tracheostomy in the United States. However, it is difficult to accurately quantify the actual number of long-term ventilator patients in the United States. One way to gauge the increase in prolonged ventilation is to look at the use of tracheostomies. Tracheostomy use for PMV rose from 8.3 per 100,000 population in 1993 to 24.2 per 100,000 in 2002.[2] A survey of long-term ventilation in Boston published in 2010 found the prevalence of long-term mechanical ventilation to be 7.4 per 100,000.[5] If this is extrapolated to the entire US population, there are approximately 10,966 people on long-term invasive ventilation.[6] Further extrapolation from data on children in Pennsylvania yields an estimate of approximately 4802 children using invasive ventilation nationwide.[6] This article characterizes the features, outcomes, and logistics that must be taken into consideration while caring for the unique patient population requiring PMV.

VENTILATOR DEPENDENCY

Rigorous assessment of these patients has been hindered by the lack of standard definitions for what constitutes ventilator dependency. Throughout the literature and even within governmental regulatory bodies, such as the Centers for Medicare and Medicaid Services (CMS), the definition of PMV varies substantially from the number of days on mechanical ventilation (ranging from 2 to 29 days), the need for mechanical ventilation after leaving the ICU, or simply the need for tracheostomy with 96 or more hours of mechanical ventilation.[7–11] The 1998 American College of Chest Physicians Consensus Conference proposed that ventilator-assisted individuals were those with indications for mechanical ventilation beyond the ICU including persistent symptomatic respiratory insufficiency without failure to tolerate or improve with noninvasive ventilation, uncontrollable airway secretions, impaired swallowing leading to chronic aspiration and repeated pneumonias, or severely weakened or paralyzed respiratory muscles.[12] To refine these arbitrary guidelines, a 2005 consensus conference proposed a standardized definition of PMV as the need for greater than or equal to 21 consecutive days of mechanical ventilation for 6 or more hours per day.[7]

The declaration of chronic, or even lifelong, ventilator dependency differs greatly depending on the cause of respiratory failure and the probability of ventilator liberation. For example, a different threshold may be used to declare ventilator dependency in a patient recovering from acute respiratory distress syndrome compared with a patient with a high cervical spinal cord injury. The Canadian Thoracic Society published a series of disease-specific recommendations for the use of invasive ventilation in disease-specific states with the caveat that the decision to initiate or continue mechanical ventilation must be based on individual patient characteristics.[13]

Spinal Cord Injury

The need for mechanical support in individuals with spinal cord injury depends on the grade and level of injury. During the initial year of injury, however, improvements in respiratory function may occur spontaneously with only 5% of patients requiring ventilator support after the first year.[14] Complete cervical cord lesions are associated with the highest degree of respiratory dysfunction. One case series reported that 100% of patients with complete

injuries at or above the C5 level required a definitive airway and tracheostomy, although only 71% of patients required mechanical ventilation at time of discharge. In contrast, 15% of patients with complete injuries below C6 required mechanical ventilation at time of discharge, although 79% initially required mechanical respiratory support and 50% received tracheostomy. Patients with incomplete injuries rarely required tracheostomy.[15] Each patient must be evaluated individually for the need for long-term ventilation acutely and in follow-up to assess for the ability to support spontaneous breathing in the first critical year.[13] In retrospective review, ventilator dependency was the strongest negative predictor of survival during the first year after hospital discharge,[16] with respiratory complications accounting for 31% of deaths.[17] For patients who require assisted ventilation, noninvasive approaches may be associated with fewer complications as long as mental status and bulbar musculature function remain intact. Despite the risk of respiratory complications, quality of life and life satisfaction scores remain high in patients with tetraplegia and many of these patients are able to be managed at home.[18–20]

Chronic Respiratory Diseases

Acute episodes of respiratory failure in patients with chronic lung disease, such as chronic obstructive pulmonary disease (COPD) or interstitial lung disease (ILD), account for a significant number of ICU admissions every year. The need for mechanical ventilation in these cases is dictated by the immediate clinical picture. Ventilator liberation, however, is often complicated by pre-existing parenchymal disease, which is an independent predictor of failure to wean from the ventilator in the inpatient setting.[21] It has been estimated that COPD accounts for 25% of weaning failures leading to the need for PMV.[11,22,23] Very few studies have reviewed the incidence of PMV in other forms of chronic lung diseases, such as ILD. Furthermore, it is unclear if the natural history of respiratory failure in an ILD exacerbation secondary to idiopathic pulmonary fibrosis is the same as a patient with ILD from an antisynthetase syndrome. Nevertheless, reports from weaning centers suggest that patients with any “previous lung disease” are significantly less likely to be weaned from the ventilator (odds ratio, 0.08; 95% confidence interval, 0.02–0.31).[24] In the pediatric world, long-term invasive mechanical ventilation is an effective treatment option for patients with chronic respiratory insufficiency from pulmonary disease, central hypoventilation, or thorax deformities.[25] Unfortunately, similar evidence has not been demonstrated in adult patients with chronic diseases. To reduce utilization of health care resources, some experts have suggested the use of long-term noninvasive ventilation in patients with chronic hypercapnia and frequent episodes of respiratory failure requiring inpatient ventilatory support,[26] although there is also no evidence to support this practice.

Amyotrophic Lateral Sclerosis

Amyotrophic lateral sclerosis (ALS) is a progressive neurodegenerative disorder that ultimately results in death, typically as a result of respiratory muscle involvement. In stark contrast to many other neuromuscular diseases (NMD), there is a rapid progression to death with approximately 50% of patients dying within 3 years of symptom onset.[27] Acute respiratory failure in patients with ALS can result because of diaphragm weakness, ineffective cough, and inability to handle oropharyngeal secretions. Randomized controlled trials have demonstrated improved survival and quality of life indices with the use of

noninvasive ventilation for this patient population.[28] Based on this and other studies, noninvasive ventilation is the preferred option for respiratory support even when ventilation is required 24 hours a day. Initiation of ventilation is based on parameters that predict nocturnal hypoventilation or progression to death. Dreyer and colleagues[29] proposed treatment with home mechanical ventilation for patients with a vital capacity less than 50%, morning P_{CO_2} greater than 45 mm Hg, symptomatic sleep-disordered breathing, or nocturnal hypoxemia. Sniff nasal pressure less than 40% or maximal inspiratory pressure less than 40 cm H_2O may be used rather than vital capacity in advanced stages of the disease to predict respiratory failure and/or death.

In an ALS cohort from Denmark over 15 years, approximately 42% of patients required only noninvasive ventilation, 17% received noninvasive support first then switched to invasive ventilation, and 5% proceeded directly to tracheostomy without attempting noninvasive ventilation.[29] Tracheostomy and invasive ventilation can be initiated in patients with severe bulbar function who cannot tolerate noninvasive ventilation or when noninvasive ventilation becomes difficult because of disease progression.[30] In a proportion of patients, invasive ventilation is initiated in the setting of acute respiratory deterioration rather than prophylactically as discussed previously. Following tracheostomy for acute respiratory failure, one study reported that 70% of patients with ALS were discharged completely ventilator dependent and 28% partially ventilator dependent. Only one patient was completely liberated from the ventilator.[31] Similar to previous studies, this case series found that quality of life and life satisfaction scores in patients receiving ventilator support could be sustained despite disease progression.

Neuromuscular Diseases

NMD refers to a heterogeneous population including those with muscular dystrophy (eg, Duchenne or Becker), myotonic dystrophy, and chest wall disorders. Home ventilation has been used for decades in Duchenne muscular dystrophy with significant improvements demonstrated in survival. Noninvasive ventilation should be initiated once vital capacity drops to less than 40% predicted because these patients are at significant risk for nocturnal hypercapnia and clinical deterioration within 1 to 2 years without ventilatory support. Nocturnal noninvasive support should also be offered in the presence of symptoms consistent with nocturnal hypoventilation, sleep-disordered breathing, nocturnal hypoxemia, or diurnal hypercapnia even without symptoms.[13] In patients requiring daytime ventilation, mouthpiece ventilation is an alternative to invasive tracheostomy. Invasive ventilation is typically established when chronic respiratory failure cannot be managed with noninvasive approaches or when insufficient swallowing and secretion management warrant a tracheostomy. However, there are some who argue that patients with muscular dystrophy may never require tracheostomy if managed correctly.[21] In the NMD population, 1-year survival after tracheostomy remains around 79%, although 50% of patients require hospitalization in the first year.[30,32]

LOGISTICS OF MECHANICAL VENTILATION

The intricacies of delivering long-term ventilation differ somewhat depending on the patient population involved. For example, infants and children with NMD comprise a sizable proportion of patients on home ventilation and have vastly different needs than patients with advanced COPD who are unable to wean from ventilatory support following acute exacerbation. Patients recovering from an acute illness are likely to be considered for ventilator weaning, whereas a patient with a progressive degenerative process may start off on nocturnal ventilation and gradually transition to 24-hour ventilator support. Nevertheless, there are many common issues to consider when making the transition from ICU to other venues for long-term ventilation, such as hospital step-down units, long-term acute care facilities (LTACs), skilled nursing facilities, or home.

Patient Considerations for Ventilation Outside the Intensive Care Unit

When beginning the process of transitioning to ventilation beyond an ICU, the first hurdle that must be overcome is patient stability. The patient's nonpulmonary medical problems need to have been stabilized. At a minimum this means that intravenous medications and cardiac monitoring are no longer necessary and a plan is in place for managing the patient's medical problems. Respiratory-specific considerations include being able to oxygenate adequately on Fio_2 of less than 0.4 to 0.5 with positive end-expiratory pressure less than 10 cm H_2O, having a stable tracheostomy tube, and tolerating stable ventilator settings. Secretions need to be manageable with coughing or suctioning.[6,12,33] The required overall stability of a patient varies based on where the patient is initially being transferred. A hospital step-down unit or LTAC can actively manage many complex medical issues, whereas a patient being transferred to a skilled nursing facility or home needs to be stable.

Sites of Service

Options for long-term ventilation range from acute hospitals, LTACs, skilled nursing facilities, and home. There are advantages and disadvantages to each of these sites and their use is determined in part by geography, reimbursement issues, medical issues, and patient preferences (Table 1). In some regions, ventilator patients may stay in ICUs or other parts of an acute hospital for months or longer because of lack of other available facilities. However, most hospitals have moved to avoid this because they often receive limited reimbursement after limits for diagnosis-related groups have been reached. Additionally, an ICU is not ideal for a long-term patient. They are not designed to allow for patient autonomy and have limited capacity to allow family members to spend time with patients and participate in their care. Long-term ventilator patients in ICUs tend to have higher cost of care and lower satisfaction compared with other sites of care.[6]

LTACs are another option that came to prominence during the 1990s. These can be free standing hospitals or may be housed within another hospital. LTACs are able to provide care to patients with multiple acute medical issues and have lengths of stay exceeding 25 days, although they may have the ability to house long-term ventilator patients for prolonged stays. Traditionally, Medicare reimbursement for LTACs per discharge is higher than for other acute facilities. Therefore, LTACs became particularly common in areas of the country

with large Medicare populations.[34] Advocates for LTACs argue that specialized rehabilitation provided in LTACs and better continuity of care may allow for better outcomes compared with ICUs, whereas others fear that fewer physicians and nurses per patient at LTACs may jeopardize care. Thus far, studies suggest that outcomes are comparable between LTACs and ICUs and costs may be lower in LTACs.[35,36] The population of long-term ventilation patients at LTACs is consistent with patients discharged from acute care ICUs who are unable to be weaned, that is, there is a high proportion of advanced COPD and patients recovering from acute lung injury/acute respiratory distress syndrome. The goal of LTACs in general is to continue weaning from mechanical ventilation and transition patients to home or care elsewhere. Cohort studies from LTACs suggest that more than half of their patients can be successfully weaned from ventilation.[37]

Freestanding nursing rehabilitation facilities are another option for the care of long-term ventilator patients. The number of these facilities that take ventilator patients varies throughout the country and accurate numbers are difficult to obtain, but as a reference figure, there are approximately 50 nursing homes in New York state that take ventilator patients.[34] Ventilator patients transferred from hospitals to nursing homes are more similar to home ventilator patients than LTAC patients. Their medical problems need to be stable and they need to have adequate oxygenation on 40% to 50% oxygen and positive end-expiratory pressure less than or equal to 10 cm H_2O. Many nursing homes are capable of weaning patients and often have populations that transition to home, some on ventilation, and some having been liberated. In 2007, the reimbursement rate per discharge was approximately $20,000 less than for LTACs.[34] Factors that delay or prevent patients from transitioning home on mechanical ventilation include lack of suitable housing, social issues related to the patient's family, delays in equipment funding, and inadequate home nursing care.[38]

Home ventilation is the ideal location for long-term ventilation. It is more cost effective than other venues for ventilation. In 1992, home ventilation was estimated to cost one-third as much per day compared with a hospital setting.[39] Living at home provides many of the psychosocial benefits missing from hospitals, LTACs, or nursing homes. Patients have autonomy and are surrounded by loved ones. Home ventilation leads to better quality of life and fewer infections compared with other sites of care.[40] For long-term ventilator patients, home ventilation should be the goal. However, many families do not have adequate resources to allow for it.

Equipment for Long-Term Ventilation

Long-term ventilation in the home is often described as the most complex medical intervention that is done outside the hospital and an extensive amount of equipment and personnel is needed for it to be successful (Table 2).[41] Nonrespiratory equipment includes a wheelchair; lift; commode chair; shower chair; transportation, such as adaptive van; hospital bed; gastrostomy supplies; feeding pump; and patient communication tools. Tracheostomy supplies include replacement tubes, inner cannulae, tracheostomy dressings, hydrogen peroxide, syringes for cuff deflation/inflation, and gloves.[12] Ventilator-related equipment could include a portable suction machine, tubing, and catheters. Many patients require supplemental oxygen and therefore need both stationary and portable oxygen. Patients often

need a stationary oxygen concentrator and oxygen tanks. Humidification is necessary and in general a heated humidifier is preferable to a heat-humidity exchanger, although the latter is useful for mobility and is adequate as the only humidifier in some patients.[13]

There are many different ventilators well suited for home use. Ventilators used outside of the hospital need to be smaller and lighter than traditional ICU ventilators. In the past, the available settings on home ventilators were quite limited but now most ventilators offer a variety of volume-targeted and pressure-targeted modes. Many of today's home ventilators can be set up with either a dual-limb circuit, with separate inspiratory and expiratory limbs, or with a single limb for inhalation and exhalation. The former closed system allows for tighter monitoring of ventilator parameters and higher levels of ventilator support. Single-limbed, open systems, require less tubing; may be easier to set up; and are better suited to dealing with intentional leaks, such as from cuffless tracheostomy tubes. Older home ventilators were generally limited to basic volume-targeted ventilation and had limited options for mobility. Newer home ventilators have internal batteries that allow up to 9 hours of battery life and can also be connected to external lithium ion batteries. The CMS and insurers have divided devices into ventilators and respiratory assist devices (RAD). CMS considers devices with separate exhalation valves capable of volume-targeted modes as ventilators, and bilevel positive pressure devices used for noninvasive ventilation as RADs.[6] This distinction has been used for years to determine Medicare coverage decisions. Ventilators have been billed as an ongoing monthly rental, whereas RADs were covered for a 13-month rent-to-own schedule. At the time of this writing, CMS is in the process of changing the Healthcare Common Procedure Coding System for ventilators and the distinctions between ventilators and RADs have become blurred because there are devices available now that can be used noninvasively as a bilevel positive pressure device or as a volume-targeted ventilator via a cuffed endotracheal tube or tracheostomy tube. It is beyond the scope of this article to provide detailed reviews of specific ventilators, but there are many ventilators available that are lightweight, quiet, and can provide safe ventilator support in all commonly used modes. Patients may notice differences between ventilators and may prefer one to another.[42] It is the authors' experience that the choice of ventilator is frequently determined by the durable medical equipment provider, because they often have contracts with certain manufacturers. However, if a clinician or patient has a strong reason for selecting a particular device, this may be achievable with persistent communication to the durable medical equipment provider and adequate letters of medical necessity. There are little data to indicate that any particular mode of ventilation is superior to others for long-term home ventilation. A variety of modes, including noninvasive ventilation, has been compared and has been shown to be successful for maintaining improvements in P_{CO_2}.[43] A consensus statement from 1998, although outdated, made reasonable recommendations to use standard tidal volumes or pressures adequate to achieve those tidal volumes and advocated for using the assist-control (either volume- or pressure-targeted) mode. The backup rate should be set low enough for triggering in patients with an ability to trigger and with an intact respiratory drive, but should be set high enough to maintain CO_2 levels for those patients that cannot trigger the ventilator.[12] It was suggested that synchronized intermittent mandatory ventilation should be avoided,[44] because opening the demand valve

on portable ventilators may increase the work of breathing. It is unclear if this is still a concern on newer devices.

Monitoring Long-Term Ventilator Patients

The possibility of ventilator failure, other equipment malfunctions, and maintaining the cleanliness of ventilator tubing are common device challenges experienced in the home care setting. It has been estimated that a ventilator failure occurs for every 1.25 years of continuous use.[6] Reports of home mechanical ventilator failure indicate that defective equipment, mechanical failure, and equipment improperly used by caregivers are the most commonly reported device problems in the home.[45] Patients who cannot maintain spontaneous ventilation for 4 or more hours and those who live in an area where a replacement ventilator cannot be provided within 2 hours should be furnished with a back-up ventilator in case of device failure.[33] Access to back-up ventilators is not always provided by insurance agencies,[6] so careful planning of emergency procedures, use of alarms to alert caregivers of an emergent event, and access to 24-hour technology support for trouble shooting is highly recommended.[33,46]

Monitoring of home ventilation patients is most frequently limited to pulse oximetry because end-tidal CO_2 monitoring is rarely used.[47] Ventilators should be equipped with a patient disconnect (low pressure) alarm and a high-pressure alarm. Patients generally need to have at least two family members that can be available around the clock to provide care.[38] Additionally, most home ventilated patients have nursing assistance, although the hours of supported nursing care varies greatly depending on the patient's age, complexity, and insurance coverage. Family members are often expected to do complicated care including suctioning and tracheostomy tube changes.[47] Studies of home nurses involved in care of ventilator patients have found that they do not always receive adequate training for emergency situations[48] and often are in a challenging situation as a guest in the patient's home.[41] A possible solution to this paucity of skilled nurses is to further explore the use of telemedicine in monitoring home ventilation patients. A study by Vitacca and colleagues[49] monitored 13 patients on invasive home mechanical ventilation through modem transmission of oxygen saturation along with scheduled and as needed telephone calls. Approximately 86% of the identified problems were able to be managed by home nursing, and the remote nurses were able to identify problems that required hospitalization. This use of centralized monitoring with mobilization of nurses as needed could help maximize the availability of resources.

Airway Management

The sterile procedures for tracheostomy care often performed in acute care settings are not required in the home setting, although caregivers should be trained on appropriate aseptic techniques to minimize unnecessary pathogen exposure.[13,46] Tracheostomy sites pose a particular challenge to the success of invasive home mechanical ventilation. A study by Edwards and colleagues[50] presented mortality data of children receiving invasive home ventilation and found that 8.5% died as a result of bleeding complications from their tracheostomy sites, 8.5% died as a result of airway obstructions, and 2% died as a result of other tracheostomy accidents.[6,50] Uncuffed tracheostomy tubes are the preferred method of

airway maintenance for those who retain a cough and gag reflex, are able to swallow, and can breathe on their own.[51] Complications from uncuffed tubes include bleeding, tracheitis, recurrent pneumonia, tracheal-esophageal fistula development, and lung entrapment (eg, atelectasis or collapse with prolonged ventilatory support).[13,30] Cuffed tubes are appropriate in those who are a high risk for aspiration, but limit speech and can lead to tracheal necrosis from overinflated cuffs. It is recommended that cuff pressure not exceed 25 cm H_2O to prevent tissue damage.[52] Once lost, regaining speech ability is a difficult process and patients may need support in accepting that their voice quality may be permanently changed.[53] The availability of electronic devices with audio software, computers, and alarms helps patients feel less isolated and allows for communication of needs to caregivers if uncuffed tubes are not an option.

Respiratory events, although common and expected,[54] can typically be managed by nursing staff or trained caregivers through minimally invasive suctioning, coughing to clear secretions if patient is able, inner cannula replacement, and use of mechanical insufflation-exsufflation to mimic a cough response.[13] A study by Reiter and colleagues[55] concluded a significant number of emergency respiratory events are often handled at home without the need for acute medical interventions. A replacement tracheostomy tube of the appropriate size and one size smaller should be available at all times[33] in case of accidental decannulation, along with other emergency equipment as outlined by the AARC (American Association of Respiratory Care) 2007 practice guidelines. Moreover, caregivers should be trained to respond to airway-related emergencies. A survey of home ventilated children in Italy reported that 39% of family caregivers have successfully replaced tracheostomy tubes.[47] The newly ventilated patient requires special consideration because they may have an increased risk of a respiratory event within the first few months of starting ventilation.[54] Steiglitz and colleagues reported that 50% of 17 newly ventilated patients experienced a respiratory event requiring the use of a manual resuscitation bag or a tracheostomy tube replacement within 2 months of being placed on mechanical ventilation. Ongoing education and training of lay caregivers and nursing staff regarding response to respiratory emergencies is highly recommended.[13,33,48]

Ventilator-associated infections are a common problem in long-term ventilation patients and home ventilator patients often do not adhere to cleaning protocols as well as recommended. A study in Belgium found that 69% of home vent circuits were visually dirty, and this was more common in invasive ventilation than noninvasive. Patients with tracheostomy were also more likely to have colonization of tubing with potentially pathogenic organisms.[56] The 2007 AARC guidelines for home ventilation recommends that ventilator circuits should be changed at a minimum of once per week, although other published guidelines recommend changing only when tubing is visibly soiled.[57,58] Dishwashing is effective at cleaning and disinfecting ventilator circuits.[56]

Secretion Clearance

Although ensuring adequate ventilation is generally the essential component of mechanical ventilation, many of these patients have inadequate ability to cough and clear secretions on their own. Appropriate ventilation is only achieved if the airways are kept free of mucus

plugs.[13] Suctioning is performed routinely for most patients on long-term invasive ventilation but is less effective compared with mechanical insufflation-exsufflation. A mechanical insufflator-exsufflator (MI-E) is a device that applies positive pressure (often 30–40 cm H_2O) to the airway and then rapidly cycles to a negative pressure (−30 to −40 cm H_2O), thereby simulating the action of a cough and generating high expiratory pressures. Sancho and colleagues[59] assessed oxygen saturation, peak inspiratory pressure, and work of breathing before and after suctioning and after MI-E. MI-E resulted in improvements in oxygen saturation and decreased peak pressures that were not seen with suctioning. The Canadian Thoracic Society recommends that MI-E be considered in addition to or as a replacement to deep suctioning.[13]

Ethical Issues and Terminal Care

There are many ethical challenges that can arise when pursuing long-term ventilation. These are considered within the common ethical principles of autonomy, beneficence, justice, and nonmaleficence.[60] Ideally, discussions about a patient's wishes regarding long-term ventilation are held in advance when patients can voice their desires. Unfortunately, this is often not possible and clinicians need to be aware of particularly influential family members who may override a patient's wishes. Health care providers are often at odds on questions of beneficence in patients with end-stage disease and whether long-term ventilation is in their best interest. Issues of justice are common in the United States and worldwide when it comes to long-term ventilation, because the availability of resources varies greatly from region to region and decisions regarding home ventilation are often made based on insurance coverage, available family support, and available nursing care. Lastly, nonmaleficence is of importance to the ventilator patient and also their caregivers because studies have shown a great deal of stress and depression in caregivers of ventilator patients.[61] It is important for clinicians to be aware that terminal withdrawal of ventilator support can be done outside of the ICU, even in the home.[62] One series of patients with ALS in the Netherlands describes 12 patients who after a median time on invasive ventilation of 22 months, chose to discontinue ventilation. This decision was based on a general "loss of meaning in life." The patients were given deep sedation before discontinuing mechanical ventilation and all cases were believed to be medically, legally, and ethically justified.[63]

SUMMARY

The use of PMV has increased over the years because of improved outcomes in critically ill and chronically progressive conditions. Noninvasive ventilation is the preferred approach for many causes of respiratory failure, but many patients are supported for years through invasive ventilation. The transition from an ICU to other settings for PMV is complicated and requires a large amount of medical equipment and orchestration among physicians, nurses, discharge planners, home care agencies, insurers, case managers, and family members. When it can be arranged, home is the preferred setting for PMV because of reduced costs to the health care system, better health outcomes, and increased quality of life. Resource limitations including unstable living conditions and family dynamics, and limited access to skilled caregivers are recognized as significant challenges to home mechanical ventilation. Care-givers, including family members and nursing staff, must be trained in

tracheostomy care, airway clearance, and responses to emergency situations, such as device failure, but studies show that most patient needs are safely and successfully addressed in the home setting. Disease progression and quality of life should be carefully considered throughout PMV use, and advanced directives for care should be obtained to help guide decision making in regards to terminal withdrawal.

REFERENCES

1. Engoren M, Arslanian-Engoren C, Fenn-Buderer N. Hospital and long-term outcome after tracheostomy for respiratory failure. Chest 2004;125:220–7. [PubMed: 14718444]
2. Carson SS. Outcomes of prolonged mechanical ventilation. Curr Opin Crit Care 2006;12:405–11. [PubMed: 16943717]
3. Cox C, Carson SS, Holmes G, et al. Increase in tracheostomy for prolonged mechanical ventilation in North Carolina, 1993–2002. Crit Care Med 2004;32: 2219–26. [PubMed: 15640633]
4. Esteban A, Frutos F, Tobin MJ, et al. A comparison of four methods of weaning patients from mechanical ventilation. Spanish Lung Failure Collaborative Group. N Engl J Med 1995;332:345–50. [PubMed: 7823995]
5. Divo MJ, Murray S, Cortopassi F, et al. Prolonged mechanical ventilation in Massachusetts: the 2006 prevalence survey. Respir Care 2010;55:1693–8. [PubMed: 21122178]
6. King AC. Long-term home mechanical ventilation in the United States. Respir Care 2012;57:921–30 [discussion: 30–2]. [PubMed: 22663967]
7. MacIntyre NR, Epstein SK, Carson S, et al. Management of patients requiring prolonged mechanical ventilation: report of a namdrc consensus conference. Chest 2005;128:3937–54. [PubMed: 16354866]
8. Gracey DR, Naessens JM, Krishan I, et al. Hospital and posthospital survival in patients mechanically ventilated for more than 29 days. Chest 1992;101: 211–4. [PubMed: 1729073]
9. Douglas SL, Daly BJ, Gordon N, et al. Survival and quality of life: short-term versus long-term ventilator patients. Crit Care Med 2002;30:2655–62. [PubMed: 12483055]
10. Spicher JE, White DP. Outcome and function following prolonged mechanical ventilation. Arch Intern Med 1987;147:421–5. [PubMed: 3827415]
11. Scheinhorn DJ, Chao DC, Hassenpflug MS, et al. Post-ICU weaning from mechanical ventilation: the role of long-term facilities. Chest 2001;120:482S–4S. [PubMed: 11742970]
12. Make BJ, Hill NS, Goldberg AI, et al. Mechanical ventilation beyond the intensive care unit: report of a consensus conference of the American College of Chest Physicians. Chest 1998;113:289S–344S. [PubMed: 9599593]
13. McKim DA, Road J, Avendano M, et al. Home mechanical ventilation: a Canadian Thoracic Society clinical practice guideline. Can Respir J 2011;18: 197–215. [PubMed: 22059178]
14. Zimmer MB, Nantwi K, Goshgarian HG. Effect of spinal cord injury on the respiratory system: basic research and current clinical treatment options. J Spinal Cord Med 2007;30:319–30. [PubMed: 17853653]
15. Como J, Sutton E, McCunn M, et al. Characterizing the need for mechanical ventilation following cervical spinal cord injury with neurologic deficit. J Trauma 2005;59:912–6. [PubMed: 16374281]
16. DeVivo M, Ivie C. Life expectancy of ventilator-dependent persons with spinal cord injuries. Chest 1995;108:226–32. [PubMed: 7606963]
17. Shavelle RM, DeVivo MJ, Strauss DJ, et al. Long-term survival of persons ventilator dependent after spinal cord injury. J Spinal Cord Med 2006;29:511–9. [PubMed: 17274490]
18. Nelson VS, Dixon P, Warchausky S. Long-term outcomes of children with high tetraplegia and ventilator dependence. J Spinal Cord Med 2004;27: S93–7. [PubMed: 15503710]
19. Hall KM, Knudsen ST, Wright J, et al. Follow-up study of individuals with high tetraplegia (c1-c4) 14 to 24 years postinjury. Arch Phys Med Rehabil 1999;80:1507–13. [PubMed: 10569448]
20. Bach JR, Tilton M. Life satisfaction and well-being measures in ventilation assisted individuals with traumatic tetraplegia. Arch Phys Med Rehabil 1994;75:626–32. [PubMed: 8002759]

21. Huttmann SE, Windisch W, Storre JH. Invasive home mechanical ventilation: living conditions and health-related quality of life. Respiration 2015;89:312–21. [PubMed: 25791249]
22. Pilcher DV, Bailey MJ, Treacher DF, et al. Outcomes, cost and long term survival of patients referred to a regional weaning centre. Thorax 2005;60:187–92. [PubMed: 15741433]
23. Davidson AC. The pulmonary physician in critical care. 11: critical care management of respiratory failure resulting from COPD. Thorax 2002;57: 1079–84. [PubMed: 12454305]
24. Modawal A, Candadai NP, Mandell KM, et al. Weaning success among ventilator-dependent patients in a rehabilitation facility. Arch Phys Med Rehabil 2002; 83:154–7. [PubMed: 11833016]
25. Weiss S, Van Egmond-Frohlich A, Hofer N, et al. Long-term respiratory support for children and adolescents in Austria: a national survey. Klin Padiatr 2016;228:42–6. [PubMed: 26697738]
26. Tuggey JM, Plant PK, Elliott MW. Domiciliary non-invasive ventilation for recurrent acidotic exacerbations of COPD: an economic analysis. Thorax 2003;58:867–71. [PubMed: 14514940]
27. Haverkamp LJ, Appel V, Appel SH. Natural history of amyotrophic lateral sclerosis in a database population validation of a scoring system and a model for survival prediction. Brain 1995;118:707–19. [PubMed: 7600088]
28. Bourke SC, Tomlinson M, Williams TL, et al. Effects of non-invasive ventilation on survival and quality of life in patients with amyotrophic lateral sclerosis: a randomised controlled trial. Lancet Neurol 2006; 5:140–7. [PubMed: 16426990]
29. Dreyer P, Lorenzen CK, Schou L, et al. Survival in ALS with home mechanical ventilation noninvasively and invasively: a 15-year cohort study in west Denmark. Amyotroph Lateral Scler Frontotemporal Degener 2014;15:62–7. [PubMed: 24067168]
30. Rafiq MK, Proctor AR, McDermott CJ, et al. Respiratory management of motor neurone disease: a review of current practice and new developments. Pract Neurol 2012;12:166–76. [PubMed: 22661348]
31. Vianello A, Arcaro G, Palmieri A, et al. Survival and quality of life after tracheostomy for acute respiratory failure in patients with amyotrophic lateral sclerosis. J Crit Care 2011;26:329.e7–14.
32. Sancho J, Servera E, Diaz JL, et al. Home tracheotomy mechanical ventilation in patients with amyotrophic lateral sclerosis: causes, complications and 1-year survival. Thorax 2011;66:948–52. [PubMed: 21693569]
33. AARC, Respiratory Home Care Focus Group. AARC clinical practice guideline. Long-term invasive mechanical ventilation in the home: 2007 revision & update. Respir Care 2007;52: 1056–62. [PubMed: 17715560]
34. White AC, O'Connor HH, Kirby K. Prolonged mechanical ventilation: review of care settings and an update on professional reimbursement. Chest 2008;133:539–45. [PubMed: 18252920]
35. Seneff MG, Wagner D, Thompson D, et al. The impact of long-term acute-care facilities on the outcome and cost of care for patients undergoing prolonged mechanical ventilation. Crit Care Med 2000;28:342–50. [PubMed: 10708164]
36. Kahn JM, Werner RM, David G, et al. Effectiveness of long-term acute care hospitalization in elderly patients with chronic critical illness. Med Care 2013;51:4–10. [PubMed: 22874500]
37. Scheinhorn DJ, Hassenpflug MS, Votto JJ, et al. Post-ICU mechanical ventilation at 23 long-term care hospitals: a multicenter outcomes study. Chest 2007;131:85–93. [PubMed: 17218560]
38. Amin R, Sayal A, Syed F, et al. How long does it take to initiate a child on long-term invasive ventilation? Results from a Canadian pediatric home ventilation program. Can Respir J 2015; 22:103–8. [PubMed: 25848720]
39. Bach JR, Intintola P, Alba AS, et al. The ventilator-assisted individual. Cost analysis of institutionalization vs rehabilitation and in-home management. Chest 1992;101:26–30. [PubMed: 1729079]
40. Marchese S, Lo Coco D, Lo Coco A. Outcome and attitudes toward home tracheostomy ventilation of consecutive patients: a 10-year experience. Respir Med 2008;102:430–6. [PubMed: 18023334]
41. Dybwik K, Nielsen EW, Brinchmann BS. Home mechanical ventilation and specialised health care in the community: between a rock and a hard place. BMC Health Serv Res 2011;11:115. [PubMed: 21605365]
42. Senent C, Lepaul-Ercole R, Chiner E, et al. Home mechanical ventilators: the point of view of the patients. J Eval Clin Pract 2010;16:832–4. [PubMed: 20557413]

43. Duiverman ML, Bladder G, Meinesz AF, et al. Home mechanical ventilatory support in patients with restrictive ventilatory disorders: a 48-year experience. Respir Med 2006;100:56–65. [PubMed: 15939581]
44. Kacmarek RM, Stanek KS, McMahon KM, et al. Imposed work of breathing during synchronized intermittent mandatory ventilation provided by five home care ventilators. Respir Care 1990; 35:10.
45. Chatwin M, Heather S, Hanak A, et al. Analysis of home support and ventilator malfunction in 1,211 ventilator-dependent patients. Eur Respir J 2010; 35:310–6. [PubMed: 19643945]
46. Escarrabill J. Organisation and delivery of home mechanical ventilation. Breathe 2009;6:6.
47. Racca F, Berta G, Sequi M, et al. Long-term home ventilation of children in Italy: a national survey. Pediatr Pulmonol 2011;46:566–72. [PubMed: 21560263]
48. Kun SS, Beas VN, Keens TG, et al. Examining pediatric emergency home ventilation practices in home health nurses: opportunities for improved care. Pediatr Pulmonol 2015;50:691–7. [PubMed: 24706404]
49. Vitacca M, Assoni G, Pizzocaro P, et al. A pilot study of nurse-led, home monitoring for patients with chronic respiratory failure and with mechanical ventilation assistance. J Telemed Telecare 2006;12: 337–42. [PubMed: 17059649]
50. Edwards JD, Kun SS, Keens TG. Outcomes and causes of death in children on home mechanical ventilation via tracheostomy: an institutional and literature review. J Pediatr 2010;157:955–9.e2. [PubMed: 20713294]
51. Barnett M Back to basics: caring for people with a tracheostomy. Nursing and Residential Care 2012; 14:5.
52. Alzahrani AR, Al Abbasi S, Abahoussin OK, et al. Prevalence and predictors of out-of-range cuff pressure of endotracheal and tracheostomy tubes: a prospective cohort study in mechanically ventilated patients. BMC Anesthesiol 2015;15:147. [PubMed: 26471790]
53. Laakso K, Markstrom A, Idvall M, et al. Communication experience of individuals treated with home mechanical ventilation. Int J Lang Commun Disord 2011;46:686–99. [PubMed: 22026570]
54. Stieglitz S, George S, Priegnitz C, et al. Frequency and management of respiratory incidents in invasive home ventilation. Chron Respir Dis 2013;10:135. [PubMed: 23897929]
55. Reiter K, Pernath N, Pagel P, et al. Risk factors for morbidity and mortality in pediatric home mechanical ventilation. Clin Pediatr 2011;50:237–43.
56. Toussaint M, Steens M, Van Zeebroeck A, et al. Is disinfection of mechanical ventilation tubing needed at home? Int J Hyg Environ Health 2006; 209:183–90. [PubMed: 16376145]
57. Hess D, Burns E, Romagnoli D, et al. Weekly ventilator circuit changes. A strategy to reduce costs without affecting pneumonia rates. Anesthesiology 1995;82:903–11. [PubMed: 7717562]
58. Kollef MH, Shapiro SD, Fraser VJ, et al. Mechanical ventilation with or without 7-day circuit changes. A randomized controlled trial. Ann Intern Med 1995; 123:168–74. [PubMed: 7598297]
59. Sancho J, Servera E, Vergara P, et al. Mechanical insufflation-exsufflation vs. tracheal suctioning via tracheostomy tubes for patients with amyotrophic lateral sclerosis: a pilot study. Am J Phys Med Rehabil 2003;82:750–3. [PubMed: 14508404]
60. Dybwik K, Nielsen EW, Brinchmann BS. Ethical challenges in home mechanical ventilation: a secondary analysis. Nurs Ethics 2012;19:233–44. [PubMed: 22183963]
61. Douglas SL, Daly BJ. Caregivers of long-term ventilator patients: physical and psychological outcomes. Chest 2003;123:1073–81. [PubMed: 12684296]
62. Lanken PN, Terry PB, Delisser HM, et al. An official American Thoracic Society clinical policy statement: palliative care for patients with respiratory diseases and critical illnesses. Am J Respir Crit Care Med 2008;177:912–27. [PubMed: 18390964]
63. Dreyer PS, Felding M, Klitnaes CS, et al. Withdrawal of invasive home mechanical ventilation in patients with advanced amyotrophic lateral sclerosis: ten years of Danish experience. J Palliat Med 2012;15: 205–9. [PubMed: 22283411]

KEY POINTS

- The population of patients using long-term noninvasive and invasive ventilation has been growing over the last two decades, requiring better resources to support ventilation outside of hospitals.
- Long-term ventilation is performed in a variety of settings including long-term acute care facilities, skilled nursing facilities, and home. The latter provides better quality of life and greater satisfaction at lower cost, but poses challenges that prevent some from using it.
- The equipment available for long-term ventilation has improved and is good but issues of reimbursement and availability of trained caregivers are ongoing problems.

Table 1

Prolonged mechanical ventilation settings for care

Setting	Pros	Cons
ICU	Optimal medical and staffing resources to respond to changes in respiratory status	• High costs of care • Limited Medicare reimbursement • Competing bed space with the acutely ill • Limited psychosocial and family support
LTAC	• Designed to support acute care patients requiring specialized care and rehabilitation services • Lower costs compared with ICUs • Higher discharge reimbursements compared with ICUs	• Increased patient/staff ratios may jeopardize care compared with ICUs • Long-term goals of care are to wean off ventilators or to transition to home, not to support lifetime PMV
Nursing home	• Alternative to at-home care when family support and/or resources are inadequate • Can support those requiring lifetime PMV, and those who may be weaned in time	• Varying accessibility of facilities • Must be medically stable • Lower discharge reimbursements compared with LTAC facilities
Home	• Increased quality of life through family caregiving, psychosocial support, and increased patient autonomy • Most cost-effective setting • Reduced infection rates	• Must be medically stable • Requires a stable and safe home environment • Requires considerable family and professional caregiver support • Continued emergency response education required for all caregivers

Table 2

Equipment for home ventilation

Mobility and Other Accessories	Ventilator-Related Equipment	Tracheostomy-Related Supplies
Wheelchair	Primary ventilator	Inner cannulae
Lift	Backup ventilator	Replacement tracheostomy tubes
Commode chair	Manual resuscitation bag	Suction machine
Shower chair	Replacement circuits	Suction catheters
Adaptive van	Heated humidifier	Saline bullets
Hospital bed	Heat/moisture exchanger	Syringes
Communication devices	Tube feed pump	Rubber gloves
Pulse oximeter	Oxygen concentrator/tanks	Tracheostomy dressings
Hydrogen peroxide	Generator	
Mechanical inexsufflator		