Section 2: Initiation of in-hospital long-term mechanical ventilation and transition to home

Ian MacLusky, Reshma Amin & David Zielinski on behalf of the CTS Pediatric Home Ventilation Guidelines Panel

To cite this article: Ian MacLusky, Reshma Amin & David Zielinski on behalf of the CTS Pediatric Home Ventilation Guidelines Panel (2018) Section 2: Initiation of in-hospital long-term mechanical ventilation and transition to home, Canadian Journal of Respiratory, Critical Care, and Sleep Medicine, 2:sup1, 5-15, DOI: 10.1080/24745332.2018.1494490

To link to this article: https://doi.org/10.1080/24745332.2018.1494490

Published online: 23 Oct 2018.

Submit your article to this journal

Article views: 483

View related articles

View Crossmark data
Section 2: Initiation of in-hospital long-term mechanical ventilation and transition to home

Ian MacLuskya, Reshma Aminb,c, and David Zielinski d on behalf of the CTS Pediatric Home Ventilation Guidelines Panel

Introduction

There is very little comparative literature on the precise indications and patient selection process, optimal timing, or optimal methodology for successful initiation of home mechanical ventilation (HMV). Studies describe marked variability in frequency, types of patients and patterns of ventilation between different centers, while the field continue to evolve. What literature there is generally describes the types of individuals treated, how ventilation was initiated and some outcome data (with little of this data specific to pediatrics). Most programs have developed criteria and protocols for initiation of HMV based largely on empirical experience. Although these protocols are generally fairly similar, being based on similar experiences and therapeutic goals, there is still a lack of agreement, and even less objective data, as to precisely who would benefit from long-term HMV or exactly when in the child’s disease process it should be optimally initiated. Driven by costs, recognition that long-term institutionalization is a far-from-ideal environment for both child and family and development of technology that allows for children on long-term ventilation to be safely cared for at home, the stated goal in almost every program is for long-term ventilation to occur within the home environment. Consequently, consideration of the practicalities of discharge to home need to be an integral component of the decision-making process. Given that these children, by definition, are facing life-limiting illnesses, and that caring for these children at home has a huge impact on family finances and functioning, the relative absence of objective evidence providing support for these protocols is problematic.

Results

We retrieved 2760 English-language publications that were relevant to our inclusion criteria and dealing with HMV in children. There were 547 duplicates. The abstracts of the remaining 2213 articles were reviewed to ensure the content was relevant. We excluded editorials, commentaries and review articles. A total of 33 articles were included.

Discussion

Initiation of ventilation: Summary of the literature

Most published articles describe the course in hospital and the discharge process; the majority of the papers are commentaries, editorials or review articles. We found a total of eight articles from Turkey, US, Italy, the UK and Canada that reported on the length of stay for children initiated on long-term invasive ventilation for the first time. This ranged between 46 days to 9.6 months. For NIV, the majority of patients are initiated as an outpatient or in a polysomnography (PSG) laboratory. Barriers that were encountered during the discharge process can be classified into eight categories: 1) housing issues (e.g., lack of running water or electricity); 2) funding of equipment; 3) receiving equipment for home; 4) social issues related to the family; 5) illness of the child from another disease; 6) issues with community caregivers (e.g., inconsistent caregivers, lack of training of caregivers in the community) or arranging out-of-home placements; 7) lack of a coordinated approach to discharge and the absence of a clear coordinator; and 8) delays in organizational decision making and attitudes of professionals. For example, some parental caregivers have reported that their children stayed in hospital for prolonged periods of time because some professionals did not think the families could cope at home, while other healthcare providers felt the children were safer in hospital.

Most papers simply describe which individuals were placed on long-term ventilation, how ventilation was initiated and some outcome data (Table 1). There are also usually descriptions of the various components to be established in the HMV program. Even with adult programs there is rarely, however, any detailed description as to:

a. the specific criteria (other than hypercapnea) used to determine that long-term ventilation was appropriate or required

b. the processes involved in evaluating and providing family and patient education
<table>
<thead>
<tr>
<th>Author (Year)</th>
<th>Objectives</th>
<th>Study design</th>
<th>Study population</th>
<th>Sample size</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appierto (2002)</td>
<td>15 year retrospective review of outcomes of children discharged home from the intensive care unit</td>
<td>Retrospective review</td>
<td>Children with chronic respiratory failure using ventilation at home</td>
<td>34</td>
<td>Length of stay, median (range): 109.5 (54–214)</td>
</tr>
<tr>
<td>Graf (2008)</td>
<td>Design an educational program and timeline for discharge of children on tracheostomy</td>
<td>Retrospective Pilot Case Series over 24 months</td>
<td>Newly initiated tracheostomy patients; 61 depended on positive pressure ventilation</td>
<td>70</td>
<td>Length of stay (median): 46 days Barriers to discharge: social issues (lack of sibling care), intercurrent illness, language barriers, unavailability of home nursing, lack of running water, lack of funding, lack of electricity and telephone, lack of housing, parental fear, delay in completion of caregiver education, discharge disposition, medical equipment delays, inconsistent caregivers time needed for caregiver training median (range): 14 days (5–110)</td>
</tr>
<tr>
<td>Noyes (2002)</td>
<td>Identification of barriers that prevented discharge from the hospital</td>
<td>Retrospective, qualitative interviews</td>
<td>Children and family caregivers of children that had been admitted to hospital for initiation of long-term ventilation</td>
<td>34 children</td>
<td>25 family caregivers</td>
</tr>
<tr>
<td>DeWitt (1993)</td>
<td>Identification of factors that delayed hospital discharge to home from the point of medical stability</td>
<td>Retrospective review</td>
<td>Ventilator-assisted children who were discharged home on ventilation</td>
<td>54 children</td>
<td>Length of stay in hospital mean (SD): 172 (161) days. Time to achieve medical stability mean (SD): 55 (67) days. Time to arrange homecare 18 (144) days or 73 (29) percent of the total admission Time for parent training: 52 (65) days 27 children were successfully discharged home; seven died but none as a result of ventilation failure at home</td>
</tr>
<tr>
<td>Edwards (2004)</td>
<td>Describe experience over the past seven years of coordinating the discharge home of ventilator-assisted children</td>
<td>Retrospective review</td>
<td>Ventilator-assisted children initiated on long-term invasive ventilation</td>
<td>39 children</td>
<td>Length of stay in hospital, median (range): 9.6 months (3.6 months to 3.5 years) Barriers to discharge: funding for staffing and equipment, local organizational delays (defined as delays in decision making at a local level), both of which occurred in 41% of cases, housing and family issues: - 33% of cases had unsuitable family homes - 15% had significant family or social reasons - 15% had the child’s medical condition change, which affected the level of support</td>
</tr>
<tr>
<td>Fraser (1998)</td>
<td>To determine why children become dependent on mechanical ventilation and what their outcomes are</td>
<td>Retrospective review</td>
<td>Ventilator-assisted children who required ventilation for more than 28 days</td>
<td>40 children</td>
<td>Length of stay from tracheostomy to home, median (IQR): 78 (44–254) - children spent on average 2.6 months (75% of their length of stay) awaiting discharge after medical stability</td>
</tr>
<tr>
<td>Oktem (2008)</td>
<td>Review clinical conditions and outcome of children who were discharged from the hospital on respiratory support</td>
<td>Retrospective review</td>
<td>Children receiving ventilator support at home for more than three months</td>
<td>34</td>
<td>Length of stay: median (range): 64 (3–180) waiting in hospital to be discharged Barriers to discharge: delay in obtaining equipment</td>
</tr>
</tbody>
</table>
Goldberg (1990)\(^{10}\) Ascertain needs, resources, generate recommendations and recruit community involvement

Prospective survey

453 ventilator-assisted individuals

453 ventilator assisted individuals; 27 were children

Barriers to discharge: inadequate payment for community-based services, limited community resources, constrained consumer finances, lack of access to information

Recommendations for future: establishing a technology transfer system, homecare case management, integrated management system, documentation center, trials and demonstrations prior to program and policy development

Tearl (2006)\(^{7}\) To determine if there are benefits to a dedicated RT discharge coordinator system

Prospective pre- and post-study

Parental caregivers of children newly initiated on ventilation

Length of stay, mean (SD) Pre: 82 (45) Post: 48 (44), \(p = 0.06\)

Patient satisfaction: statistically significant increases in the number of times the home equipment companies:
- did not receive family requests for assistance
- did not note inadequate family knowledge of equipment
- did not note deficiencies in family performance
- did not find that the home equipment selected best suited the patient \((p < 0.001)\)
- after implementation, the multidisciplinary team members had increased satisfaction with the discharge process \((p < 0.001)\)

Amin (2015)\(^{8}\) To report the length of stay needed to initiate children on long-term mechanical ventilation at home

Retrospective review

Children initiated on invasive ventilation at home via tracheostomy

Length of stay median (interquartile range) 162 (98–279) days

Kun (2010)\(^{33}\) Determine how much primary caregivers know about tracheostomy and home ventilator emergency care

Prospective questionnaire study

Primary caregivers (PC): parental and nurses

- Mean score was 20.2 (81%)
- 96 PCs (63%) did not know that the low pressure alarm would not sound if the tracheostomy tube was decannulated while still connected to the ventilator
- 79 PCs (52%) failed to understand high pressure mucus plugging
- 66 PCs (43%) did not know how much power a battery stored after the suction machine was fully charged
- 61 PCs (40%) did not know when the low pressure or low minute volume alarm sounds
- 56 PCs (37%) relied on the ventilator alarm to determine the presence of mucus plugs
- the experience of the PCs did not make a difference in their knowledge of HMV emergency care at home; alarms sound and the length of time the child was on HMV did not affect the scores
- parental caregivers scored as well as nurses

Conclusion-more in depth education on the technical aspects of ventilator alarms and tracheal mucous plugging may help to reduce or prevent emergencies among children on HMV
1. **Indications for initiation of HMV:** As with any other treatment, before initiating long-term ventilation, there should be a clear discussion and documentation of the indications and long-term therapeutic goal(s). Over the years, several criteria have been suggested as indications for initiation of HMV:

a. **Prolongation of life:** This is the most common justification, particularly for invasive ventilation.

   i. **Invasive ventilation:** For children in end-stage respiratory failure in whom noninvasive ventilation (NIV), for whatever reason, is not an option, invasive ventilation remains the only option to prolong survival. The decision to proceed with invasive ventilation via tracheostomy involves a discussion surrounding the individuals’ expected outcome and quality of life. This obviously precludes the performance of randomized control trials.

   ii. **NIV:** The indications for NIV are less clear than for invasive ventilation, particularly for patients where ventilatory support is “optional” (patient able to breathe without support, but borderline and hence at risk, such as during respiratory infections). Although the authors know of no randomized control studies looking at the impact of NIV on increased survival, there is good comparative data documenting an increased survival benefit in specific populations.11–14 There is only one study, however, that evaluated prophylactic initiation of NIV (initiating NIV before onset of respiratory failure).15 Seventy patients with Duchenne muscular dystrophy and Forced Vital Capacity (FVC) between 20 to 50%, yet without daytime hypercapnea, were randomized to receive either prophylactic NIV or conventional care. There was no evidence of any impact on deterioration in pulmonary function or hypercapnea. The study was terminated early, however, because of a paradoxical fourfold increase in mortality rate in patients on NIV. There was no clear cause for this increased mortality risk. There were also concerns raised as to the methodology (patients were unblinded as to treatment), so whether prophylactic initiation of NIV offers a survival benefit remains open to question. This contrasts with the study by Ward et al.,16 where children with neuromuscular or chest wall disease, and nocturnal but not daytime hypoventilation, were randomized to either NIV or spontaneous breathing at night. Although there were no deaths, nine of 10 controls required institution of ventilatory support within an average of 8.3 months. In addition, patients with nocturnal hypoventilation progressed to daytime hypercapnia within 12–24 months.

b. **Improved quality of life (QoL):** This is discussed in Section 13 (Psychosocial issues) and in some of the disease-specific sections.

c. **Prevention of either deterioration in pulmonary function or respiratory exacerbations:** Several studies have shown that initiation of NIV fails to prevent subsequent deterioration in pulmonary function.15,17 NIV does, however, reduce the probability of requiring re-admission, at least within the year following its initiation.18

2. **Identifying the long-term HMV candidate:** Children that are being considered for HMV at home have life-limiting conditions. Multiple failed extubation attempts and/or dependence on mask NIV for ≥16 hours per day and not a candidate for mouthpiece ventilation are medical indications to move forward with invasive HMV. HMV may have a huge impact on not only the child’s QoL and life expectancy, but also the entire family’s QoL, free time and financial well-being.19–21 This is further compounded by the marked variability in resource availability, not only within the community but also between families.

a. **Screening:** There is good evidence that in children with progressive neuromotor or pulmonary disease, there is a predictable evolution in their respiratory failure: sleep-disordered breathing (SDB) without hypercapnea, SDB with hypercapnea in REM sleep, SDB with hypercapnea in REM and slow-wave sleep and then daytime hypercapnia.22 It is also well recognized that this can be an insidious process (obviously being altered or hastened by respiratory infection or other impairments of respiratory function). Patient symptoms and clinical evaluation is therefore frequently insufficient for reliable diagnosis.23

b. **Location for initiation:** Initiation of ventilation can occur in hospital (ward or intensive care unit), in the sleep laboratory or even as an outpatient, depending not only on the child’s clinical status, but also the local resources, particularly the availability of knowledgeable personnel, and the ability to perform comprehensive monitoring to assess adequacy of ventilation (i.e., PSG and/or oximetry plus capnography. One randomized trial demonstrated that NIV could be initiated just as successfully in an
outpatient as an inpatient setting.\textsuperscript{24} The initiation of invasive ventilation can occur in an ICU setting.

c. Ability to care for the child in the home environment: The ability of the family to care for the child needs to be carefully evaluated. The child should be medically stable (unless palliative), including the presence of a stable airway, stable oxygen requirements (usually less than 40\%), should be able to maintain blood carbon dioxide levels within safe limits on the home ventilator and nutritional intake must be adequate to maintain growth and development. All other health conditions, pain and dyspnea included, should be well controlled. It also must be feasible to provide the level of support and intervention that the child will need at home. The need for laboratory tests and frequent changes in treatments should be at a minimum to ensure community caregivers can manage the child in the home environment. The parents need to understand the long-term prognosis and must be willing and capable to meet the child’s complex needs in the home environment.\textsuperscript{25}

3. Preparation of family and patient: Families with a child who has chronic respiratory failure must choose between accepting long-term assisted ventilation and forgoing life–assisting technology for their child.\textsuperscript{26}

a. The patient and family need to have a clear understanding of the potential benefits of HMV in their child (e.g., improved function, prolongation of life) as well as the risks, for either noninvasive (e.g., pressure effects of mask, inadequate or loss of ventilation due to dislodgement) or invasive (e.g., risks of surgery, accidental decannulation or mucus plugging of tracheostomy) ventilation, as appropriate. Other considerations at the family level are described in Section 13 (Caregivers). This is a major decision for many families. Most published protocols emphasize the need for the patients and their families to be given adequate time and information prior to initiation of HMV to allow them appropriate planning and support their ability to provide informed consent. Discussion regarding possibility of HMV should commence close to the time of diagnosis of the illness, be progressively discussed as the disease advances and certainly mentioned long before imminent respiratory failure.\textsuperscript{27} Unfortunately, even when the child’s disease has a predictable course and outcome, all too often, this does not occur.\textsuperscript{27} See Section 14 for a detailed discussion of the ethical considerations when initiating long-term mechanical ventilation.

b. The medical team and the patient and family need to be in agreement with the decision to move forward with HMV.

Conclusion

HMV has become an accepted therapy for a variety of diseases. Although multiple protocols exist for initiation of HMV, these protocols are largely based on empirical observation and clinical necessity, with very little in the way of comparative data to evaluate the optimal methodology and selection criteria for initiation of long-term HMV. Such evidence-based protocols are urgently needed.

Recommendations

The following recommendations are based on limited evidence from studies and consensus of the pediatric HMV guidelines panel.

Initiation of long-term ventilation in children

1. Each institution caring for children at risk of respiratory failure should establish a screening protocol (suggestions: symptom review, routine polysomnogram [oximetry and capnography if polysomnogram is not available], pulmonary function), for the identification of sleep-disordered breathing. (Grade 1C)

2. Each institution caring for children at risk of respiratory failure should establish protocols for the initiation of HMV, with initiation of ventilation occurring as part of a structured plan of care. (Grade 1C)

3. Wherever possible, the patients and their families should be given sufficient time and information to allow them to make an informed decision regarding advanced care planning prior to initiation of ventilation. Initial discussions as to the possibility of HMV should begin at the time of diagnosis and revisited progressively as the disease progresses and according to the needs of the family (Grade 1C).

4. A national registry is needed to track which patients are initiated on HMV, the indications and technologies employed, as well as patient outcomes, to provide objective data on the exact role and indications for HMV in individual patients. (Consensus).

Transition to home. Once the decision has been made to move ahead with HMV via tracheostomy, discharge planning should begin immediately. The course in hospital can be subdivided into three main categories: 1) establishing the mechanical ventilation parameters for the transition to home; 2) caregiver training; and 3) discharge planning.

1. Ventilation parameters for the transition to home: As soon as the patient is deemed medically stable and the decision has been made to go ahead with HMV, work should begin to determine the ventilator model, mode of ventilation and settings. The patient should try potential home ventilators to ensure that their gas exchange can be adequately managed on an appropriate home unit. An early introduction of the home ventilator will also facilitate adherence and serve to identify any pitfalls early. Oximetry, transcutaneous carbon dioxide measurements, blood gases and bedside assessments can be used to titrate the settings and maximize the time off
of the ventilator in a 24-hour period. Consideration should also be given for a polysomnogram prior to discharge for titration of the ventilator settings if clinically indicated. Readiness for a speaking valve should also be investigated once there is a significant leak through the tracheostomy tube, if the patient is clinically stable and able to tolerate it. In general, it is recommended that children should be on stable ventilator settings, with adequate gas exchange, for two weeks prior to discharge home.

2. **Caregiver training requirements**: Caregiver training is dependent upon several factors:

   a. Medical fragility of the child: There is an interrelationship between the medical fragility of the child, their ability to self-care and the complexity of the care they require. This is influenced by the following:

      i. Children who are dependent on ventilation for survival (failure of ventilatory support leads to rapid demise) are more fragile than those who are able to breathe without assistance (e.g., those with neuromotor disabilities).

      ii. Children who also have other diseases that require additional technological support, such as enterostomy feeds or catheterization, are also more fragile.

   b. Mode of ventilation (invasive vs. noninvasive) and, hence, the complexity of equipment required: This has a significant impact on the depth of caregiver training required, being greatest for children on invasive ventilation. These patients require caregivers knowledgeable not only in ventilator but also tracheostomy management, with tracheostomy-related events being a principal cause of death in these patients.\(^{28}\) Since adverse events can occur at anytime,\(^{29,30}\) it is recommended that a child with a tracheostomy receive 24/7 care by an alert, trained caregiver.\(^{31}\) This requires a minimum of two caregivers who are able and willing to be trained in tracheostomy and ventilator care to care for the child once he or she goes home. The length of the caregiver training program varies (usually in the order of six-to-eight weeks), but depends on the readiness, availability and abilities of the designated caregivers.\(^{29,30}\) The family should also receive support to care for the child in the community from paid caregivers, who may include nurses, personal support workers or trained laypeople. However, the number and type of paid community caregiver hours available to families varies across regions and provinces. Many families are therefore forced to rely on other supports, such as unpaid caregivers, family members, nannies, etc. These supports need to have sufficient knowledge and education to safely care for these children. A formal training schedule is therefore required for all of the child’s caregivers. Although most programs have similar protocols, there are no validated criteria outlining the needed knowledge and skills necessary to care for a child on HMV. Most programs emphasize the need for a period of care by the parent(s) as the last step prior to discharge. During this time, the child remains an inpatient with family caregivers being responsible for the ongoing care of the child in an environment where help is nearby if needed. In addition, all family caregivers must be Basic Life Support (BLS)-certified prior to the child’s discharge home. Close to the time of discharge, family caregivers should have their knowledge and skills formally reassessed.

   c. Ability of the child to self-care: Infants and young children are dependent upon the continuous provision of care by adult caregivers. The long-term goal, however, is for the child to achieve as much independence as their illness and developmental level allows. Consequently the child should also participate, within the limits of their abilities, in the training program, and be encouraged to assume as much of a role in their self-care as they wish to and are capable of.

3. **Financial considerations**: Given the necessity of 24/7, eyes-on care, one parent often has to stop working to become the primary caregiver. This results in a significant income loss for the family. Although most local governments provide some financial support for the required equipment, the relative contribution to the cost of the ventilator and needed supplies varies across provinces, and is rarely sufficient to cover all expenses. Furthermore, transportation costs (e.g., wheelchair accessible vans), costs associated with mobility devices (e.g., wheelchairs) as well as the cost of extra supplies when the child is ill all become added expenditures for the family. This inevitably results in a significant financial burden to most families.\(^{31}\)

4. **Housing assessment**: All children going home on invasive HMV require a housing assessment to determine suitability. Adequate space for the equipment and supplies, wide enough doorways for wheelchair access as well as the ability to do adaptations for home oxygen are all relevant considerations. Ideally the ventilator-dependent child would have his or her own room with adequate storage for supplies and equipment. There needs to be an adequate number of grounded electrical outlets and access to a telephone. The children need to live in a home with functional heating and cooling systems. An evacuation process in case of fire should be established. The need to find alternate housing that is suitable for the child is often a significant barrier to discharge.

5. **Community services**: The community-based homecare providers should be identified early. Furthermore, implementing “shadow shifts” in the ICU for the community-based paid caregivers prior to discharge home facilitates continuity of care as well as a greater sense of trust in the community caregivers by the family. On occasion, community-based paid caregivers may have insufficient previous experience with this population, necessitating
formal retraining. Similarly, tracheostomy and ventilator training may also be required for staff at the local hospital. The number of hours and type of paid caregiver hours funded by the government varies across provinces. Additionally, the specific needs of the family and fragility of the child will vary and a multi-disciplinary needs assessment is required on a patient-by-patient basis. Homecare, including home visits from nurses and other professional services such as physiotherapy, respiratory therapy, occupational therapy, social work, psychology and respite care, all take time to arrange. Rehabilitation needs should also be considered. In addition, children with tracheostomies often have or are at risk for feeding difficulties. Feeding specialists or speech pathologists can be invaluable. A community pediatrician should also be identified and involved in the discharge planning. Therefore, it is essential that community partners are identified as early as possible in the process to prevent discharge delays.

6. Discharge planning: A multi-disciplinary assessment including the family, the patient, intensive care, respiratory medicine, nursing, social work, occupational therapy, physical therapy, respiratory therapy, the primary care pediatric provider, the community homecare agency and discharge planning should be performed to identify the particular needs of the child and family. The multi-disciplinary team needs to be coordinated by one primary case manager. The benefits of a dedicated case coordinator for a patient have been demonstrated, resulting in improvements in both length of stay as well as patient satisfaction. The case manager acts as a liaison between the hospital-based teams and the community-based care providers. Some discharge programs will have two coordinators, a community practitioner and a hospital case manager. Regular multi-disciplinary team meetings should be scheduled regularly and a projected discharge date should be set. This should begin as soon as a decision has been made to proceed with HMV at home.

**Discharge from hospital to home.**

1. Discharge care plan: An essential component of a successful discharge from hospital to home is a discharge care plan. This should include the clinical information around ventilator dependence, the underlying disease and prognosis, the current ventilator settings, a plan in the case of acute illness or deterioration as well as the names and contact information of the main healthcare advisors. This treatment plan should be shared with local police, ambulance and fire department in case of an emergency. Furthermore, the local utility and telephone companies need to be informed that a child dependent on a ventilator is living in the area, so that they can prioritize service in case of service interruptions. The family caregivers need to be aware of what to do in the case of a medical emergency as well as in the case of a power failure. The family needs to have the telephone numbers of healthcare advisors, emergency services and home equipment providers all easily accessible. The healthcare team must ensure that the family has an adequate mode of transportation to transport the child to follow-up appointments as well as around the community. For children who require ventilation during transit, or have tracheostomy in place, it is recommended that if one caregiver is driving, there needs to be an additional caregiver in the vehicle monitoring the child’s airway.

2. Ongoing care: A plan for ongoing follow-up and coordinated care between the local and specialized clinical teams is essential to successfully support the child and his or her family. The family needs to be aware of this follow-up care plan. Depending on the child’s status and needs, this will likely include an HMV program clinic follow-up two-to-four weeks after discharge and then every three-to-six months. The follow-up care of the child will also need to be coordinated with other specialists following the child. In addition, the child will, in many centers, undergo surveillance polysomnograms to assess the ongoing control of ventilation as the child grows. Consideration as to the frequency of investigations and monitoring may depend upon the distance the family is from the specialized center. Furthermore, family caregivers need to continue to receive ongoing tracheostomy and ventilator skills assessments and retraining. Kun et al. reported that overall, primary caregivers are reasonably well trained when assessed after their child has been discharged. However, further training on the technical aspects of ventilator alarms and tracheal mucous plugging may help to reduce or prevent emergencies of children on long-term HMV.

3. School: Many children with a tracheostomy and invasive HMV attend school. Prior to the child attending school, there are a few essential considerations. An emergency plan needs to be clearly delineated for the child and the nearest emergency department to the school must be identified. A mobility plan for the child around the school, and the equipment that needs to be brought to school on a daily basis, needs to be identified. In addition, a tracheostomy and ventilation-trained caregiver needs to accompany the child at school and other allied healthcare services the child will receive at school need to be arranged.

4. Equipment: There is an extensive list of home equipment and supplies needed to care for an invasively ventilated child. Additionally, the child always needs to travel with a certain subset of equipment at all times (see Appendix 2). An itemized checklist of needed equipment should be developed and checked by the team. Depending on the province, funding may need to be obtained to purchase the ventilator equipment or it may be on loan from a central agency. However, the families are responsible for the ordering of tracheostomy supplies from their local vendor. All of the essential equipment as well as supplies for the first three months should be delivered to the home prior to discharge. Equipment and supplies should be ordered as early as possible in
the transition process to avoid delays in discharge. Depending on the level of support required, alternate power sources need to be on hand in the case of a power failure, such as back-up batteries, back-up ventilator and generators. Furthermore, consideration needs to be given for additional equipment that may be needed, including enterostomy tubes and pumps, Hoyer lifts for transfers, wheelchairs and call bells.

5. **Psychosocial Considerations**: See Section 13 for psychosocial considerations of long-term ventilation.

### Conclusion

The overwhelming majority of children receiving HMV are successfully discharged from the hospital to home. The success of HMV programs is in large part due to a coordinated, comprehensive multi-disciplinary approach driven by a central, hospital-based case manager and includes the dedication and commitment of family and community caregivers.

### Research questions—Initiation of ventilation

1. What are the criteria for initiation of long-term ventilation? What are the sensitivity and specificity for each?
   a. Clinical
      i. Are there standard clinical indicators to best identify when initiation of long term ventilation is indicated, or likely to be successful over the long term? Is it generally true that there is no role for prophylactic initiation?
      ii. Are there specific diseases/clinical scenarios where NIV is going to be more therapeutically effective than others (acute vs. chronic, respiratory vs. skeletal/neuromotor)?
   b. Laboratory
      i. Is polysomnography the gold standard, or are simpler, ambulatory methodologies (oxygen saturation + capnography) sufficient for the titration of ventilator settings?
      ii. Is invasive pCO₂ measurement (ABG, CBG) required to confirm noninvasive CO₂ measurements (transcutaneous or end tidal CO₂ measurement) during PSGs and/or oximetry + capnography?

2. What needs to be in place prior to initiation of home mechanical ventilation?
   a. Is there a gold standard for parental (and child, where appropriate) discussion, education and informed consent?
   b. What are the minimal and optimal resources required (medical, financial, equipment, social, family) for long-term success?

3. What is the most effective organizational structure for successful initiation of ventilation?
   a. Patient, family and other caregiver training prior to discharge home?
   b. Standardized documentation/orders?
   c. Patient, family and other caregiver training prior to initiation of ventilation?
   d. Community liaisons and resources required to be in place?

4. What is the patient and family experience of the initiation of long-term mechanical ventilation?
   a. What is the best predictor of a positive experience?
   b. What is the best predictor of a negative experience?
   c. What structure needs to exist for optimal coordinated involvement of the family with the rest of the team?

### Research questions—Transition to home

1. What is the current state of the service delivery model for long-term ventilation in children across Canada? Are there significant interprovincial differences? Are there any gaps that need to be addressed?
2. What is the ideal duration of in-hospital training for family caregivers? Logically this will vary from caregiver to caregiver — how do we assess what is sufficient for each individual?
3. How often should family and community caregivers undergo formal retraining of their knowledge and skills for caring for a child using long-term mechanical ventilation at home?
4. What is the ideal number of hours of care and type of community-based paid caregivers? Nurses, respiratory therapists, personal support workers?
5. Do more hours of paid community caregiver services per week translate into less morbidity and mortality in children on long-term mechanical ventilation in the home?
6. What is the ideal way of ensuring adequate knowledge and skills training competencies of community-based paid caregivers?

### Recommendations

The following recommendations are based on limited evidence from 10 studies and consensus of the pediatric HMV guidelines panel.

#### Transition of children on long-term ventilation to home

1. Each institution caring for children on long-term mechanical ventilation to home should collaboratively develop a written care plan, with the family, healthcare providers in the referring center, as well as the community healthcare/homecare team involved in the patient’s long-term care. (Grade 1C)
2. Lines of communication need to be established between regional centers and the community caregivers, with clear outlines as to respective responsibilities both for routine follow up, and emergencies associated with unexpected events such as illness or equipment failure. (Grade 1C)
The following recommendations have been adapted from the adult home mechanical ventilation guidelines and are based on the consensus of the expert pediatric HMV panel.

3. Each institution discharging a child home should have a designated case coordinator to streamline the discharge process, minimize the length of stay and ensure a safe transition home. (Consensus)

4. The patient should be medically stable with a need for a level of monitoring or treatment interventions that can be managed at home. (Consensus)

5. The patient and the family must be highly motivated. (Consensus)
   a. The family is willing/able to ensure provision of “24/7 eyes-on care” for all invasively ventilated children and for children receiving NIV that are deemed medically fragile and in need of this level of care at home.
   b. The family is aware that the discharge destination is home, not a long-term care facility.
   c. The family is willing to provide needed supports (financial, physical, emotional).

6. The patient must have a home that is safe for a child requiring long-term mechanical ventilation. (Consensus)

7. The patient must have sufficient caregiver support. (Consensus)
   a. Two primary, family caregivers identified and trained.
   b. Sufficient community caregivers identified and trained to provide parental support. In the absence of private funding, sufficient government funding available to pay for these caregivers.
   c. Sufficient out-of-home respite needs to be available.
   d. Family caregivers in agreement that they are responsible for the majority of the care.

8. Each institution or HMV program caring for these children must ensure the patient has the appropriate equipment and supplies needed for long-term ventilation. (Consensus)
   a. There must be a list of needed equipment and the institution or HMV program must ensure that it is ordered and delivered to the home or is in use.
   b. Sources for ongoing required supplies need to have been identified.
   c. There should be a clear protocol in place for maintenance and replacement of necessary equipment.

9. There must be comprehensive initial competency-based training regarding the knowledge and skills needed to care for a child using HMV, plus ongoing education and training for patient and caregivers once they are in the home setting. (Consensus)
   a. The initial education is organized to accommodate learning, practice and inclusion of caregivers in the care routine as early as possible

10. The patient must have access to healthcare support in the community. (Consensus)
   a. Follow-up care is available as appropriate (tracheostomy tube changes, ventilator reassessments, interface fit and skin breakdown, adherence and assessment of the ongoing effectiveness of the ventilator support).

b. Medical follow-up to allow for appropriate changes to the mode of ventilation (i.e., from invasive to noninvasive and vice-versa, from continuous to nocturnal and vice-versa)

References

Appendix 1

The four stages of the transition from initiation of long-term mechanical ventilation to home.

<table>
<thead>
<tr>
<th>Stage of the transition process</th>
<th>1. Identification of the HMV patient</th>
<th>2. Informed consent for HMV for the patient and family</th>
<th>3. Course in hospital</th>
<th>4. Discharge from hospital to home</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical stability</td>
<td>Medical stability</td>
<td>Medical stability</td>
<td>Medical stability</td>
<td></td>
</tr>
<tr>
<td>Disease and patient appropriate for HMV</td>
<td>Disease and patient appropriate for HMV</td>
<td>Disease and patient appropriate for HMV</td>
<td>Disease and patient appropriate for HMV</td>
<td></td>
</tr>
<tr>
<td>Risks and benefits of HMV</td>
<td>Risks and benefits of HMV</td>
<td>Risks and benefits of HMV</td>
<td>Risks and benefits of HMV</td>
<td></td>
</tr>
<tr>
<td>Caregiver training requirements</td>
<td>Caregiver training requirements</td>
<td>Caregiver training requirements</td>
<td>Caregiver training requirements</td>
<td></td>
</tr>
<tr>
<td>Financial considerations</td>
<td>Financial considerations</td>
<td>Financial considerations</td>
<td>Financial considerations</td>
<td></td>
</tr>
<tr>
<td>Housing</td>
<td>Housing</td>
<td>Housing</td>
<td>Housing</td>
<td></td>
</tr>
<tr>
<td>Equipment</td>
<td>Equipment</td>
<td>Equipment</td>
<td>Equipment</td>
<td></td>
</tr>
<tr>
<td>Psychosocial considerations</td>
<td>Psychosocial considerations</td>
<td>Psychosocial considerations</td>
<td>Psychosocial considerations</td>
<td></td>
</tr>
<tr>
<td>Ventilation parameters for the transition to home</td>
<td>Ventilation parameters for the transition to home</td>
<td>Ventilation parameters for the transition to home</td>
<td>Ventilation parameters for the transition to home</td>
<td></td>
</tr>
<tr>
<td>Family caregiver training</td>
<td>Family caregiver training</td>
<td>Family caregiver training</td>
<td>Family caregiver training</td>
<td></td>
</tr>
<tr>
<td>Community services</td>
<td>Community services</td>
<td>Community services</td>
<td>Community services</td>
<td></td>
</tr>
<tr>
<td>Discharge planning</td>
<td>Discharge planning</td>
<td>Discharge planning</td>
<td>Discharge planning</td>
<td></td>
</tr>
<tr>
<td>Discharge care plan</td>
<td>Discharge care plan</td>
<td>Discharge care plan</td>
<td>Discharge care plan</td>
<td></td>
</tr>
<tr>
<td>Anticipatory care</td>
<td>Anticipatory care</td>
<td>Anticipatory care</td>
<td>Anticipatory care</td>
<td></td>
</tr>
<tr>
<td>School</td>
<td>School</td>
<td>School</td>
<td>School</td>
<td></td>
</tr>
</tbody>
</table>

Note: If initiated as an outpatient (NIV), a similar protocol needs to be followed, with the four stages adapted to available resources (sleep laboratories, outpatient clinics, availability of monitoring in the community).

Appendix 2

The recommended equipment needed for HMV.

<table>
<thead>
<tr>
<th>Specific equipment needed for invasive long-term mechanical ventilation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suctioning equipment</td>
</tr>
<tr>
<td>• suction machine (electrical or portable)</td>
</tr>
<tr>
<td>• disposable suction catheters of correct size</td>
</tr>
<tr>
<td>• suction tips for oral/Yankauer suctioning</td>
</tr>
<tr>
<td>• suction extension tubing</td>
</tr>
<tr>
<td>• suction canister</td>
</tr>
<tr>
<td>• sterile distilled water</td>
</tr>
<tr>
<td>• clean container for flushing solution</td>
</tr>
<tr>
<td>• manual resuscitator bag</td>
</tr>
<tr>
<td>• extra inner cannula if needed</td>
</tr>
<tr>
<td>• obturator</td>
</tr>
<tr>
<td>• suction unit plug and charger</td>
</tr>
<tr>
<td>• plastic bag for disposal of materials</td>
</tr>
<tr>
<td>• supplies for cleaning suction canister</td>
</tr>
<tr>
<td>• o mild dishwashing soap</td>
</tr>
<tr>
<td>• o white vinegar</td>
</tr>
<tr>
<td>• o water</td>
</tr>
<tr>
<td>• o two pails (one with warm soapy water and one with vinegar and water)</td>
</tr>
<tr>
<td>• o clean towel</td>
</tr>
<tr>
<td>• Stoma care</td>
</tr>
<tr>
<td>• o sterile distilled water or sterile normal saline</td>
</tr>
<tr>
<td>• o cotton tipped swabs</td>
</tr>
<tr>
<td>• o sterile tracheostomy dressings</td>
</tr>
<tr>
<td>• o disposable cups for water</td>
</tr>
<tr>
<td>• o suction machine and supplies</td>
</tr>
<tr>
<td>• o emergency tracheostomy kit</td>
</tr>
<tr>
<td>• o tracheostomy tubes of same size</td>
</tr>
<tr>
<td>• o tracheostomy tubes 1/2 size smaller</td>
</tr>
<tr>
<td>• o obturator</td>
</tr>
<tr>
<td>• o tracheostomy ties</td>
</tr>
<tr>
<td>• o water soluble lubricant</td>
</tr>
<tr>
<td>• o normal saline nebules</td>
</tr>
<tr>
<td>• o tracheostomy gauze</td>
</tr>
<tr>
<td>• o scissors</td>
</tr>
<tr>
<td>• o suction machine and supplies</td>
</tr>
<tr>
<td>• o manual resuscitator bag</td>
</tr>
<tr>
<td>• o oximeter (if applicable)</td>
</tr>
<tr>
<td>• o small syringe</td>
</tr>
<tr>
<td>• o tweezers</td>
</tr>
<tr>
<td>• Ventilator equipment</td>
</tr>
<tr>
<td>• o two ventilators</td>
</tr>
<tr>
<td>• o battery charger</td>
</tr>
<tr>
<td>• o heated humidifier</td>
</tr>
<tr>
<td>• o external battery for emergency power only</td>
</tr>
<tr>
<td>• o battery cable</td>
</tr>
<tr>
<td>• o re-usable ventilator circuits</td>
</tr>
<tr>
<td>• o sterile distilled water</td>
</tr>
<tr>
<td>• o mild dishwashing soap</td>
</tr>
<tr>
<td>• o pail for soaking</td>
</tr>
<tr>
<td>• o white vinegar</td>
</tr>
<tr>
<td>• o clean towel</td>
</tr>
<tr>
<td>• o storage bag</td>
</tr>
<tr>
<td>• Manual ventilation</td>
</tr>
<tr>
<td>• o manual resuscitation bag</td>
</tr>
<tr>
<td>• o adapter for tracheostomy tube</td>
</tr>
<tr>
<td>• o flex hose/tube</td>
</tr>
<tr>
<td>• o PEEP adapter and valve, if required</td>
</tr>
<tr>
<td>• o oxygen tubing (if needed)</td>
</tr>
<tr>
<td>• Travel equipment</td>
</tr>
<tr>
<td>• o emergency tracheostomy kit</td>
</tr>
<tr>
<td>• o portable suction unit and supplies</td>
</tr>
<tr>
<td>• o oximeter (if applicable)</td>
</tr>
<tr>
<td>• o manual resuscitation bag</td>
</tr>
<tr>
<td>• o ventilator</td>
</tr>
<tr>
<td>• o back-up battery</td>
</tr>
<tr>
<td>• o power cords to plug in while out</td>
</tr>
<tr>
<td>• Oximeter equipment</td>
</tr>
<tr>
<td>• o heated Moisture Exchanger</td>
</tr>
<tr>
<td>• o oximeter</td>
</tr>
<tr>
<td>• OPEX adapter and valve, if required</td>
</tr>
<tr>
<td>• o tape</td>
</tr>
<tr>
<td>• o probes for the oximeter</td>
</tr>
<tr>
<td>• Pulmonary treatment</td>
</tr>
<tr>
<td>• o cough assist</td>
</tr>
<tr>
<td>• o manual resuscitation bag</td>
</tr>
<tr>
<td>• o cough assist device</td>
</tr>
<tr>
<td>• o suction machine and supplies</td>
</tr>
<tr>
<td>• o interface</td>
</tr>
</tbody>
</table>

(continued)
### Specific equipment needed for NIV

#### Suctioning equipment
- suction machine (electrical or portable)
  - suction tips for oral/Yankeur suctioning
  - suction extension tubing
  - suction canister
  - sterile distilled water
  - clean container for flushing solution
  - manual resuscitator bag
  - suction unit plug and charger
  - plastic bag for disposal of materials
  - supplies for cleaning suction canister
    - mild dishwashing soap
    - white vinegar
    - water
    - two pails (one with warm soapy water and one with vinegar and water)
  - clean towel
  - suction machine and supplies
  - one ventilator (two if dependent on ventilator, e.g., CCHS)

#### Ventilator/PAP therapy equipment
- battery charger
- heated humidifier

---

### Travel equipment
- portable suction unit and supplies
- oximeter (if applicable)
- pulmonary treatment device
- ventilator equipment
- back-up battery
- power cords to plug in while out
- oximeter
- tape
- probes for the oximeter

### Oximeter equipment
- oximeter

### Pulmonary treatment
- cough assist
  - cough assist device
  - suction machine and supplies
  - interface
  - breathstacking with a bag
    - manual resuscitator bag
    - one-way valve
    - extension tube
    - interface
    - nose clips
    - suction machine and supplies

### Equipment for School
- oximeter (if applicable)
- manual resuscitation bag
- ventilator
- back-up battery
- heated moisture exchanger
- supplemental oxygen

---

(continued)