ATS CLINICAL PRACTICE GUIDELINE: SUMMARY FOR CLINICIANS

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Pediatric Chronic Home Invasive Ventilation

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The Pediatric Assembly of the American Thoracic Society assembled an interdisciplinary panel to develop evidence-based clinical practice guidelines for the hospital discharge and outpatient management of children requiring chronic invasive mechanical ventilation entitled, *An Official American Thoracic Society Clinical Practice Guideline: Pediatric Chronic Home Mechanical Ventilation* (1). This summary is prepared for practicing physicians.

Medical Home

“For children requiring chronic home invasive ventilation, we suggest a comprehensive Medical Home co-managed by a generalist and respiratory subspecialist (Strength of Recommendation: Conditional; Quality of Evidence: Very Low).”

The foundation of the care of a child with chronic home invasive ventilation is the creation of a medical home (2). A family-centered care model is most likely to be successful when a respiratory subspecialist and community-based primary care provider establish with the family a working relationship on the basis of open communication. As children with home ventilators often have multiple medical conditions, clear delineation of medical responsibilities is an important aspect of effective communication within the medical home. Families of children with chronic home ventilation often have high stress due to the complexity of care resulting in increased hospitalization, financial burdens, and difficulty in obtaining services for their child. The creation of a medical home is designed to decrease this stress by providing an environment in which both family members and medical providers can communicate openly and effectively to optimize care for each child.

Standardized Discharge Criteria

“For children requiring chronic invasive ventilation, we suggest the use of

standardized discharge criteria to objectively assess readiness for care in the home (Strength of Recommendation: Conditional; Quality of Evidence: Very Low).”

Discharging a child to the home setting with chronic invasive ventilation is complex and challenging, requiring interdisciplinary care from providers both in and out of the hospital. Systems and available resources vary from center to center, and each child has unique medical, social, and environmental needs. Nevertheless, standardized criteria can help to ensure readiness for this significant life transition. These criteria should address: (1) the child's medical stability for discharge, (2) the preparedness of family and professional home caregivers, (3) the necessary medical equipment, and (4) the safety of the home and community environment.

Medical Stability for Discharge

The child must demonstrate medical stability before discharge. The child's oxygen requirement and ventilator settings should remain unchanged during the days to weeks before being discharged. There should also be no

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escalation of care or other acute events during this time period. The child's ventilator and oxygen requirements should not exceed those that can be delivered with the provided medical equipment. The child should be monitored for sufficient length of time on the home equipment before discharge to ensure that each device is functional. Tolerating the equipment during transportation also needs to be addressed before discharge.

Preparedness of Caregivers

"We recommend that an awake and attentive trained caregiver be in the home of a child requiring chronic invasive ventilation at all times (Strength of Recommendation: Strong; Quality of Evidence: Very Low)."

Family and professional caregivers work together and must be trained to care for ventilator-dependent children at home, as respiratory-related accidents are a significant cause of morbidity and mortality in this high-risk population of children (3). However, the degree of training is irrelevant if a caregiver fails to respond in an urgent situation due to sleepiness or fatigue. In most situations, providing an awake and alert trained caregiver at all times requires a team of family and professional caregivers in the home.

Family and Professional Caregivers

"For children requiring chronic invasive ventilation, we suggest that at least two specifically trained family caregivers are prepared to care for the child in the home (Strength of Recommendation: Conditional; Quality of Evidence: Very Low)."

Family caregivers must demonstrate the willingness and ability to care for their child. They should receive cardiopulmonary resuscitation training, be able to properly respond to emergencies, and demonstrate competency in all prescribed therapies. At least two family caregivers should be fully trained in all aspects of the child's care, because there may be times when in-home professionals are not available for extended periods. Each should be able to care for and replace the tracheostomy tube as well as respond urgently when the tube is

obstructed or dislodged. Family caregivers should stay at the hospital for at least one night before discharge to assume all care for their child and be able to respond appropriately to simulated emergencies. Families should be taught the importance of hand washing, safe transport of the child with all necessary travel items in a "Go Bag," and smoking cessation.

In most situations, in-home professional caregivers are required to support the family in caring for the ventilator-dependent child. Infant/child cardiopulmonary resuscitation certification is required, and professional caregivers should achieve the same competencies as family caregivers through an accredited agency. In-home professionals should complete training for the child's specific ventilator. Importantly, in-home caregivers should be instructed not to engage in cigarette smoking while on duty.

Training Caregivers

"We suggest that ongoing education to acquire, reinforce, and augment skills required for patient care be provided to both the family and professional caregivers of children requiring chronic home invasive ventilation (Strength of Recommendation: Conditional; Quality of Evidence: Very Low)."

Comprehensive training of family caregivers should begin early, continue throughout the child's hospital stay, and focus on caregiver competency, with verification of skills before hospital discharge and reinforcement that continues after hospital discharge. Professional caregivers should also have ongoing training to ensure maintenance of skills.

Durable Medical Equipment

A company must be identified who will provide and service durable medical equipment (DME) in the home setting. The DME company must inspect the home to ensure that the home environment and electrical systems are adequate to support the needed equipment. The company should provide 24-hour consultation and agree to service the equipment as soon as possible, including same-day replacement if a device is

malfunctioning. The DME clinician should visit the home at least once per month.

The Home and Community Environment

Children who require chronic invasive ventilation must be discharged to a home and community setting that is safe and accessible. Each child should have a formal safety plan posted nearby with emergency contact numbers and essential medical information that includes ventilator settings, medications, and allergies. A functioning phone, either a land line or a devoted mobile phone, should remain with the child at all times in case of emergency. The home itself should be kept at an ambient temperature within the recommended range indicated by the ventilator manufacturer and free of irritants such as cigarette smoke and molds. A functional fire extinguisher, removal of fire hazards, and a fire escape plan also contribute to a safer home environment. Telephone/utility companies and local emergency medical services should be made aware of the child's presence in the community.

Home Monitoring

"For children requiring chronic home invasive ventilation, we suggest monitoring, especially when the child is asleep or unobserved, with a pulse oximeter rather than use of a cardiorespiratory monitor or sole use of the ventilator alarms (Strength of Recommendation: Conditional; Quality of Evidence: Very Low)."

A significant number of deaths in children dependent on invasive ventilation are caused by tracheostomy-related accidents or complications (4). A recent study found that low-inspiratory pressure alarms did not alarm when decannulation was tested using the smaller diameter tracheostomy tubes necessary in pediatric patients (5). Pulse oximetry is the preferred method to monitor these patients, rather than relying on ventilator or other cardiorespiratory alarms. Hypoxemia is likely to be an early indicator of airway obstruction or equipment malfunction, whereas bradycardia or apnea are later complications.

Equipment-based Strategies to Reduce Mortality

“For children requiring chronic home invasive ventilation, we recommend regular maintenance of home ventilators and all associated equipment as outlined by the manufacturer.

We suggest the following pieces of equipment for use in the home when caring for a patient on home mechanical ventilation: The ventilator, a back-up ventilator, batteries, a self-inflating bag and mask, suctioning equipment (portable), heated humidifier, supplemental oxygen for emergency use, nebulizer, and a pulse

oximeter (nonrecording) (Strength of Recommendation: Conditional; Quality of Evidence: Very Low).

We suggest that a mechanical insufflation-exsufflation device be used to help maintain airway patency in patients requiring home mechanical ventilation with ineffective cough, including, but not limited to, those with neuromuscular disease with poor respiratory muscle strength (Strength of Recommendation: Conditional; Quality of Evidence: Very Low).”

Ventilator failure resulting in death is a rare event, but malfunction often results in increased use of resources. Maintenance of

ventilators and associated equipment in the home should be performed as outlined by the manufacturer. Even when the device appears to be functioning properly, adult data suggest that performance of ventilators in the home may vary considerably, risking over- or underventilation and associated complications (6). Expert clinicians identified “absolutely required” equipment for home use and also identified the need to optimize airway clearance in patients with poor respiratory strength. ■

Author disclosures are available with the text of this article at www.atsjournals.org.

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