

## The Current State of Home Mechanical Ventilation in Children

One of the first portable ventilators designed for use outside of the hospital was approved by the Food and Drug Administration in 1977, and home mechanical ventilation became a reality for many children in 1981 with the passage of a Medicaid waiver that provided reimbursement for ventilator-dependent patients beyond the ICU setting.<sup>1</sup> Since that time, portable home ventilators have become more sophisticated, smaller, lighter, and have a longer battery life allowing for greater patient mobility. Advances in both medical care and technology have contributed to the growing numbers of children receiving home mechanical ventilation. Medically stable ventilator-dependent children have a better quality of life and improved psychosocial development outside of the hospital setting.<sup>2,3</sup> Furthermore, the cost for supporting home mechanical ventilation is typically less than continued care in the hospital.<sup>4-6</sup>

Children who require home mechanical ventilation are a diverse, complex, high-risk patient population. Although chronic respiratory failure is the common factor necessitating long-term ventilator support, these medically fragile children have varying underlying diagnoses such as bronchopulmonary dysplasia, neuromuscular disease, spinal cord injury, cerebral palsy, or other conditions resulting in chronic pulmonary insufficiency, as well as a multitude of different comorbidities. Some children are eventually liberated from mechanical ventilation, while others require support for the duration of their life. In both cases, many children attend school, participate in extracurricular activities with their peers, and have hobbies, hopes, and dreams, and they become young adults who graduate college and enter the workforce.

Several studies have described local or regional pediatric home ventilator populations, trends, and outcomes over periods ranging from 10 to 30 years in the both the United States and around the world, including Canada, the United Kingdom, Italy, the Netherlands, and many others.<sup>7-15</sup> In this issue of the Journal, Borges and colleagues<sup>16</sup> report outcomes from a pediatric home care service in Brazil. The authors retrospectively reviewed records for children receiving invasive home mechanical ventilation over a 10-y

period. There were 27 children included in the study, with the majority having a diagnosis of cerebral palsy. The main cause of readmission was respiratory illness attributed to

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tracheitis. Nearly half of the children died over the course of 10 y, with most of the deaths occurring in the hospital setting. The authors also report that readmission within 6 months of hospital discharge was associated with an increased chance of death.

This paper contributes to the growing body of literature depicting populations, trends, and outcomes of children dependent upon invasive home ventilation. However, the sample size is considerably smaller compared to other studies occurring over the same or shorter length of time.<sup>8-10,13,14</sup> This could be due to demographic differences, the geographic region, the availability of resources, or the fact that the study was limited to a single home care service. Many of the other descriptive studies included children receiving noninvasive ventilation, which may have led to a larger number of subjects, whereas this study included only invasive support.<sup>10-16</sup>

Most of the children in this study were reported to have a diagnosis of cerebral palsy, which is a common neurodevelopmental disorder causing physical disability.<sup>16</sup> Cerebral palsy is often considered an umbrella term because it encompasses a wide range of symptom severity and associated comorbidities that may or may not include pulmonary manifestations.<sup>17</sup> Children diagnosed with cerebral palsy who have respiratory involvement are at risk for respiratory failure due to impaired cough, upper-airway obstruction, and sleep-disordered breathing.<sup>17</sup>

Readmissions are, unfortunately, quite common for children requiring home ventilator support and are frequently related to acute respiratory illness. A retrospective cohort study of 109 invasively ventilated children reported a 40% incidence of readmissions and identified pneumonia and tracheitis as the primary causes.<sup>18</sup> Other studies evaluating readmissions following tracheostomy placement or initiation of home ventilation reported similar results.<sup>19,20</sup> Findings from the study by Borges et al<sup>16</sup> also noted respiratory infection, namely tracheitis, as a main cause of readmissions. The term tracheitis is frequently used when describing artificial airway-associated tracheobronchitis,

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Correspondence: L Denise Willis MSc RRT RRT-NPS AE-C. E-mail: willisd@archildrens.org.

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which is often characterized by fever, increased tracheal secretions, and increased work of breathing.<sup>21</sup> Artificial airway-tracheobronchitis may be a more accurate designation for tracheitis in invasively ventilated children. There are no evidence-based standards for diagnosing or treating this common occurrence in this patient population.

A notable finding from the study by Borges et al<sup>16</sup> was the 10% greater chance of death associated with hospital readmissions occurring within 6 months following discharge ( $P = .02$ ). However, this should be interpreted with caution given the small sample size from a single pediatric home service. The authors reported that nearly half (13 of 27) the children in their study died over the 10-y period and that 76.9% of deaths occurred in the hospital.<sup>16</sup> These findings are consistent with another study that evaluated deaths in children receiving invasive home ventilation in which the majority of deaths occurred in the hospital setting.<sup>22</sup>

Overall, the results from this study of invasive home mechanical ventilation in Brazil are in agreement with the findings of other comparable studies. Ventilator-dependent children typically have substantial medical needs and utilize a higher proportion of health care resources compared to children with other chronic conditions.<sup>23</sup> Despite the increasing numbers of ventilator-dependent children and improved technology, there are relatively few current guidelines and no database or registry.<sup>24,25</sup> While some individual institutional and collaborative registries may exist in the United States, there is not an established national home ventilator registry.<sup>1</sup> A registry of this nature could help identify more accurate estimates of the number of ventilator-dependent individuals, develop evidence-based standards of care and updated guidelines, discover other trends and outcomes that may be unrecognized, and provide a framework for more research to assist with improving care for this group of patients. Ideally, a comprehensive registry would include both adults and children.

The diversity and complexity of the ventilator-dependent population as a whole makes it challenging to create universal guidelines. However, there are many opportunities for future research on various aspects that could potentially benefit the entire group. Specific examples of this include standardized treatment of airway-associated tracheobronchitis, development of an evidence-based practice for transitioning from an ICU to portable home ventilator, and targeted strategies to reduce unplanned readmissions, as well as numerous other possibilities. More influential advocates are needed, such as the late Katie Beckett, who experienced long-term ventilator dependence and made a significant impact, to continue advancing the care of this fragile patient population.

**L Denise Willis**  
Arkansas Children's Hospital  
Respiratory Care Services  
Little Rock, Arkansas

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