Long-term ventilation: charting a pathway home

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Children with chronic respiratory insufficiency who require assisted ventilation are a very complex and vulnerable cohort within the growing spectrum of children with physical and developmental disabilities. Beginning in the late 1970s, technological innovation and a growing appreciation of the broader social contributions of children and adults with disabilities, facilitated the transition of these patients from hospital-based or long-term care to the home setting.1 Integrated with their families and communities, these children have not only survived but also experienced better developmental outcomes.

McDougall and colleagues2 describe the expansion of a single institution programme providing long-term mechanical ventilation for children throughout the Canadian province of British Columbia. Over a 15-year period, they documented a 10-fold increase in enrolment. I applaud the authors and their staff who worked with these children and their families. The upward trend in mechanical support is indicated by the several reports mentioned in their manuscript and illustrates the international relevance of this development. Excluding infants with premature lung disease, the authors acknowledge and describe the shift toward neuromuscular, aberrant respiratory drive, and combined upper and lower airway diagnoses as the underlying reasons for ventilation support. The implications of this changing demographic are further highlighted by the relatively low rates of discontinuation of mechanical support and tracheal decannulation. While understanding complex needs and condition trajectory is important for programme development, it is also crucial for families considering long-term ventilation and setting goals and expectations.3

Readers should regard the apparent equilibrium in programme enrolment with caution, as it may represent an epiphenomenon. The plateau in transtracheal ventilation may be also misleading, reflecting regional or institutional preference.4 Independent of hospital and local resources, practitioner perspectives on quality of life vary widely and may result in inconsistent disclosure and opinions regarding life-prolonging ventilation options.5 Referrals to tertiary care centres are often biased. The documented success of programmes, such as that in Vancouver, has the potential to change perceptions and attitudes and subsequently alter counselling for patients and families. We have also seen the emergence of new populations receiving long-term mechanical ventilation support, for example, those with complex congenital heart disease, developments that may alter both the numbers of patients and the nature of need in the future.6

In their discussion, McDougall and colleagues allude to the challenges of providing homecare for children and families utilising long-time ventilation. Specifically, they cite the need to augment training and support to prevent tracheostomy or ventilator-related events. A minority of patients die, but the realities of the lived-experiences of most families warrant more extensive considerations and allowances. Parents may assume multiple roles, including those of medical and palliative care provider, therapist, technician and educator among others, with marked variability in community supports and resources, all the while trying to maintain a semblance of family life.6 Implications for siblings, parental capacity to work outside the home, and potential social isolation must be considered. Embracing a medical home model would greatly benefit these families. Albeit difficult to operationalise, this model provides for continuous, proactive, developmentally appropriate and comprehensive care through coordination between primary providers and subspecialists. Ideally, such a model would also include preparation and means for transition to adult care services. While the numbers of those affected is small, their care needs and the associated costs are great.

Ultimately, improving care for this complex and vulnerable population requires greater understanding of the successful components of home ventilator programmes, standardisation of care, and more uniform adaptations of existing and burgeoning technologies. Medical passports (ie, a portable health summary),7 portals for electronic medical records, remote monitoring and telemedicine could augment home-based care, extending the reach of tertiary care for the families and their local community providers. Assessment of care models and targeted interventions should consider meaningful survival outcomes, symptom management and resource utilisation. Determining the broader impact on families is important for employers, hospitals, homecare and equipment agencies, community programmes, and for payers, whether government-based or private, and will be critical for sustainable and reproducible comprehensive care. Models cannot depend upon the beneficence and capabilities of a handful of medical practitioners, such as those in Vancouver. We must change the paradigm of care. Long-term ventilation is no longer simply a bridge; it has evolved into an established method fostering growth, development and family.

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