EDITORIALS

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It's Time to Invest in Children Receiving Home Mechanical Ventilation

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Children receiving home mechanical ventilation (HMV), including noninvasive ventilation (NIV) or invasive mechanical ventilation (IMV) via tracheostomy, represent a growing population with high rates of healthcare utilization and dependence on specialized pediatric care (1-3). Models of outpatient care vary, but this vulnerable population is often followed by specialized care teams and home ventilation programs with the intent to mitigate readmissions, reduce overall healthcare utilization, and improve longterm outcomes (4-7). Although research has demonstrated that children who receive HMV are high-cost users of the healthcare system (7, 8), comprehensive evaluation of the healthcare utilization patterns and associated costs, direct and indirect, is essential for all stakeholders, including parents facing decision making, patient advocates,

primary care providers, hospitals, healthcare providers, policymakers, and payers.

In this issue of AnnalsATS, Amin and colleagues (pp. 1421-1431) present the results of a retrospective Canadian population/province-based cohort study of 835 children receiving HMV via NIV or IMV (9). Over a 14-year accrual period, they examined healthcare utilization and costs, comparing 2 years before and 2 years after HMV implementation. Pertinent findings of this study included fewer intensive care unit (ICU) and total hospitalization days in the first two years of HMV, which was countered by increased charges for home care services and a shift to outpatient clinic visits. This corresponded to higher total healthcare costs but reduced all-cause hospital admission costs. In multivariable models, IMV, the number of home technological supports, and increased healthcare costs in the year immediately before HMV approval were associated with children in the highest total healthcare and home service cost quartile. Complex chronic conditions (10), the number of technological supports, and higher healthcare costs in the year before HMV approval were associated with higher hospital admission costs.

This study is a valuable contribution to the pediatric complex care landscape and health service field, as a whole, in which cost analyses for cohorts of children receiving HMV are limited in number and scope. The comprehensive nature of the dataset is certainly a strength. The detailed information about costs, acute care utilization, outpatient visits, nursing supports, pertinent testing (including polysomnography and pulmonary function tests), and medical supplies in this analysis provides a degree of detail that sets it apart from studies based in the United States, where it is less feasible to query longitudinal and linked inpatient-outpatient data. The pattern of healthcare utilization described in this study, in conjunction with prior studies, supports earlier consideration of ventilatory support via tracheostomy to optimize a range of outcomes, including healthcare utilization,

in-hospital length of stay, and even mortality (11–13).

As pointed out by the authors, the limitations of their study center on the use of retrospective administrative data. Outcomes, such as weaning from HMV or tracheal decannulation, were not determined and might have a significant impact on healthcare utilization. There are also intrinsic challenges using patients as their own control subjects for a pre-post comparison in conditions that may have variable trajectories, cumulative morbidities, and, likely, clustering of encounters in advance of initiating new technological supports. That is, longer follow-up would have been very interesting. Cost persistence is often not observed in the chronic population, as a given child may have high resource utilization for a period associated with illness or interventions but then have periods of quiescence (7, 14).

Importantly, health services research continues to struggle to capture the "savings" of averted hospital admissions, a result of either the consistent and effective use of technology supports or the partnering of families with specialized care teams. Albeit implicit in this type of inquiry and challenging with this cohort, there is no means to determine how much a given child would have accessed health services, and thus accrued healthcare costs, if their family and care team had not pursued HMV or transitioned from NIV to IMV. Not pursuing a tracheostomy, in fact, may result in zero encounters and expenditure, for example, if the child died or increased costs if the child continued to struggle with noninvasive and less effective supports. Reduction in ICU utilization for those with complex chronic conditions and HMV may also have significant downstream implications for hospitals and systems, in an era when the proportional use of pediatric ICU beds is increasing (15).

Beyond the potential cost and economic benefits of HMV, the calculus must include tangible and intangible impact on children and their families, including but not limited to equality in access, the complex domains

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of health-related quality of life and parental employment (presenteeism and absenteeism). The findings of Amin and colleagues (9) highlight that our systems are not keeping pace with our technologic capacity to support complex children in the community. Providers would be remiss not to include discussion of financial costs when embarking on decision making around HMV with families but should be cautioned not to allow that to overshadow the benefits. It is also incumbent on us to advocate and help our systems evolve to meet this burgeoning need. Comprehensive care, payment models, allowances for home care nursing, or assistance for these high-risk patients, currently, look very different between and even within countries. At a policy level, the findings of the present study, paired with the findings from a growing body of work in this field, should inform ongoing efforts to support a trained and adequately compensated workforce to meet the needs of medically complex children and their families (16). Investing in this growing cohort of children is essential for the future of our field as well as the adult services to which they will eventually transition.

<u>Author disclosures</u> are available with the text of this article at www.atsjournals. org.

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