Patients, caregivers and health system costs of home ventilation

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Long-term ventilation has been a successful part of the management of chronic respiratory failure since the use of the iron lungs was introduced during the polio epidemics in the 1930s and 1940s. The transition from hospital-based therapy to genuine home ventilation was pioneered by a number of physicians and patients including Robert Cavendish whose story was dramatised in the recent biopic 'Breathe'. Robert Cavendish used his financial backing and engineering contacts to develop the first wheelchair mounted ventilator marking a watershed in the management of ventilator-dependent patients; empowering patients with chronic respiratory failure to live independent of a healthcare environment. Improvements in technology, for example, positive pressure ventilation, have facilitated the move from hospital to community support for complex respiratory patients; however, this comes at a cost to the patient, caregivers and the health system. The cost to the health system is rising as the number of patients' requiring home mechanical ventilation (HMV) increases[1] in line with growing data to demonstrate its effectiveness in chronic respiratory failure secondary to different clinical conditions.[2–5]

Many patients prefer to receive HMV to promote quality of life, despite the potential physical, psychological and financial burden for themselves and their families.[6] Data on costs of home ventilation in this patient group are limited or retrospective. In their *Thorax* paper, Nonoyama and colleagues[7] conducted a prospective study evaluating the annual cost of the management of ventilator-dependent patients in two different models of care within the Canadian health system. They reported these costs from a societal perspective and in a comprehensive manner at an individual patient and health system level. The investigators managed to contact patients every 2 weeks to collect cost data in order to limit recall bias. However, it is important when interpreting the results of this study to appreciate that, even with an exhaustive attempt to quantify costs, the study assessed only a small proportion of the total HMV population in Canada (134/1100 patients from two provinces) using a non-random sampling approach. A relatively large proportion of the sampled patients were invasively ventilated (34% compared with 13% in the Eurovent study[8]). The care of invasively ventilated patients is more complex than those managed with non-invasive ventilation (NIV) and as such would be expected to incur higher costs (median (IQR) monthly cost of care for NIV $C3925 ($C1212–$C7390); invasive ventilation $C8733 ($C5868–$C15 274)). Furthermore, when applying these data to other health systems, the distribution of the underlying diseases leads to chronic respiratory failure and therefore HMV need to be assessed for applicability. The broader health and social system that is used to support such individuals also needs to be investigated further.

As may be expected, there were significant differences in costs between disease groups. Patients with more severe disability and consequential greater community support incurred significantly higher costs than those with higher levels of functional ability. The magnitude of the difference is striking with patients in the lowest functional category (measured using the functional independence measure) incurring a 300%–700% higher median cost than the highest functioning group. Furthermore, the proportion of healthcare funded costs and cost of lost caregiver time were inversely related, so that as public costs were reduced, the shortfall was bridged by an increasing caregiver burden. This has clear consequences when considering packages of care in the increasingly fragmented social structure of developed urban economies where extensive family support may be less prominent than it once was.

One of the most striking features of the presented data is the variation in cost between two states within the same country (median monthly healthcare costs: British Columbia $C6009, Ontario $C4538). The variation in costs did not appear to be due to differences in the distribution of underlying disease or patient functional capacity, but was attributed to differences in healthcare delivery between the two states. The more expensive state, British Columbia, has a more comprehensive system specifically designed for provision of HMV with 98% of median costs in this state being attributed to public funded healthcare costs and 0% to caregiver lost time. This compares with 39% and 56%, respectively, in Ontario which does not have access to the same comprehensive package of HMV personnel and equipment. This raises many interesting questions regarding healthcare provision. The cost of care for patients undergoing prolonged mechanical ventilation in institutionalised care is high and it may be that a more comprehensive system supports more patients to transition to the community and live independently without the need for extensive family support that not all patients can provide. Although, this question is not directly addressed in the current paper and may be the focus of future work.

As the HMV population expands, the health system must develop to support patients in their chosen care setting with the level of caregiver input being decided by the patient and their caregivers rather than dictated by the structure of the funding system to ensure equitable care for all.

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Funding This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient consent Not required.

Provenance and peer review Commissioned; internally peer reviewed.

To cite Murphy PB, Douiri A. *Thorax* 2018;**73**:601–602.

Accepted 12 February 2018
Published Online First 6 March 2018

Linked

► http://dx.doi.org/10.1136/thoraxjnl-2017-211138

Thorax 2018;**73**:601–602.
doi:10.1136/thoraxjnl-2018-211659

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