ORIGINAL ARTICLE:

TITLE: Paediatric invasive long-term ventilation – A ten-year review

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Summary at a glance:

A ten-year review of demographics and outcomes for patients commenced on invasive long-term mechanical ventilation (LTMV) in a tertiary Irish Paediatric hospital was conducted. Year on year, less patients were commenced on LTMV and they were weaned and decannulated with ever more success, with implications for hospital costs and resources.

Abstract:

Background and objective: The number of children with complex physical and developmental pathologies, including chronic respiratory insufficiency, surviving and growing beyond early childhood continues to rise. No study has examined the clinical pathway of children on invasive LTMV in an Irish setting. Our data over a 10-year period was reviewed to see if our demographics and outcomes are in line with global trends.

Materials and Methods: Children's Health Ireland (CHI) at Crumlin, Dublin is Ireland's largest tertiary paediatric hospital. A retrospective review analysed data from children in

our centre commenced on LTMV via a tracheostomy over 10 years (2009 – 2018). This data was subdivided into two epochs for statistical analysis of longitudinal trends.

Results: Forty-six children were commenced on LTMV from 2009 to 2018. Many had complex medical diagnoses with associated co-morbidities. Far less children, 30.4% (n=14) commenced on LTMV in the latter half of the 10-year period, they also fared better in all aspects of their treatment course. Focusing solely on children who have needed LTMV over this timeframe we have been able to isolate trends specific to this cohort. Less patients commenced LTMV on a year on year basis, and for those that require tracheostomy and LTMV, their journey to decannulation tends to be shorter.

Conclusion: Over the period reviewed, less patients over time necessitated long-term invasive therapy and those patients are being weaned and decannulated with ever more success. This has implications in terms of predicting numbers transitioning to adult services and allocation of hospital and community care resources.

Introduction:

Over recent years the number of children with complex physical and developmental disabilities surviving and growing beyond early childhood continue to rise as advances in medical knowledge and technology enable support of their myriad of needs. Children and infants with chronic respiratory insufficiency due to any number of underlying pathologies are an ever increasing part of this cohort [6]. For over two decades there has been a move to transition children with complex needs including tracheostomy and invasive Long-term Mechanical Ventilation (LTMV) towards full home care [8]. Home care when appropriately supported is not only a cost effective strategy but has also been shown to provide psychological and developmental advantages for chronically unwell children [5]. Across the world, countries have noted a downward trend in the number of children per year requiring tracheostomy LTMV as the numbers of those managed with non-invasive ventilation continue to rise [93]. Despite this downward trend, children on invasive LTMV still spend lengthy periods of time in hospital before being discharged home causing significant psychological issues and emotional distress for families [1]. To date, no study has ever examined the clinical pathway of children on invasive LTMV in an Irish setting. A review of our data over a 10 year period was prompted to see if our patient demographics and outcomes are in line with global trends.

Materials and Methods:

Children's Health Ireland (CHI), Crumlin, Dublin is the largest paediatric tertiary referral centre in Ireland. We conducted a retrospective review a 10 year period (2009 – 2018) of children who were commenced on long-term mechanical ventilation (LTMV) via a tracheostomy at CHI, Crumlin during that time. For the purposes of this review, LTMV was defined as a requirement for tracheostomy and mechanical invasive ventilation for greater than three months without the need for intensive medical supervision or regular intervention. In our hospital patients no longer needing PICU level management are stepped down to our purpose-built Transitional Care Unit (TCU) where health care staff have the training and equipment for the management of these children. Such units have significant cost saving implications compared with PICU, as well allowing reallocation of PICU beds and resources to other patients in need [4]. The study was approved by the hospital's ethics committee.

A clinical database was used to collate data obtained via a retrospective chart review of paediatric patients less than 18 years of age. Starting point for inclusion was day one of invasive ventilatory support and end point was conclusion of data collection (31st December, 2018). This data was subdivided into two epochs for statistical analysis of longitudinal trends: 2009 – 2013 and 2014 - 2018.

Results:

Forty six children were commenced on LTMV from 2009 to 2018 and nearly two thirds were male (60.8%, n = 28). The median age at time of initiation of LTMV was 141 days with an interquartile range (IQR) of 96 days (day of birth to 15 years). The vast majority (91.3%, n = 42) were commenced on LTMV within the first year of life. Over two thirds (69.5%, n=32) of patients commenced LTMV in the earlier subgroup between 2009 and 2013. Statistical analysis of the results was performed using a student t-test on continuous variables and a chi squared test on categorical variables using SPSS 24.0.

Many of our patients had numerous medical diagnoses often with multi-systemic pathologies and associated co-morbidities. When analysing the data we took co-morbidities to mean distinct pathological entities as opposed to consequences of the same underlying disease process within a system. Primary airway/pulmonary pathology was the principal reason for LTMV requirement in the majority of patients (80.4%, n = 37) as can be seen in Table 1.

Of these, over one third (39.1%, n = 18) had airway malacia as their primary respiratory diagnosis. It is important to note that isolating the primary indication for LTMV risks over-simplifying a complex cohort and the vast majority of patients (84.7%, n = 39) had more than one pathology contributing to their need for LTMV inclusive but not limited to prematurity (59%, n = 27), trachea-oesophageal fistula with or without oesophageal atresia (TOF +/- OA), secondary cardiac anomalies, neurological abnormalities, major gastrointestinal pathologies and skeletal dysplasia. Almost half of the patients (43.4%, n = 20) had three or more distinct co-morbidities or separate organ system pathologies which

contributed to the complexity of the delivery of medical care and the management of acute intercurrent illnesses during their course of stay.

The latter half of the 10 year review noted far less children commenced on LTMV with only 30.4% (n = 14) falling into this group, 43% less than the preceding five years. This group also fared better in all aspects of their treatment course (Table 2) when compared with the patients in the 2009 – 2013 cohort. They demonstrated a shorter median overall hospital stay (501 versus 445 days, p=0.013). Those patients commenced on LTMV in the latter group (2014 – 2018) who subsequently successfully weaned off ventilatory support had a significantly shorter median time where they were ventilator dependant (539 vs 333 days, p=0.008) than their peers in the earlier group. There was no statistical difference in the median length of PICU stay (111 vs 109 days, p=0.221) or time to decannulation (443 vs 227 days, p=0.08) once LTMV ceased.

Figure 1 demonstrates that our current trend is towards less patients commencing LTMV on a year-on-year basis, and for those that do require tracheostomy and LTMV, they are tending towards shorter overall journeys from instigation of LTMV to decannulation. Overall, 8.7% (n=4) of patients died during the era reviewed (Table 3), all of whom were in the earlier cohort (2009 – 2013). Of these, two remained on LTMV at the time of death and two had weaned off LTMV but their tracheostomy remained in-situ. Three patients (6.5%) were lost to follow-up whilst still requiring LTMV having moved abroad after their discharge from hospital.

Discussion:

Long-term ventilation in children is an ever-changing, ever-advancing field of paediatrics. Our study reports that there are less children commenced on LTMV via a tracheostomy now when compared with ten years ago. Over the latter five years encompassed by our study, children on LTMV have a shorter duration of time on LTMV and spend less time in hospital compared with the previous five years. These findings are similar to other retrospective reviews from international counterparts which reveal a relative reduction in children ventilated via tracheostomy compared to those needing NIV [12]. Unlike other similar reviews that found that primary neurological/neuromuscular disorders were the most common reason for LTMV [7109], the majority of our patients had a primary airway/pulmonary pathology. This may be explained by the fact that our study excluded patients using NIV, whilst the above-mentioned studies included both LTMV and NIV managed patients in their data set. One other key difference between our cohort and other international reviews is that the vast majority of patients with primary neurological/neuromuscular pathologies are managed in a separate tertiary centre with its own capacity to initiate and follow-up patients on LTMV.

It is likely that reduction in the overall number of patients with respiratory insufficiency of any aetiology progressing to the need for LTMV is the result of significant changes and improvements in the use of non-invasive ventilation (NIV) strategies over the past ten years [9]. There was a 43.7% reduction in the number of patients commenced on LTV from 2014 – 2018 when compared with 2009 – 2013 with patients who historically may have progressed to tracheostomy and LTMV now often discharged home on NIV [3]. Developing and expanding the NIV provision to our patients has enabled us to provide an alternative to tracheostomy in many instances which not only has implications for the duration of

hospital stay and discharge planning but also likely results in substantial cost savings both in hospital and at home. With the variety of pathologies presenting to our service as candidates for LTMV it is important to note that as much as possible our therapeutic goal is to utilise LTMV as a weaning tool rather than a destination therapy. Significant Multi-Disciplinary Team (MDT) input and expertise is sought, taking into account each child's individual diagnoses and prognosis, before deciding whether tracheostomy and LTMV is ultimately in their best interest. This approach has also likely contributed to our relatively low numbers and is reflected in the fact that 69.4% (n=32) of all of the patients had weaned off LTMV at the time of cessation of data collection.

Time to discharge home on LTMV has been shortened, as has overall initial hospital stay for these patients, with a striking decrease in the length of total hospital stay in the latter group, although delays and unforeseen complications persist. These trends have implications not only on limited hospital resources but also on important non-medical parameters such as quality of life, growth and development as well as the financial and psychological burdens placed on family units during prolonged inpatient hospital stays [11]. The shorter stay in hospital for the second cohort was, we felt, in part due to the appointment of an LTV nurse specialist in 2017, whose role allowed for more efficient and effective discharge planning, coordination and execution.

It is notable that while a higher percentage of patients in the 2014 – 2018 group remain on LTMV or are awaiting decannulation it must be borne in mind that these patients are all earlier on in their tracheostomy journey than those in the earlier cohort. The reasons for delayed discharge were multi-faceted and did not fall under one category. There were a number of reasons recorded for delayed discharges causing increased length of stay in

hospital including awaiting suitable accommodation, awaiting adequate home care packages, education of parents and allocation of community resources. By stepping down the need for PICU earlier in their clinical course with the majority of inpatient management in our TCU and shortening average duration of total hospital stay we have been prompted to focus earlier on discharge planning with facilitation and co-ordination of at home care packages. This is led by our LTMV Nurse, who provides care-giver education, co-ordinates financial assistance and the oversees the myriad of other components that contribute to successful and sustainable provision of home LTMV. A dedicated team as well as a focal point in the form of a Tracheostomy Care Manager / Nurse has been shown to result in significant Time Driven Activity Based cost savings of 61% in the discharge planning phase of neonatal tracheostomy patients [2].

This study has several limitations, it is a retrospective study that relied heavily on chart review with 6.5% (n=3) lost to follow-up after discharge home on LTMV, all having moved abroad. Whilst the data collected may be from a single facility, it is one of only two facilities nationally that initiate and manage LTMV in children so does give good insight into our national demographics. This study gave a broad focus as to overall outcomes and evolving trends in what is a dynamic population and will help us to analyse and predict the priorities for improving our service provision and patient care into the future and demonstrates comparable findings with our international counterparts.

Many international reviews of LTMV patients combine their numbers with counterparts maintained on NIV. By focusing solely on the children who have needed LTMV over a ten-year period we have been able to isolate trends specific to this cohort including a decrease in the numbers requiring LTMV over the latter half of the study period as well as seeing improvements in all parameters of inpatient hospital stay and tracheostomy course.

In conclusion, whilst LTMV remains an important tool in the management of respiratory insufficiency it is encouraging to note that over the ten-year period reviewed there were less patients who necessitated long-term invasive therapy and that they are being weaned and decannulated with ever more success. These findings have far-reaching implications both in terms of predicting numbers transitioning to adult services as well as in allocation of hospital and community care resources.

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DATA AVAILABILITY STATEMENT:

Data available on request due to privacy/ethical restrictions

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