Invasive Home Mechanical Ventilation: 10-Year Experience of a Pediatric Home Care Service

Eliza Fernanda Borges, Laerte Honorat Borges-Júnior, Antônio José Lana Carvalho, Hyster Martins Ferreira, Wallisen Tadashi Hattori, and Vivian Mara Gonçalves de Oliveira Azevedo

BACKGROUND: Children dependent on invasive home mechanical ventilation (HMV) represent a growing population worldwide. The objective of this study was to assess the experience of 10 years of medical assistance given to pediatric patients on continuous invasive HMV at a Brazilian Home Care Service (HCS), specifically patient characteristics and predictors of outcome (ie, hospital readmission, death, and location of death). METHODS: Medical records for children on invasive HMV at the HCS between 2007 and 2016 were evaluated to collect the following data: age at admission to HCS, sex, principal diagnosis, length of hospital admission and home care period, number and cause of hospital readmissions, number of procedures, death and location of death. The odds ratio was used to understand the likelihood of death for each diagnosis, hospital readmission, and admission age, using a binary logistic regression model. RESULTS: Twenty-seven children were evaluated. The most prevalent diagnosis was cerebral palsy (37.0%). The mean duration of home care was higher than the mean hospital length of stay (955.0 ± 4.6 d versus 341.0 ± 0.5 d, respectively). First hospital readmission mean was at 392.6 ± 548.9 d, and the main cause was respiratory tract infection (45.9%), especially tracheitis. Of the total number of deaths (13), 76.9% occurred in hospital units. There was no statistically significant result observed for greater odds of death for any of the diagnoses and admission age on HCS. However, children who had a hospital readmission < 6 months after hospital discharge presented 10% greater chance of death (*P* = .02). CONCLUSIONS: The most prevalent diagnosis of children on continuous invasive HMV was cerebral palsy. The main cause of hospital readmission was respiratory tract infection, especially tracheitis. Having the first hospital readmission at < 6 months after discharge was shown to be a risk factor associated with mortality. *Key words: home mechanical ventilation; public health; domiciliary health care service; pediatrics; pediatric assistants; respiratory insufficiency*. [Respir Care 2020;65(12):1800–1804. © 2020 Daedalus Enterprises]

Introduction

Ever since the widespread use of ventilator support during the polio epidemic in the 1950s, the challenge was set for maintaining subjects dependent on mechanical ventilation in a nonhospital environment.[1] Even so, until the 1990s the majority of patients dependent on prolonged mechanical ventilation remained in ICUs, where in addition to making up the majority of admitted patients, these patients represented much higher costs and a significantly longer hospital stay when compared to other admitted patients.[2]

Ms Borges, Mr Carvalho, and Mr Ferreira are affiliated with the Graduate Program in Health Science, Faculty of Medicine, Federal University of Uberlândia, Umuarama, Uberlândia, Brazil. Mr Borges-Júnior is affiliated with the Home Care Service, Uberlândia Clinic Hospital, Federal University of Uberlândia, Umuarama, Uberlândia, Brazil. Dr Hattori is affiliated with the Department of Collective Health, Federal University of Uberlândia, Umuarama, Uberlândia, Brazil. Dr Azevedo is affiliated with the Faculty of Physical Education and Physical Therapy, Federal University of Uberlândia, Uberlândia, Brazil.

The authors have disclosed on conflicts of interest.

Correspondence: Vivian Mara Gonçalves de Oliveira Azevedo PhD, Faculty of Physical Education and Physical Therapy, Federal University of Uberlândia, 1286 – Rua Benjamin Constant., Nossa Sra. Aparecida, Uberlândia - MG, 38400–678, Brazil. E-mail: viviangazevedo1@gmail.com.

DOI: 10.4187/respcare.07406

Patients dependent on home mechanical ventilation (HMV) represent a worldwide growing population, which have specific and variable care needs.[3] Mechanical ventilation at home can be provided with invasive (eg, tracheostomy) or noninvasive ventilation methods. The concern about reducing hospital costs, along with technological progress of different types of equipment, have increased the demand for HMV.[1,4,5] International studies estimate that the prevalence of HMV varies from 6.6 to 20.0 per 100,000 adults and from 4.2 to 6.7 per 100,000 children below the age of 18.[6-9]

SEE THE RELATED EDITORIAL ON PAGE 1936

To understand the epidemiological profile of this population, the identification of the main predictors of outcome for the implementation and continuation of assistance to patients who need home health care of a high complexity over the short, medium, and long term is essential for identifying, planning, and executing actions that minimize obstacles to provide adequate assistance and to promote public health policies that guarantee assistance for this specific population.

Considering that there still is no standardization in the approach given to pediatric patients who require prolonged ventilation, along with a scarcity of publications referring to invasive HMV for these children, the objective of this study was to assess the experience over 10 years of medical assistance given to pediatric patients on continuous invasive HMV at a Brazilian Home Care Service (HCS), specifically with regard to patient characteristics and predictors of outcome (eg, hospital readmission, death, and location of death).

QUICK LOOK

Current knowledge

Children dependent on home mechanical ventilation represent a growing population worldwide. These patients remain longer in the ICU and have higher costs of medical care. There is still no standardization in the approach given to pediatric patients who require prolonged ventilation, and there is a lack of publications referring to invasive home mechanical ventilation for these patients.

What this paper contributes to our knowledge

The main cause of hospital readmission was respiratory tract infection, especially tracheitis. The frequency of tracheitis highlighted the importance of caregiver training. The first hospital readmission at < 6 months after Home Care Service admission was shown to be a risk factor for death.

Methods

Subjects and Study Design

This was a cross-sectional retrospective study with data collection from medical records. The records were evaluated for children on invasive HMV in an HCS. This HCS is one of the services provided by a university hospital in the southeast region of Brazil. The university hospital has 520 beds and is the largest provider of services to the public health system for the state, and it is the third largest university hospital in the country, providing medium and high complexity health services for 86 cities. The HCS was inaugurated in 1996, becoming a reference for the Ministry of Health in Brazil. It has 2 home care teams that assist children and adults on mechanical ventilation, oxygen therapy, and antibiotic therapy, with the objective of optimizing the transfer process from hospital care to home care, avoiding unnecessary hospitalizations.

All children assisted by this service between January 1, 2007, and December 31, 2016, were included in this study. For the child to be admitted to HCS on invasive HMV, it was necessary to be clinically stable and to have at least 2 caregivers or family members trained for daily care. In addition, a child underwent an adaptation period of at least 1 week on the mechanical ventilator that was used at home; additional equipment included an external battery and reserve oxygen. This adaptation was made while the children eligible for hospital discharge remained in the pediatric ward. The children who received care from the HCS on invasive HMV had a guaranteed place in the hospital in case of readmission, as well as a mobile ICU available for urgent and emergency care and transport to the hospital, all of which were subsidized by the public health system.

Exclusion criteria consisted of patients already admitted to other services, due to the impossibility of accessing data registered in their medical records. However, none of the eligible sample subjects were excluded. This study received prior approval from the Institutional Research Ethics Committee (protocol number 1.688.241).

Procedures

The identification of subjects eligible for the study was performed by means of the subjects' admission protocol made available by HCS. After subjects were identified, their medical records were requested from the archive system. Data collection was performed to obtain age at admission; sex; principal diagnosis; hospital length of stay and length of home care; number, cause, and length of hospital readmission, number of complications; and outcome (ie, length of

Table 1. Subject Characteristics

Characteristics	Subjects, *n* (%)
Age range	
Infant (29 d to 2 y)	12 (44.4)
Preschool (2–7 y)	9 (33.3)
School (7–12 y)	6 (22.2)
Disease groups	
Cerebral palsy	10 (37.0)
Neuromuscular diseases	6 (22.2)
Genetic syndromes	5 (18.5)
Others	4 (14.8)
Pulmonary disease	2 (7.4)
Sex	
Female	11 (40.7)
Male	16 (59.3)

Table 2. Principal Causes of Hospital Readmission

Cause	Subjects, %
Infection of the respiratory tract	48.3
Device failure	13.3
Infection of the urinary tract	13.3
Other causes	11.7
Gastrointestinal disturbances	5.0
Myopathies	5.0
Metabolic disturbances	3.3

Table 3. Factors Associated With Child Death

Deaths	Odds Ratio (95% CI)	*P*
Cerebral palsy	0.88 (0.19–4.24)	.88
Pulmonary disease	0.96 (0.06–16.46)	.96
Genetic syndrome	1.85 (0.34–10.01)	.48
Neuromuscular disease	0.42 (0.03–5.32)	.51
Hospital readmission (≤ 6 mo after discharge)	0.10 (0.02–0.65)	.02
Admission age on Home Care Service	0.92 (0.75–1.12)	.41

stay, discharge, and death, including location and cause of death). In addition to individual subjects' medical records, the length of stay and number of beds at the ICU of the pediatric hospital were also evaluated to calculate the impact of home care on hospital bed availability.

Statistical Analysis

Continuous variables were evaluated using the Kolmogorov-Smirnov normality test. The odds ratio was used to understand the likelihood of death for each diagnosis, hospital readmission, and admission age, using a binary logistic regression model. For all analyses, $P < .05$ was considered significant. The tests were performed with SPSS 21 (IBM, Armonk, New York).

Results

Medical records were evaluated for all 27 subjects admitted over the data collection period. The mean ± SD age of home admission was 4.04 ± 3.96 y. Of these 27 children, 59.3% were male, and the most prevalent diagnosis was cerebral palsy (37.0%). The mean ± SD time to first hospital readmission was 392.6 ± 548.9 d. In Table 1, the data referring to age group, sex, and the diagnosis per category of disease are presented.

The sum of the total home stay periods for all children evaluated was 25,797 d; this sum for hospital stay was 9,207 d. The mean ± SD total stay period of the children in home care was higher than the average period of hospital stays (955.0 ± 4.6 d versus 341 ± 0.5 d, respectively).

After calculating exclusively the period of home stay for all children on invasive HMV (ie, 25,797 d) and considering that the average length of stay in the pediatric ICU at the institution was 10.35 d from 2007 to 2016, one can estimate that the discharge of these children on invasive HMV freed up 2,492 beds for new admittances over the 10-y period, which equates to ~249 new admittances per year.

The main cause behind hospital readmission was respiratory tract infection (48.3%), with tracheitis representing 66.5% of the respiratory tract infections (Table 2).

From the total number of children that remained in home care, 13 died, 13 remained in home care, and 1 was discharged. Of the total number of deaths, 10 occurred in hospital units (76.9%), and 3 occurred while in home care (23.1%). Regarding other outcomes, 2 children (7.4%) transitioned to noninvasive ventilation or went on to develop total independence from mechanical ventilation.

Odds ratios indicated no statically significant result for greater odds of death for any of the diagnoses and admission age. However, there was a statistical significance related to odds of death for children who were readmitted to the hospital within < 6 months of hospital discharge (Table 3).

Discussion

The main cause of hospital readmission observed in this study was infection of the respiratory tract, which is considered the most common aggravating factor in hospital admissions.[10-12] We noted that, among the respiratory tract infections, tracheitis was the most frequent diagnosis, which itself may be due to the quality of provided care. In previous research, the main cause of complications in tracheostomized subjects was granuloma; infections were the second most common cause of complications, followed by tracheostomy

tube obstruction.[13] Therefore, the need to intensify the training of caregivers and improve the care provided with the tracheotomy is essential to alleviate the risk of these complications, which are stressors for family caregivers because they are related to the fear of the child needing to return to the hospital.[14]

The mortality rate encountered in this study was expected because these subjects were in palliative care and because infections are common aggravating factors in this patient profile due to the complexity of treatment for children in need of invasive ventilation.[13] However, we still identified a high length of stay for home admission when compared to hospital length of stay. No causes of death related to failure of equipment or devices were highlighted in our results, which is different from observations made in previous studies.[11,15] This reinforces the quality of care provided, as well as the advancement of technological resources, which provide greater safety and autonomy to caregivers.[10]

We did not observe a greater likelihood of death for any of the disease groups investigated, which is likely due to the clinical similarity among the children, independent of diagnosis. However, the likelihood of death increased significantly for patients readmitted < 6 months after hospital discharge, when considered from the first hospital readmission. This fact could be related to the gravity of this patient group, as well as the inexperience of the caregiver in the first instant.[10] These factors reinforce the need to intensify professional care in this initial period after discharge to provide adequate follow-up related to the gravity of patients, to meet the demands of caregivers, and to verify the effectiveness of training with the objective of avoiding hospital readmissions in the first 6 months after hospital discharge.

The transition from the pediatric ICU to home care requires committed family members, various qualified professionals, technology and financial resources, and ready access to primary medical and subspecialty care because these families can be overwhelmed by the use of hospital equipment and expenses.[16] In addition, family members often need to stop working or reduce workloads to care for the child on HMV.[17]

Regarding place of death, we confirmed that the majority occurred in the hospital environment. If we consider that the objectives of palliative pediatric care include maintaining the quality of life of both the children and their families,[18] the approach taken with these patients must be reassessed to make observations into whether their needs were properly met at the time of death. In Europe, various palliative care services have been developed over the last two decades, which can be found in different sectors and are divided into hospitals, autonomous installations, or home services.[19] However, there is still no consensus as to which of these offers the best continuation of care.[20]

We also observed the impact of HCS in assisting children with invasive HMV for the release of hospital beds. HMV can have a direct impact on the availability of highly complex hospital beds,[10,21] in addition to reducing the exposure of these individuals to hospital infections.[22] There is a significant increase in the use of HMV, and this could impact the health care system positively.[23,24]

This study has several limitations. Because this was a retrospective study, some data registered in the medical records were missing or incomplete. As such, it was not possible to analyze the socioeconomic conditions, nutritional state, and the experience of the main caregiver, which could have helped in the assessment of the care provided. A prospective study could elucidate these complementary questions. Another limitation is the small sample size, so our results may not be generalizable to the general population. However, even with these limitations, it still stands as an original study and our results indicate the importance of this type of service, especially when we consider the worldwide increase of this population and the scarcity of publications referring to the theme.

These children's health care profiles have been a challenge for new forms of care, where the incentive for new public policies specific to this group of children is indispensable, together with the training of qualified teams and the standardization of protocols that aim to provide adequate health care. In addition, technological progress is essential in this form of care that, along with the incorporation of telemonitoring of patients, represent the future possibility for improving care.

Conclusions

The most prevalent diagnosis of children on continuous invasive HMV was cerebral palsy. The primary cause of hospital readmission was respiratory tract infections, with tracheitis being the most commonly cited infection. Being readmitted to the hospital < 6 months after discharge was a risk factor associated with mortality. The frequency of tracheitis highlights the importance of caregiver training and the need for continued home follow-up for the maintenance and improvement of home health care.

ACKNOWLEDGMENTS

The authors thank all partners for contributing in the development of this article, especially the Clinical Hospital of the Federal University of Uberlândia, an institution of tertiary level and of national reputation for its Home Care Service and the Coordination for the Higher Education Personnel - Brazil (CAPES).

REFERENCES

1. McKim DA, Road J, Avendano M, Abdool S, Cote F, Duguid N, et al. Home mechanical ventilation: a Canadian Thoracic Society clinical practice guideline. Can Respir J 2011;18(4):197-215.

2. Thompson A. Home mechanical ventilation: an increasingly frequent reality. Pulmão 2015;24(3):49-53.
3. Rose L, McKim DA, Katz SL, Leasa D, Nonoyama M, Pedersen C, et al. Home mechanical ventilation in Canada: a national survey. Respir Care 2015;60(5):695-704.
4. Lloyd-Owen SJ, Donaldson GC, Ambrosino N, Escarabill J, Farre R, Faurox B, et al. Patterns of home mechanical ventilation use in Europe: results from the Eurovent survey. Eur Respir J 2005;25 (6):1025-1031.
5. Laub M, Berg S, Midgren B, Swedish Society of Chest Medicine. Home mechanical ventilation in Sweden: inequalities within a homogenous health care system. Respir Med 2004;98(1):38-42.
6. Racca F, Berta G, Sequi M, Bignamini E, Capello E, Cutrera R, et al. Long-term home ventilation of children in Italy: a national survey. Pediatr Pulmonol 2011;46(6):566-572.
7. Goodwin S, Smith H, Langton Hewer S, Fleming P, Henderson AJ, Hilliard T, Fraser J. Increasing prevalence of domiciliary ventilation: changes in service demand and provision in the South West of the UK. Eur J Pediatr 2011;170(9):1187-1192.
8. Nasiłowski J, Szkulmowski Z, Migdał M, Andrzejewski W, Drozd W, Czajkowska-Malinowska M, et al. Prevalence of home mechanical ventilation in Poland. Pneumonol Alergol Pol 2010;78(6):392-398.
9. Hanashiro M, Franco AOC, Ferraro AA, Troster EJ. Treatment alternatives for pediatric patients on chronic mechanical ventilation. J Pediatr (Rio J) 2011;87(2):145-149.
10. Downes JJ, Boroughs DS, Dougherty J, Parra M. A statewide program for home care of children with chronic respiratory failure. Caring 2007;26(9):16-18.
11. Racca F, Del SL, Mongini T, Vianello A, Ranieri VM. Respiratory management of acute respiratory failure in neuromuscular diseases. Minerva Anestesiol 2010;76(1):51-62.
12. Splaingard ML, Frates RC, Harrison GM, Carter RE, Jefferson LS. Home positive-pressure ventilation: twenty years' experience. Chest 1983;84(4):376-382.
13. Dal'Astra APL, Quirino AV, Caixêta JADS, Avelino MAG. Tracheostomy in childhood: review of the literature on complications and mortality over the last three decades. Braz J Otorhinolaryngol 2017;83(2):207-214.
14. Lima EC, Ribeiro N. The family caring for the child dependent on mechanical ventilation at home. Cienc Cuid Saúde 2009;8:110-116.
15. Sterni LM, Collaco JM, Baker CD, Carroll JL, Sharma GD, Brozek JL, et al. An Official American Thoracic Society clinical practice guideline: pediatric chronic home invasive ventilation. Am J Respir Crit Care Med 2016;193(8):e16-e35.
16. Gethins M. Pediatric palliative care in Europe expands. J Natl Cancer Inst 2012;104(1):10-11.
17. Edwards JD, Panitch HB, Constantinescu A, Miller RL, Stone PW. Survey of financial burden of families in the U.S. with children using home mechanical ventilation. Pediatr Pulmonol 2018;53(1):108-116.
18. Weaver M, Wichman C, Darnall C, Bace S, Vail C, MacFadyen A. Proxy-reported quality of life and family impact for children followed longitudinally by a pediatric palliative care team. Journal of Palliat Med 2018;21(2):241-244.
19. Friedel M, Brichard B, Fonteyne C, Renard M, Misson J-P, Vandecruys E, et al. Building bridges, paediatric palliative care in Belgium: a secondary data analysis of annual paediatric liaison team reports from 2010 to 2014. BMC Palliat Care 2018;17(1):77.
20. King AC. Long-term home mechanical ventilation in the United States. Respir Care 2012;57(6):921-932.
21. Costa MTF, Gomes MA, Pinto M. Chronic dependence on mechanical ventilation in pediatric care: a necessary debate for SUS. Cien Saude Colet 2011;16(10):4147-4159.
22. Han YJ, Park JD, Lee B, Choi YH, Suh DI, Lim BC, Chae JH. Home mechanical ventilation in childhood onset hereditary neuromuscular diseases: 13 years' experience at a single center in Korea. PLoS ONE 2015;10(3):e0122346.
23. Amirnovin R, Aghamohammadi S, Riley C, Woo MS, Del Castillo S. Analysis of a pediatric home mechanical ventilator population. Respir Care 2018;63(5):558-564.
24. Povitz M, Rose L, Shariff SZ, Leonard S, Welk B, Jenkyn KB, et al. Home mechanical ventilation: a 12-year population-based retrospective cohort study. Respir Care 2018;63(4):380-387.