


# Profile of the pediatric population on mechanical ventilation monitored by the Better at Home Program in Porto Alegre

## Perfil da população pediátrica em ventilação mecânica acompanhada pelo Programa Melhor em Casa de Porto Alegre

Bruna Luciano Farias<sup>1</sup> Luiz Fernando Calage Alvarenga<sup>2</sup> Ariane Ethur Flores<sup>3</sup> <sup>1</sup>Corresponding contact. Grupo Hospitalar Conceição (Porto Alegre). Rio Grande do Sul, Brazil. brunalucianofarias8@gmail.com<sup>2</sup>Universidade Federal do Rio Grande do Sul (Porto Alegre). Rio Grande do Sul, Brazil.<sup>3</sup>Universidade do Porto (Porto). Porto, Portugal.

**ABSTRACT | INTRODUCTION:** Home care constitutes a healthcare strategy that extends assistance beyond the hospital environment, particularly in cases requiring technological support, such as mechanical ventilation. **OBJECTIVE:** To characterize the profile of pediatric patients receiving mechanical ventilation under the supervision of the Better at Home Program in the municipality of Porto Alegre. **METHODS:** This descriptive study was conducted through the analysis of medical records of children and adolescents receiving home mechanical ventilation. **RESULTS:** A total of eighteen medical records were analyzed. The majority of patients were male (61%), with a mean age of 7.84 years. The most prevalent primary diagnosis was Duchenne muscular dystrophy (22%). Invasive mechanical ventilation was employed in 78% of cases, with an average daily use of 18 hours. Ventilatory insufficiency was the leading cause of ventilatory dependence (68%), and 78% of patients required oxygen therapy. In terms of nutritional support, 56% of patients were fed orally, while gastrostomy was used in 71% of cases. Regarding hospitalizations, 72% had been hospitalized at least once, with urinary tract infections being the most prevalent cause (33%). In 94% of cases, the mother served as the primary caregiver, typically with low educational attainment and fully dedicated to providing home care. **CONCLUSION:** This study contributes to the understanding of the clinical and social needs of pediatric patients on mechanical ventilation, underscoring the importance of home care and the need for intersectoral public policies that promote comprehensive and integrated care.

**KEYWORDS:** Home Care Services. Respiration. Artificial. Pediatrics.

**RESUMO | INTRODUÇÃO:** A atenção domiciliar representa uma estratégia de cuidado que amplia as possibilidades assistenciais além do ambiente hospitalar, especialmente em casos que demandam suporte tecnológico como a ventilação mecânica. **OBJETIVO:** Caracterizar o perfil da população pediátrica em ventilação mecânica acompanhada pelo Programa Melhor em Casa, no município de Porto Alegre. **MÉTODOS:** Realizado um estudo descritivo, por meio da análise de prontuários de crianças e adolescentes em ventilação mecânica domiciliar. **RESULTADOS:** Foram avaliados 18 prontuários, a maioria era do sexo masculino (61%), com média de idade de 7,84 anos. O diagnóstico principal mais frequente foi a distrofia muscular de Duchenne (22%). A ventilação mecânica invasiva foi utilizada por 78% da amostra, com uso médio diário de 18 horas. A insuficiência ventilatória foi a principal causa da dependência (68%) e 78% necessitavam de oxigenoterapia. Em relação à alimentação, 56% utilizavam via oral e 71% faziam uso de gastrostomia. Quanto às internações, 72% foram hospitalizados ao menos uma vez, sendo a infecção urinária a causa mais prevalente (33%). Em 94% dos casos, a mãe era a cuidadora principal, com baixa escolaridade e dedicação exclusiva ao domicílio. **CONCLUSÃO:** O estudo contribui para o reconhecimento das necessidades clínicas e sociais da população pediátrica em ventilação mecânica, reforçando a importância da atenção domiciliar e de políticas públicas intersetoriais voltadas ao cuidado integral.

**PALAVRAS-CHAVE:** Serviços de Assistência Domiciliar. Ventilação Mecânica. Pediatria.

## 1. Introduction

Home care is an integral component of the Brazilian *Sistema Único de Saúde* (SUS), functioning as a modality that extends the scope of healthcare beyond the hospital setting<sup>1-3</sup>. As established by Ordinance No. 825/2016<sup>4</sup>, it comprises a range of actions focused on health promotion, disease prevention, treatment, rehabilitation, and palliative care delivered at home, thereby ensuring continuity of care. The complexity of home care varies according to the patient's clinical condition and the need for life-support technologies. Its benefits include the humanization of care, a reduction in infection rates and healthcare costs, and the prevention of unnecessary hospitalizations through early discharge<sup>4</sup>.

In response to the growing number of conditions requiring mechanical ventilation and the clinical stability of certain patients, the Brazilian *Ministério da Saúde* launched a home-based non-invasive ventilatory support program in 2001<sup>5,6</sup>, initially targeting individuals with Progressive Muscular Dystrophy. This initiative was expanded in 2008<sup>7</sup> to include other neuromuscular diseases. In 2011, the Better at Home Program was established, and in 2017, Consolidated Ordinance No. 5<sup>8</sup> reinforced its integration into the *Rede de Atenção à Saúde* (RAS)<sup>9</sup>, strengthening policies related to hospital discharge and continuity of care. That same year, invasive mechanical ventilation was officially incorporated into SUS, following a recommendation by CONITEC<sup>10</sup>.

With ongoing structural and technological advancements in healthcare, home care has increasingly encompassed the pediatric population, whose need for mechanical ventilation is frequently associated with prolonged stays in neonatal and pediatric intensive care units<sup>11-14</sup>. This expansion reflects a governmental commitment to deinstitutionalization through the promotion of support mechanisms that facilitate the transition from hospital to home — an alternative that

was previously unfeasible for patients requiring prolonged or permanent hospitalization<sup>15,16</sup>. In this context, understanding the profiles of pediatric patients assisted by Home Care Services (SAD) is essential for the development of effective and safe strategies for delivering care in the home setting.

Describing this population is particularly relevant, as the implementation and expansion of home-based mechanical ventilation for children remain relatively recent developments within the Brazilian healthcare system, especially in the municipality of Porto Alegre. Furthermore, there is a notable lack of studies that specifically characterize this group. Given the potential of this care modality to strengthen the bond between the patient, their family, and social environment, this study aimed to characterize the profile of the pediatric population receiving mechanical ventilation monitored by the Better at Home Program in Porto Alegre.

## 2. Methodology

This descriptive study utilized data obtained through a structured instrument developed by the researchers, which was applied to the analysis of medical records. The sample consisted of all children (under 12 years of age) and adolescents (aged 12 to 18 years) receiving home mechanical ventilation, in accordance with the definitions established by the *Estatuto da Criança e do Adolescente*<sup>17</sup>. Individuals who were not using mechanical ventilation at home or who no longer required this support during the follow-up period were excluded from the study.

The sample was non-probabilistic and selected by convenience, comprising all cases of children and adolescents on home mechanical ventilation monitored by the Better at Home Program in the municipality of Porto Alegre between January 1st and September 30th, 2021. As this was a census sample — including all eligible cases during the study period — no sample size calculation was performed.

The variables analyzed included: sex, date of birth, age (in years), primary diagnosis, secondary diagnosis, use of mechanical ventilation, type, mode, interface, cause of ventilatory dependence, daily duration of use, need for oxygen therapy, oral feeding, use of other medical devices, need for hospitalization and reason, healthcare teams involved in follow-up, medical specialties involved in follow-up, primary caregiver, caregiver's age, marital status, educational level, and occupation.

Data analysis was conducted based on primary information, organized and interpreted using descriptive statistical techniques to provide an initial characterization of the variables under investigation. For quantitative variables, the mean was calculated, while categorical variables were analyzed using absolute frequency (n) and relative frequency (%). Statistical analysis was performed using SPSS software, version 29.0.1.1.

This study complied with Resolution No. 466/2012 of the Brazilian National Health Council (CNS)<sup>18</sup>, and data collection began only after approval was granted by the Research Ethics Committee (REC) of the *Universidade Federal do Rio Grande do Sul* (CAAE: 50844321.2.0000.5347). As the institution where the study was conducted is affiliated with a municipal authority, it is subject to the provisions of Law No. 12.527, dated November 18th, 2011<sup>19</sup>, which, under Article 10, allows any interested party to request access to information from public bodies and entities, provided the requester is identified and the requested information is specified. The institution formally authorized the study through a Letter of Agreement signed by its administrator. The researchers affirmed their commitment to ensuring the confidentiality of the data collected, in accordance with CNS Resolution 466/2012 and its complementary regulations, by signing a Data Use Agreement (DUA).

### 3. Results

Based on the general characteristics presented in Table 1, the initial study population consisted of 30 patients. Following the application of the exclusion criteria, 12 medical records were excluded, resulting in a final sample of 18 patients, of whom 61% were male and 39% female. The mean age was 7.84 years.

Regarding the primary diagnosis, 22% of the patients were diagnosed with Duchenne muscular dystrophy and 11% with achondroplastic dwarfism, while the remaining baseline diagnoses accounted for 67% of the sample. With respect to secondary diagnoses, 78% of the patients presented with at least one additional condition (Table 1).

Regarding ventilatory support, 78% of the patients were receiving invasive mechanical ventilation (IMV). Ventilatory insufficiency was identified as the primary cause of dependence in 68% of cases, with a mean daily usage of 18 hours. Additionally, 78% of the patients required oxygen supplementation.

Regarding nutrition, 56% of the patients were fed orally; however, 78% utilized a combination of feeding routes involving additional devices, with gastrostomy being the most frequent (71%).

Regarding hospitalizations during the follow-up period, 72% of the patients experienced at least one hospitalization. Notably, however, 56% had not been hospitalized in the year preceding the study. The primary causes of hospitalization were urinary tract infection (33%), unspecified infection (22%), and ventilatory dysfunction (22%).

**Table 1.** Characteristics of Children and Adolescents (to be continued)

Characteristics		n <sub>i</sub> (n)	f <sub>i</sub> (%)	Mean
Sex				
	Male	11	61%	
Age (years)				7.84
Primary Diagnosis				
	Duchenne Muscular Dystrophy	4	22%	
	Achondroplastic Dwarfism	2	11%	
	Other diagnoses	12	67%	
Secondary Diagnosis per Patient				
	1	3	17%	
	2	2	11%	
	3	7	39%	
	4	1	6%	
	5	1	6%	
	No secondary diagnosis	4	22%	
Use of MV				
	NIMV	4	22%	
	IMV	14	78%	
Connected Equipment				
	IMV – Life support	8	57%	
	IMV - Bilevel	6	43%	
	NIMV - Bilevel	4	100%	
Cause of MV				
	Ventilatory insufficiency	12	67%	
	Other causes	6	33%	
Daily Use of MV				
	3 to 8 hours	5	28%	
	10 to 20 hours	3	18%	
	24 hours	10	56%	
Daily MV Use (hours) - Mean				18
Oxygen Supplementation				
	Yes	14	78%	
Oral Feeding				
	Yes	10	56%	
Use of Other Devices				
	Yes	14	78%	
Types of Devices				
	Nasoenteric tube	4	29%	
	Gastrostomy	10	71%	
	Intermittent urinary catheter	2	14%	

**Table 1.** Characteristics of Children and Adolescents (conclusion)

Characteristics		n <sub>i</sub> (n)	f <sub>i</sub> (%)	Mean
Hospitalizations – Previous Year	Hospitalizations			
	Yes	13	72%	
	0	10	56%	
	1	6	33%	
	2	1	6%	
Reasons for Hospitalization	4	1	6%	
	Urinary tract infection	6	33%	
	Unspecified infection	4	22%	
	Ventilatory dysfunction	4	22%	
	Respiratory infection	3	17%	
	Tracheostomy myiasis	3	17%	
	Right subclavian thrombosis	2	11%	
	Surgery	1	6%	
	Elective – tracheostomy replacement	1	6%	
	Acute viral bronchiolitis	1	6%	
	Mechanical ventilation equipment replacement	1	6%	
	Not reported	1	6%	

Source: the authors (2021).

MV: Mechanical Ventilation. OF: Oral Feeding.

\*The sum of percentages may not equal exactly 100% due to rounding.

At the secondary care level, the most frequently involved specialties were pediatric pulmonology (56%) and pediatric neurology (50%), followed by otorhinolaryngology, medical genetics, and pediatric surgery, each participating in 33% of the cases.

**Table 2.** Teams Responsible for Patient Follow-up (to be continued)

		n	%
Teams from the Better at Home Program	Medicine	18	100
	Nursing	18	100
	Nursing Technician	18	100
	Physical Therapy	16	89
	Social Work	17	83
	Nutrition	13	72
	Speech Therapy	13	17

**Table 2.** Teams Responsible for Patient Follow-up (conclusion)

	n	%
Outpatient Medical Specialties		
Pediatric Pulmonology	10	56%
Pediatric Neurology	9	50%
Otorhinolaryngology	6	33%
Genetics	6	33%
Pediatric Surgery	6	33%
Pediatrics	5	28%
Orthopedic Trauma	3	17%
Pediatric Cardiology	3	17%
Pediatric Gastroenterology	3	17%
Physical Medicine and Rehabilitation	3	17%
Pediatric Endocrinology	2	11%
Sleep Pulmonology	2	11%
Pediatric Nephrology	1	6%
Thoracic Surgery	1	6%
Clinical Nutrition	1	6%
Psychiatry	1	6%

Source: the authors (2021).

\*The sum of the percentages may not equal exactly 100% due to rounding.

In 94% of the cases, the mother was identified as the primary caregiver, with a mean age of 35 years (Table 3). Regarding educational level, 56% had not completed elementary education, and 89% reported being exclusively dedicated to household responsibilities.

**Table 3.** Primary Caregiver Characteristics (to be continued)

Characteristic	n	%	Mean
Primary Caregiver			
Mother	17	94	
Aunt	1	6	
Age – Primary Caregiver			35
Marital Status – Primary Caregiver (Self-reported)			
Married	11	61%	
Single	3	17%	
Separated	3	17%	
Widowed	1	6%	
Educational Level – Primary Caregiver			
Incomplete elementary education	10	56%	
Complete elementary education	1	6%	
Incomplete high school education	1	6%	
Complete high school education	3	17%	
Not reported	3	17%	

**Table 3.** Primary Caregiver Characteristics (conclusion)

Characteristic	n	%	Mean
Occupation – Primary Caregiver			
Stay-at-home parent	16	89%	
Housemaid	1	6%	
Daily house cleaner	1	6%	

Source: the authors (2021).

\*The sum of the percentages may not equal exactly 100% due to rounding.

## 4. Discussion

This study aimed to characterize the profile of the pediatric population dependent on mechanical ventilation (MV) and monitored by the Better at Home Program in the municipality of Porto Alegre. The findings contribute to a deeper understanding of the clinical, caregiving, and social specificities of this population, while also reinforcing the ongoing discussion surrounding pediatric home care.

In this context, a predominance of male patients (61%) and a mean age of 7.84 years were observed, consistent with findings reported in parts of the literature<sup>11,12,20</sup>. However, some studies have identified more balanced gender distributions<sup>21,22</sup> or even a higher proportion of female patients<sup>23</sup>. These variations may reflect not only methodological differences but also disparities in access to diagnosis and healthcare services, particularly in socially vulnerable contexts. Regarding primary diagnoses, neuromuscular diseases were the most prevalent, as also reported by Hanashiro et al.<sup>22</sup> and Resener et al.<sup>23</sup>, which aligns with the progressive nature of these conditions and their frequent association with prolonged ventilatory dependence. In contrast, Borges<sup>20</sup> identified cerebral palsy as the leading cause, underscoring the clinical heterogeneity among patients who evolve to chronic use of mechanical ventilation and, consequently, the importance of individualized approaches in home care.

Invasive ventilatory support was required in 78% of the cases, highlighting the clinical severity of the sample and corroborating findings from previous studies<sup>11,23-25</sup>. The need for oxygen therapy among all of these patients further indicates significant respiratory compromise, emphasizing the importance of meticulous planning in terms of team qualifications, supply logistics, and the continuity of care in situations of clinical instability.

Moreover, among users of non-invasive mechanical ventilation (NIMV), the bilevel pressure mode was employed in 100% of the cases, in contrast to the findings of Sovtic et al.<sup>26</sup>, who reported its use in 33% of cases. This discrepancy may be attributed to differences in clinical protocols, team expertise, or resource availability. The selection of ventilatory mode should consider not only clinical factors, but also the family context, caregiver training, and the level of support provided by the healthcare network.

Regarding the etiology of mechanical ventilation dependence, ventilatory insufficiency was identified in 68% of the cases, a finding consistent with that reported by Park et al.<sup>25</sup>. Early recognition of this condition is essential to reduce risks and avoid prolonged hospitalizations, particularly among patients with neuromuscular diseases or congenital malformations. This scenario is further reflected in the continuous use of mechanical ventilation by 56% of the patients, underscoring the high complexity of these cases and their profound impact on family routines. This level of dependence, which exceeds that reported in parts of the literature<sup>23,26-30</sup>, highlights the need for strengthened support from home care teams and intersectoral initiatives that offer emotional, financial, and educational assistance to families.



Regarding nutrition, the majority of patients were fed orally (56%), while gastrostomy was the primary alternative route (71%), which is consistent with findings reported by Lot et al.<sup>21</sup> and Redouane et al.<sup>31</sup>. Studies such as those by Sovtic et al.<sup>26</sup> and Ottonello et al.<sup>27</sup>, which describe lower rates of gastrostomy use and higher reliance on nasoenteric tubes, suggest that the selection of feeding devices may be influenced by the expected duration of mechanical ventilation and institutional protocols or policies.

Regarding hospitalizations, 72% of the patients were admitted during the follow-up period; however, more than half had not been hospitalized in the year prior to the study, a finding also reported by Carvalho<sup>32</sup>. These results suggest a potential protective effect of structured home care. While Lot et al.<sup>21</sup> reported readmissions in all cases, the reduction observed in the present study may indicate the effectiveness of continuous monitoring and timely interventions. The identification of urinary tract infection as the leading cause of hospitalization — differing from the predominance of respiratory infections described in other studies<sup>20,21,33</sup> — may be related to the use of indwelling urinary catheters, home hygiene conditions, and the severity profiles and comorbidities of the patients.

In terms of healthcare follow-up, the most frequently involved medical specialties — pediatric pulmonology, pediatric neurology, otorhinolaryngology, medical genetics, and pediatric surgery — reflect the predominant clinical conditions observed in the sample and highlight the need for coordinated care across different levels of the health system to ensure continuous and multidisciplinary management.

Within the family context, the caregiver profile reveals important considerations: 100% were women, with the mother identified as the primary caregiver in over 90% of the cases. Consistent with the findings of Mariani et al.<sup>12</sup>, this underscores the central role of mothers in caregiving and the resulting implications for their health, educational attainment, and participation in the labor market. The predominance of low educational levels — specifically, incomplete elementary education — contrasts with Mariani et al.'s<sup>12</sup> findings, in which most caregivers had completed high school. This discrepancy highlights the need for public policies that integrate health,

education, and social assistance initiatives aimed at supporting caregivers.

In this context, home care — as a strategic component of the Brazilian *Sistema Único de Saúde* (SUS) — represents a significant advancement by facilitating safe hospital discharge, preserving family bonds, and promoting patient autonomy. However, its effectiveness relies on intersectoral coordination, continuous professional training, and sufficient funding to address the complexity of care required in these cases.

However, as with any scientific study, this research presents limitations that must be acknowledged. The small sample size limits the generalizability of the findings, although it reflects all cases monitored during the study period. The retrospective and descriptive design, based on medical record analysis, is subject to incomplete or inconsistent documentation, which may have impacted the accuracy of certain data, such as causes of rehospitalization, comorbidities, and identification of ventilatory equipment brands. Additionally, the absence of standardized instruments to assess functionality, quality of life, and caregiver burden restricted the analysis to more objective variables and limited the exploration of the subjective impact of home care. The fact that the study was conducted in a single municipality, using a specific home care model, further limits the applicability of the results to other contexts with differing resources and infrastructure.

Given these limitations, future research should include larger, multicenter samples to allow for regional comparisons and improve the representativeness of findings. The use of mixed-method approaches — combining quantitative and qualitative data — may deepen the understanding of home care by incorporating the perspectives of patients, caregivers, and healthcare professionals. It is also recommended to employ validated instruments to assess both clinical and psychosocial dimensions and to conduct studies exploring the intersection of health, social assistance, and education — particularly in relation to the living conditions and educational backgrounds of caregivers. Finally, investigations assessing the cost-effectiveness of home care compared to traditional hospital-based models are essential to inform the development of more sustainable, person-centered public policies that support longitudinal care.



## 5. Conclusion

This study enabled the characterization of the pediatric population on mechanical ventilation monitored by the Better at Home Program in the municipality of Porto Alegre. The majority of patients were male, with a mean age of 7.84 years, and Duchenne muscular dystrophy emerged as the most frequent primary diagnosis. Notably, all primary caregivers were women, underscoring key characteristics of the caregiving profile and providing valuable insights into the sociodemographic characteristics of caregivers.

The findings of this study are particularly significant, as it represents the first survey of this type of pediatric patient profile in the city of Porto Alegre. It contributes directly to a deeper understanding of this population, which continues to grow nationwide and demands a committed approach and targeted initiatives to address its specific needs. These results underscore the importance of further research to expand knowledge and respond effectively to the challenges posed by this evolving care context.

### Author's contributions

The authors declare having made substantial contributions to the study in terms of its conception or design; the acquisition, analysis, or interpretation of data; and the drafting or critical revision of the manuscript for important intellectual content. All authors approved the final version to be published and agreed to take full responsibility for all aspects of the work.

### Competing interests

No financial, legal, or political conflicts involving third parties (such as government entities, corporations, or private foundations) were declared in relation to any aspect of the submitted work, including—but not limited to—grants and funding, participation on advisory boards, study design, manuscript preparation, and statistical analysis.

## Indexing

The Journal of Physiotherapy Research is indexed by [DOAJ](#), [EBSCO](#), [LILACS](#) and [Scopus](#).



## References

1. Portaria nº 2.029, de 24 de agosto de 2011 (Brazil). Institui a Atenção Domiciliar no âmbito do Sistema Único de Saúde (SUS). [Internet]. Ministério da Saúde. Available from: [https://bvsms.saude.gov.br/bvs/saudelegis/gm/2011/prt2029\\_24\\_08\\_2011.html](https://bvsms.saude.gov.br/bvs/saudelegis/gm/2011/prt2029_24_08_2011.html)
2. Portaria nº 963, de 27 de maio de 2013 (Brazil). Redefine a Atenção Domiciliar no âmbito do Sistema Único de Saúde (SUS). [Internet]. Ministério da Saúde. Available from: [https://bvsms.saude.gov.br/bvs/saudelegis/gm/2013/prt0963\\_27\\_05\\_2013.html](https://bvsms.saude.gov.br/bvs/saudelegis/gm/2013/prt0963_27_05_2013.html)
3. Portaria nº 2.527, de 27 de outubro de 2011 (Brazil). Redefine a Atenção Domiciliar no âmbito do Sistema Único de Saúde (SUS). [Internet]. Ministério da Saúde. Available from: [https://bvsms.saude.gov.br/bvs/saudelegis/gm/2011/prt2527\\_27\\_10\\_2011.html](https://bvsms.saude.gov.br/bvs/saudelegis/gm/2011/prt2527_27_10_2011.html)
4. Portaria nº 825, de 25 de abril de 2016 (Brazil). Redefine a Atenção Domiciliar no âmbito do Sistema Único de Saúde (SUS) e atualiza as equipes habilitadas. [Internet]. Ministério da Saúde. Available from: [https://bvsms.saude.gov.br/bvs/saudelegis/gm/2016/prt0825\\_25\\_04\\_2016.html](https://bvsms.saude.gov.br/bvs/saudelegis/gm/2016/prt0825_25_04_2016.html)
5. Portaria nº 1.531, de 04 de setembro de 2001 (Brazil). Institui, no âmbito do Sistema Único de Saúde, o Programa de Assistência Ventilatória Não Invasiva a Pacientes Portadores de Distrofia Muscular Progressiva. [Internet]. Ministério da Saúde. Available from: [https://bvsms.saude.gov.br/bvs/saudelegis/gm/2001/prt1531\\_04\\_09\\_2001.html](https://bvsms.saude.gov.br/bvs/saudelegis/gm/2001/prt1531_04_09_2001.html)
6. Portaria SAS nº 364, de 9 de abril de 2013 (Brazil). Aprova o Protocolo Clínico e Diretrizes Terapêuticas – Esquizofrenia. [Internet]. Ministério da Saúde Available from: [https://bvsms.saude.gov.br/bvs/saudelegis/sas/2013/prt0364\\_09\\_04\\_2013.html](https://bvsms.saude.gov.br/bvs/saudelegis/sas/2013/prt0364_09_04_2013.html)

7. Portaria nº 1.370, de 03 de julho de 2008 (Brasil). Institui o Programa Assistência Ventilatória Não Invasiva Aos Portadores de Doenças Neuromusculares 2008. [Internet]. Ministério da Saúde. Available from: [https://bvsms.saude.gov.br/bvs/saudelegis/gm/2008/prt1370\\_03\\_07\\_2008.html](https://bvsms.saude.gov.br/bvs/saudelegis/gm/2008/prt1370_03_07_2008.html)
8. Portaria de Consolidação nº 5, de 28 de setembro de 2017 (Brasil). Consolidação Das Normas Sobre as Ações e Os Serviços Saúde Do Sistema Único Saúde 2017. [Internet]. Ministério da Saúde. Available from: <https://www.gov.br/saude/pt-br/assuntos/saude-de-a-a-z/s/saude-da-pessoa-com-deficiencia/legislacao/portaria-de-consolidacao-no-05-de-28-de-setembro-de-2017.pdf>
9. Rodrigues LBB, Silva PCS, Peruhype RC, Palha PF, Popolin MP, Crispim JA, et al. Primary Health Care in the coordination of health care networks: an integrative review. *Cien Saude Coletiva*. 2014;19(2):343–52. <https://doi.org/10.1590/1413-81232014192.18032012>
10. Comissão Nacional de Incorporação de Tecnologias no SUS (CONITEC). Ventilação invasiva domiciliar: relatório de recomendação [Internet]. Brasília: Ministério da Saúde; 2017. Available from: [http://antigo-conitec.saude.gov.br/images/Relatorios/2017/Relatorio-ventilacao-invasiva-domiciliar-CP\\_58.pdf](http://antigo-conitec.saude.gov.br/images/Relatorios/2017/Relatorio-ventilacao-invasiva-domiciliar-CP_58.pdf)
11. Alencar AMC, Losso E, Carvalhal TT, Martello SK. Evaluation of the use of technologies in children and teenagers home care in the city of Curitiba. *R. Saúde Públ*. 2018;1(1):11-19. <https://doi.org/10.32811/2595-4482.2018v1n1.42>
12. Mariani FEP, Duarte ED, Manzo BF. Profile of children, adolescents and their caregivers assisted by a Home Care Program. *Rev Rene*. 2016;17(1):137-43. <https://doi.org/10.15253/2175-6783.2016000100018>
13. Cohen E, Kuo DZ, Agrawal R, Berry JG, Bhagat SKM, Simon TD, et al. Children with medical complexity: An emerging population for clinical and research initiatives. *Pediatrics*. 2011;127(3):529–538. <https://doi.org/10.1542/peds.2010-0910>
14. Vernier ETN, Cabral IE. The characterization of children with special health care needs and their families caregivers. Santa Maria (Rs). 2004-2005: Supporting to nursing intervention. *Rev Soc Bras Enferm Ped* [Internet]. 2006;6(1):37-45. Available from: [https://journal.sobep.org.br/wp-content/uploads/articles\\_xml/2238-202X-sobep-06-01-0037/2238-202X-sobep-06-01-0037\\_x53125.pdf](https://journal.sobep.org.br/wp-content/uploads/articles_xml/2238-202X-sobep-06-01-0037/2238-202X-sobep-06-01-0037_x53125.pdf)
15. Rajão FL, Martins M. Home Care in Brazil: an exploratory study on the construction process and service use in the Brazilian Health System. *Cien Saude Coletiva*. 2020;25(5):1863–76. <https://doi.org/10.1590/1413-81232020255.34692019>
16. Ministério da Saúde; Hospital Alemão Oswaldo Cruz. Recomendações para a ventilação mecânica domiciliar. [Internet]. Brasília: Ministério da Saúde; 2018. Available from: [https://bvsms.saude.gov.br/bvs/publicacoes/recomendacoes\\_ventilacao\\_mecanica.pdf](https://bvsms.saude.gov.br/bvs/publicacoes/recomendacoes_ventilacao_mecanica.pdf)
17. Presidência da República (Brasil). Lei nº 8.069, de 13 de julho de 1990. Dispõe sobre o Estatuto da Criança e do Adolescente e dá outras providências. [Internet]. Diário Oficial da União. Available from: [https://www.planalto.gov.br/ccivil\\_03/leis/8069.htm](https://www.planalto.gov.br/ccivil_03/leis/8069.htm)
18. Resolução nº 466, de 12 de dezembro de 2012 (Brasil). Aprova as seguintes diretrizes e normas regulamentadoras de pesquisas envolvendo seres humanos. [Internet]. Diário Oficial da União. Available from: <https://www.gov.br/conselho-nacional-de-saude/pt-br/aceso-a-informacao/atos-normativos/resolucoes/2012/resolucao-no-466.pdf>
19. Presidência da República (Brasil). Lei nº 12.527, de 18 de novembro de 2011. Regula o acesso a informações previsto no inciso XXXIII do art. 5º, no inciso II do § 3º do art. 37 e no § 2º do art. 216 da Constituição Federal; altera a Lei nº 8.112, de 11 de dezembro de 1990; revoga a Lei nº 11.111, de 5 de maio de 2005, e dispositivos da Lei nº 8.159, de 8 de janeiro de 1991; e dá outras providências. [Internet]. Diário Oficial da União. Available from: [https://www.planalto.gov.br/ccivil\\_03/\\_ato2011-2014/2011/lei/l12527.htm](https://www.planalto.gov.br/ccivil_03/_ato2011-2014/2011/lei/l12527.htm)
20. Borges EF. Ventilação mecânica invasiva domiciliar: a experiência de 10 anos de um serviço de atenção domiciliar pediátrico [Dissertação] [Internet]. Uberlândia: Universidade Federal de Uberlândia; 2019. <https://doi.org/10.14393/ufu.di.2019.58>
21. Lot RG, Cruz Filho AD. Clinical-epidemiological profile of pediatric patients assisted by the interdisciplinary home care program of a reference hospital in Rio de Janeiro. *Resid pediatri* [Internet]. 2022;12(3):460. Available from: <https://residenciapediatria.com.br/Content/pdf/v12n3aop460.pdf>
22. Hanashiro M, Franco AOC, Ferraro AA, Troster EJ. Care alternatives for pediatric chronic mechanical ventilation. *J Pediatr (Rio J)* [Internet]. 2011;87(2):145-9. Available from: <https://www.scielo.br/j/jped/a/3pnNvhRnMPm8XHK4hfQ9dvQ/?format=pdf&lang=pt>

23. Resener TD, Martinez FE, Reiter K, Nicolai T. Home ventilation of pediatric patients - description of a program. *J Pediatr (Rio J)*. 2001;77(2):84-8. <https://doi.org/10.1590/s0021-75572001000200006>
24. Amirnovin R, Aghamohammadi S, Riley C, Woo MS, Del Castillo S. Analysis of a pediatric home mechanical ventilator population. *Respir Care*. 2018;63(5):558-64. <https://doi.org/10.4187/respcare.05644>
25. Park M, Jang H, Sol IS, Kim SY, Kim YS, Kim YH, et al. Pediatric Home Mechanical Ventilation in Korea: The Present Situation and Future Strategy. *J Korean Med Sci*. 2019;34(42):e268. <https://doi.org/10.3346/jkms.2019.34.e268>
26. Sovtic A, Minic P, Vukcevic M, Markovic-Sovtic G, Rodic M, Gajic M. Home mechanical ventilation in children is feasible in developing countries. *Pediatr Int*. 2012;54(5):676-81. <https://doi.org/10.1111/j.1442-200X.2012.03634.x>
27. Ottonello G, Ferrari I, Pirroddi IMG, Diana MC, Villa G, Nahum L, et al. Home mechanical ventilation in children: Retrospective survey of a pediatric population. *Pediatr Int*. 2007;49(6):801-5. <https://doi.org/10.1111/j.1442-200X.2007.02463.x>
28. Amin R, Sayal P, Syed F, Chaves A, Moraes TJ, MacLusky I. Pediatric long-term home mechanical ventilation: Twenty years of follow-up from one Canadian center. *Pediatr Pulmonol*. 2014;49(8):616-24. <https://doi.org/10.1002/ppul.22868>
29. Goodwin S, Smith H, Hewer SL, Fleming P, Henderson JA, Hilliard T, et al. Increasing prevalence of domiciliary ventilation: Changes in service demand and provision in the South West of the UK. *Eur J Pediatr*. 2011;170:1187-92. <https://doi.org/10.1007/s00431-011-1430-9>
30. Jardine E, O'Toole M, Paton JY, Wallis C. Current status of long term ventilation of children in the United Kingdom: Questionnaire survey. *BMJ*. 1999;318:295. <https://doi.org/10.1136/bmj.318.7179.295>
31. Redouane B, Cohen E, Stephens D, Keilty K, Mouzaki M, Narayanan U, et al. Parental perceptions of quality of life in children on long-term ventilation at home as compared to enterostomy tubes. *PLoS One*. 2016;11(2):e0149999. <https://doi.org/10.1371/journal.pone.0149999>
32. Carvalho AJL. Análise da efetividade de um Serviço de Atenção Domiciliar pediátrico brasileiro [Dissertação] [Internet]. Uberlândia: Universidade Federal de Uberlândia; 2019. <https://doi.org/http://dx.doi.org/10.14393/ufu.di.2019.2178>
33. Han YJ, Park JD, Lee B, Choi YH, Suh DI, Lim BC, et al. Home mechanical ventilation in childhood-onset hereditary neuromuscular diseases: 13 Years' experience at a single center in Korea. *PLoS One*. 2015;10(3):e0122346. <https://doi.org/10.1371/journal.pone.0122346>