



Short Communication

Non-Sedated Cannula Replacement in Home-Care Patients With Amyotrophic Lateral Sclerosis: Cost Reduction and Patient-Family Satisfaction Evaluation

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ABSTRACT

This study describes a home-based tracheostomy tube replacement protocol for individuals diagnosed with amyotrophic lateral sclerosis (ALS) requiring invasive mechanical ventilation. Implemented between May 2020 and July 2024, the protocol was offered to 16 eligible patients, with 14 opting for home-based care under the supervision of the Carlos III/La Paz Hospital. Procedures were conducted without sedation by a multidisciplinary team, with the aim of maintaining patient safety and continuity of care. A total of 120 home-based replacements were performed, most without major complications or the need for emergency hospitalization. In comparison to hospital-based procedures, the home protocol was associated with an estimated cost reduction of approximately €340 per case, potentially resulting in annual savings of €10,200. Patients reported high satisfaction, noting decreased caregiver burden and improved perceived quality of care. While limited by patient selection criteria, these preliminary findings suggest that home-based tracheostomy care may be a feasible, safe, and cost-effective alternative for long-term management in ALS.

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Recambio de cánula sin sedación en pacientes con esclerosis lateral amiotrófica atendidos en su domicilio: reducción de costes y evaluación de la satisfacción del paciente y su familia

RESUMEN

Este estudio presenta un protocolo domiciliario para el recambio de cánula de traqueotomía en pacientes con esclerosis lateral amiotrófica (ELA) que requieren ventilación mecánica invasiva. Desarrollado entre mayo de 2020 y julio de 2024, el protocolo fue implementado en 14 de 16 pacientes elegibles bajo la supervisión del Hospital Carlos III/La Paz. Los procedimientos se realizaron sin sedación, a cargo de un equipo multidisciplinario, procurando garantizar la seguridad del paciente y la continuidad asistencial. Se llevaron a cabo un total de 120 recambios domiciliarios, en su mayoría sin complicaciones relevantes ni necesidad de hospitalización urgente. En comparación con los procedimientos hospitalarios, el protocolo domiciliario mostró una reducción estimada de 340 € por intervención, lo que podría suponer un ahorro

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anual aproximado de 10.200 €. Los pacientes manifestaron altos niveles de satisfacción, destacando la menor carga para los cuidadores y una mejor percepción de la calidad asistencial. Aunque existen limitaciones en la selección de pacientes, los resultados sugieren que este modelo podría ser una alternativa factible, segura y coste-efectiva para el manejo domiciliario a largo plazo en pacientes con ELA.

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Patients diagnosed with amyotrophic lateral sclerosis (ALS) who require invasive ventilation via tracheostomy often rely on long-term home care. The standard practice for tracheostomy tube replacements involves hospital visits every 3 months, in line with manufacturer recommendations (30–90 days),¹ though clinical practices vary.² The COVID-19 pandemic underscored the risks of frequent hospital visits for immunocompromised and high-risk ALS patients. In response, a home-based protocol was developed to enhance safety, reduce costs, and improve quality of life.

Ethical considerations were rigorously addressed throughout the study. The protocol was reviewed and approved by the Clinical Research Ethics Committee of La Paz University Hospital under code PI-6768 to ensure compliance with medical and ethical guidelines. Informed consent was obtained from all participants prior to enrollment, emphasizing patient autonomy and decision-making. The study also adhered to principles of medical safety and best practices, reinforcing the integrity and reliability of its findings.

The home-based procedure entails non-sedated tracheostomy tube replacement, conducted by a thoracic surgeon following comprehensive patient counseling and informed consent. Prior to the procedure, a pulmonologist evaluates ventilator settings, ensures the optimal function of cough-assist devices, and assesses symptom management. When necessary, additional interventions such as gastrostomy tube replacement and ultrasound-guided Botox injections into the salivary glands are provided as part of a holistic approach to patient care. Patients and their families receive thorough pre-procedure briefings, including remote consultations, with consent forms distributed in advance to facilitate the process.

A range of essential medical equipment is required to conduct the procedure safely at home. This includes a disposable bronchoscope for airway visualization, local hemostatic agents for minor bleeding, Ambu bags for emergency ventilation, and an assortment of tracheostomy tubes to address complications. Home visits are carried out by a multidisciplinary team: a thoracic surgeon, a pulmonologist, and a palliative care specialist. These visits occur between 8 a.m. and 3 p.m., with hospital transport support, enabling approximately 6–7 home visits per day.

Between May 2020 and July 2024, a home-based tracheostomy care protocol was proposed to 16 ALS patients requiring invasive ventilation, all managed by the Carlos III/La Paz Hospital Unit. Of these, 14 opted for home-based tracheostomy tube replacements, while 2 chose hospital-based procedures under sedation. Of the 14 participants, 8 patients started in 2020 and then 6 joined later as tracheostomy became necessary due to disease progression. All 14 started with an initial hospital-based replacement session without sedation to familiarize themselves with the procedure that would later take place at home. If sedation was later preferred, procedures were arranged in the hospital to ensure patient comfort and autonomy.

During the study period, 4 patients died: 3 due to ALS progression and 1 under palliative sedation at home. Additionally, 2 patients required scheduled hospital-based replacements—1 for tracheostoma dilation and 1 for granuloma. Both discontinued participation in the home-based protocol for safety reasons and continued care in a hospital. Finally, as of July 2024, 8 patients

remain actively engaged in the program and continue to receive tracheostomy tube replacements at home.

Over the 4-year period, a total of 120 home-based tracheostomy tube replacements were performed among these 14 patients, averaging 4 procedures per patient per year. The vast majority of replacements were completed successfully, without major complications. Minor events, such as mild bleeding, were effectively managed with local hemostatic measures. Notably, no emergency hospitalizations occurred, eliminating urgent transfers and associated costs. This flexible, patient-centered protocol allowed adaptation to individual needs while maintaining the safety, feasibility, and continuity of home-based invasive ventilation care.

A key objective was to evaluate the economic impact of home-based tracheostomy tube replacement versus hospital-based procedures. As patient participation was voluntary, the study lacked a control group. A cost analysis assessed the financial impact of the protocol. Hospital-based tracheostomy tube replacement included expenses associated with transportation (€120 for urban transfers and €240 for interurban transfers), hospital admission €695, and bronchoscopy €115, adding up to an approximate total cost of €930 per procedure, as the urban transfer was the most common transportation for the patients. Conversely, home-based procedures cost around €590 per procedure, including transport, physician consultations, and medical supplies. The protocol yielded annual savings of €10,200. These cost estimates were derived from the Health Bulletin of the Community of Madrid (December 29, 2023)³ and the 2022 UNESPA accident assistance framework in Madrid.⁴ A recent cost-utility analysis of home mechanical ventilation in ALS patients confirmed its economic advantage, showing significantly lower cumulative costs and higher quality-adjusted life years (QALYs) compared to hospital-based care.⁵

Beyond cost, the home-based protocol offered clinical and logistical advantages. By minimizing hospital visits, it substantially reduced the risk of hospital-acquired infections, which threaten immunocompromised ALS patients. Avoiding hospitalizations also minimized disruptions to patients' daily lives, allowing them to receive care in a familiar, comfortable environment. This aligns with a growing body of research advocating for home-based medical interventions to improve patient-centered care. Studies show home-based tracheostomy care reduces hospital-acquired infection risk while also improving continuity of care and adherence.⁶

Patient and caregiver satisfaction was also a key aspect. Structured questionnaires yielded a 100% response rate with overwhelmingly positive feedback. Patients and their families expressed high levels of satisfaction with the program, citing reduced caregiver burden, increased convenience, and improved overall care quality. Home-based care also fostered greater family involvement, improving the emotional and psychological well-being of both patients and caregivers. These findings align with existing literature highlighting the benefits of episodic medical home interventions for patients with severe, chronic respiratory failure.⁷ Multidisciplinary home care improves caregiver satisfaction and reduces the psychological burden, especially when tracheostomy is involved.^{8,9}

One of the main limitations of the study is the selection of patients with tracheostomy who could undergo cannula replace-

Table 1
Summary of the questions and results of the protocol survey (2020/2024).

Year	2020	2024
Sample size	8	8
Question 1 How would you rate the quality of information?	Excellent 67.14% Very Good 18.57% Good 14.29% Excellent 100%	Excellent 100%
Question 2 How would you rate the quality of care?		Excellent 100%
Question 3 What do you consider to be the best advantage? Comfort Avoiding hospitalization None Both	 14.29% 85.71%	 100%
Question 4 What drawbacks do you see? No sedation Insecurity Both None	 28.57% 28.57% 14.29% 28.57%	 20% 20% 60%
Question 5 How would you rate the protocol in general? Excellent Very good	 100%	 100%
Observations 1. I think it is an advantage to do it at home; it causes less disruption for the family and avoids the difficulties of going to the hospital, especially with at least two people and having to return home with bloody secretions, which complicates the trip back by vehicle. Thank you. 2. The home convalescence of patients with ALS, who are in a stabilized phase and whose physical and organic limitations advise against transfers outside their home, should take place at home, where they reside 365 days a year. If necessary, this should be done with the collaboration and training of the Home Hospitalization program and/or the Local Palliative Care Team. Both groups, which operate outside the hospital, should be considered essential for the Continuity of Care guaranteed by Article 14 of Law 16/2003, at least for chronic, complex, critical patients who require continuous supervision 24 h a day. At the very least, considering this possibility would be a success for patients and their families. Despite not being performed in the hospital and indicating that as a main drawback, since I don't know what might be needed in case of complications, I think not much more could be done than using forceps. Therefore, I find it much more comfortable and practical to do it at home. It's a great decision.		

ment without the need for sedation. This decision was based on prior clinical evaluation carried out in the hospital, which confirmed the absence of incidents during previous exchanges. Therefore, the results may not be extrapolated to patients in whom the procedure requires sedation or presents complications (Table 1).

In conclusion, implementing a home-based tracheostomy tube replacement protocol for ALS patients on invasive ventilation shows clear advantages. Economically, it reduces healthcare costs. From a patient-centered perspective, it enhances quality of life, reduces hospital risks, and improves caregiver support. Given these outcomes, further research and broader implementation of such protocols should be considered a viable alternative to hospital-based models. Expanding home-based programs could promote a more sustainable, efficient, and compassionate healthcare system for ALS and other patients needing long-term ventilatory support.

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Authors' contributions

All listed authors contributed actively to the design and development of the clinical protocol presented in this study.

Artificial intelligence involvement

Artificial intelligence has assisted in the translation into English.

Conflicts of interest

The authors declare not to have any conflicts of interest that may be considered to influence directly or indirectly the content of the manuscript.

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