



ORIGINAL ARTICLE OPEN ACCESS

Discharge Practice Variability in Pediatric Chronic Home Invasive Ventilation

Guillermo Beltran-Ale¹ | Ryne Simpson¹ | Terri Magruder¹ | Ajay S. Kasi² | Amit Agarwal³ | Jake A. Kaslow⁴

¹Division of Pediatric Pulmonology and Sleep Medicine, Department of Pediatrics, University of Alabama at Birmingham, Birmingham, AL, USA | ²Division of Pediatric Pulmonology, Department of Pediatrics, Emory University and Children's Healthcare of Atlanta, Atlanta, Georgia, USA | ³Division of Pulmonary and Sleep Medicine, Texas Children's Hospital and Baylor College of medicine, Houston, Texas, USA | ⁴Division of Pediatric Allergy, Immunology and Pulmonary Medicine, Department of Pediatrics, Vanderbilt University Medical Center, Nashville, Tennessee, USA

Correspondence: Guillermo Beltran-Ale (gjbeltranale@uabmc.edu)

Received: 15 November 2024 | **Revised:** 1 May 2025 | **Accepted:** 8 May 2025

Funding: The authors received no specific funding for this work.

Keywords: mechanical ventilation | pediatrics | tracheostomy | ventilator

ABSTRACT

Introduction: The Pediatric Mechanical Ventilation Society is a collaboration of pediatric pulmonologists with a focus on pediatric chronic home invasive ventilation (PCHIV). Since the initial discharge on PCHIV is not always directed by pediatric pulmonologists, we sought to understand how this variability between centers impact adherence to American Thoracic Society (ATS) guidelines for PCHIV.

Methods: A survey was distributed to pediatric pulmonologists across multiple platforms inquiring about discharging practices for PCHIV and adherence to six of the nine ATS recommendations for PCHIV. Two subgroups were created based on common practices — discharge by pediatric pulmonologists from a non-ICU unit (pulmonary group) and discharge by ICU team from an ICU unit (ICU group).

Results: A total of 107 surveys were completed, 90 from the US. Among the US centers, the ATS recommendations with lowest adherence were offering ongoing education to caregivers and the utilization of standardized criteria for discharge. Despite better adherence, the requirement of two caregivers for discharge was often made an exception for. When comparing the pulmonary and ICU groups, the number of annual discharges ($p < 0.001$), caregiver length of training ($p = 0.003$), and the utilization of standardized discharge criteria ($p = 0.04$) were significantly different.

Discussion: Our study demonstrates variable adherence to expert consensus recommendations outlined by the ATS. A significant proportion of PCHIV patients were discharged directly from the ICU and by ICU teams. Practice variability was evident between institutions and discharging teams; therefore, the identification of barriers to guideline implementation and multi-disciplinary collaboration is paramount to optimizing care.

1 | Introduction

Pediatric chronic invasive mechanical ventilation has increased significantly over the past several decades [1, 2]. With advancements in technology, the focus of care for these children has shifted away from the acute care setting [3]; however,

discharging children on chronic invasive ventilation is a complex process that requires a multidisciplinary approach for success [4–8]. In 2016, the American Thoracic Society (ATS) published clinical practice guidelines for PCHIV, providing recommendations for discharge practices and outpatient management [9]. The participants of this ATS effort included both

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial](https://creativecommons.org/licenses/by-nc/4.0/) License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

© 2025 The Author(s). *Pediatric Pulmonology* published by Wiley Periodicals LLC.

experts in pediatric pulmonology and pediatric critical care. In large academic centers, the pediatric pulmonary team is involved in the predischARGE care of PCHIV patients and the implementation of these guidelines. In other centers, the care of these patients may be directed by other teams like intensive care unit (ICU), hospital medicine, or complex care teams. Even if non-ICU teams direct a patient's care, hospital policies may dictate that patients requiring invasive ventilation remain in an ICU setting until discharge. Other institutions utilize step-down or specialized pediatric chronic invasive ventilation units, especially before the initial discharge. While previous studies have focused on discharge practice variability [10] and the composition of the outpatient provider team [11], it is less clear how the ATS guideline implementation is affected by the medical team directing the initial discharge for PCHIV patients.

The Pediatric Mechanical Ventilation Society (PMVS) is a PCHIV-focused collaboration between pediatric pulmonologists currently representing four large academic medical centers across the Southeastern United States. Following the 2023 PMVS conference and regional discussions, it became evident that an improved understanding of discharge practices was needed based on notable institutional variability in predischARGE management. Further, we identified that in several relatively smaller centers in the southern region, the care and discharge of PCHIV patients is almost exclusively directed by the ICU team. In these environments, awareness and knowledge of the ATS PCHIV guidelines may be limited.

We hypothesized that the primary discharging team, specialty, and inpatient unit influences variability in discharge practices. The aims of this study were to: (a) describe adherence to the ATS PCHIV guidelines, (b) characterize discharge practice variations, and (c) examine the impact of the discharging medical unit and inpatient medical specialty team on practice patterns.

2 | Methods

A survey was developed using an iterative process after discussion among multiple healthcare professionals from diverse geographical regions and training backgrounds. The authors solicited feedback from professional contacts for expert input. The final survey was operationalized using Research Electronic Data Capture software (REDCap, Vanderbilt University) and included multiple-choice and free-response questions. The electronic questionnaire's usability and technical functionality were tested before survey distribution.

The study was approved by the Vanderbilt University School of Medicine Institutional Board Review (IRB number 231768). Informed consent was obtained electronically before respondents opening the survey. No personal information was collected or stored aside from basic demographic information, including years in practice, location of institution, and size of the PCHIV program.

The survey was distributed using a RedCap survey link (closed survey design) to prospective participants via multiple platforms, including the Pediatric Pulmonary Training

Directors Association, Ped-Lung Discussion Group (<https://www.ped-lung.org/>), Pediatric Pulmonary Division Chiefs, professional societies, and to personal contacts. The survey was distributed in December 2023, and responses were accepted until March 2024. Survey reminders were sent monthly between January and March 2024. Respondents were requested to complete the survey once during the study period and were able to review and change their answers before submission.

The survey comprised 21 questions of which 18 were used for this manuscript (Supplemental Table 1). The survey focused on discharge practices and guideline adherence utilizing questions related to specific domains outlined in the ATS PCHIV guideline (Supplemental Table 2). Among the nine ATS guideline recommendations, three were not evaluated in this survey as they pertained to caregiver's behaviors at home after discharge and practices from durable medical equipment (DME) companies. Apart from the questions related to the ATS guideline, three additional questions explored discharge practices including the requirement of home healthcare nursing, duration of caregiver training, and duration to outpatient follow-up after initial hospital discharge [12].

The survey and subsequent analysis adheres to the Checklist for Reporting Results of Internet E-Surveys guidelines [13].

2.1 | Analysis

Each response was analyzed independently. Participants from the same institution (i.e., multiple respondents from the same institution) were considered individually for analysis considering the possibility of practice variations within the same institution. Only surveys that were completed in entirety were included in the final analysis. Categorical percentages and measures of central tendency were used to analyze respondent data.

Although the survey was available for international respondents, the primary analysis utilized only responses from the US. International responses were analyzed separately. Their demographics were compared to the US group using Fisher exact test for categorical variables and Mann-Whitney for continuous variables.

2.2 | Subgroup Analysis

Subgroup analysis was performed on the survey results received from centers across the US. Based on responses to questions about inpatient primary service team and medical unit at time of discharge, two groups were developed — pulmonary and Intensive Care Unit (ICU). The pulmonary group comprised respondents that reported discharging patients from a pulmonary floor, ward, or step-down unit with the pediatric pulmonary team as the primary medical service at discharge. The ICU group comprised respondents that reported discharging patients directly home from an ICU with the pediatric or neonatal intensivists as the primary medical service at discharge. The survey questions regarding discharge

practices and adherence to guidelines were analyzed between the groups. Fisher exact tests were used to compare the distribution of responses among the groups. Considering the low response rates in some groups and to complete Fisher test analysis, we combined answers with a small number of responses only if it was deemed appropriate by the authors (e.g. combined “never” and “rarely” group). A p -value ≤ 0.05 was deemed statistically significant.

3 | Results

3.1 | Demographics of Respondents

Among 157 participants that started the survey by completing the informed consent, 107 (68.1%) completed the survey. Ninety respondents were from the United States and 17 were international (Table 1). The 90 US respondents represented institutions from 32 states. Based on the 4 regions defined by the U.S. Census, most respondents were from the South ($n = 37$, 41.1%), followed by the Midwest ($n = 21$, 23.3%), Northeast ($n = 19$, 21.1%) and the West ($n = 13$, 14.4%).

Among the 90 US respondents, 8 (9%) were completed by non-physician personnel (5 nurse practitioners, 1 nurse, 1 respiratory therapist, and 1 physician assistant). Eighty-four (93%) respondents indicated their specialty as pediatric pulmonology. Respondents reported a median (IQR) of 11 (5–19.5) years in clinical practice. Most (98%) respondents’ practices included both inpatient and outpatient clinical care. The median (IQR) number of patients aged less than 18 years discharged annually was 15 (10–25).

3.2 | U.S Centers - Guideline Adherence and Discharge Practices

Within the US, wide variation was appreciated in the survey responses regarding adherence to the ATS recommendations (Figure 1). This was reflected across all domains outlined in the guideline. The largest variation was observed in offering or providing ongoing education to caregivers; less than 10% of the respondents “always” provided continual education with 92% responding their center either “rarely” or “never” had this option for caregivers. Nearly all (93%) “always” recommend the use of pulse oximetry. Half (50%) of the respondents noted their practice to always use standardized discharge criteria, whereas 42% utilized formal discharge criteria either “most of the time” or “sometimes”. While 73% “always” required two caregivers, over 25% of respondents did not mandate this requirement for discharge to home. A medical home was utilized in 91% of US respondents, with pediatric pulmonologists directing the care in most of the cases (68%) when a medical home was available. Most centers not utilizing pulmonologists had a different non-ICU subspecialty directing the medical home.

While not specifically outlined in the 2016 ATS guidelines, few respondents (14.4%) always required home healthcare nursing before discharge, whereas the majority either permitted exceptions to their institutional criteria for home healthcare nursing requirement or did not mandate home healthcare nursing for hospital discharge. Most respondents required caregiver training that spanned up to 6 weeks (56%). Most respondents (91%) reported that the first follow up appointment in the pediatric pulmonology clinic was within 1 month from hospital discharge.

TABLE 1 | Demographics.

	U.S.A. $n = 90$	International $n = 17$	p value
Profession			
Physician	82 (91%)	13 (77%)	0.09
Nonphysician	8 (9%)	4 (23%)	
Specialty			
Pediatric pulmonology	84 (93%)	14 (82%)	0.16
Pediatric ICU	1 (1%)	1 (6%)	
Other	5 (6%)	2 (12%)	
Practice scope			
Inpatient and outpatient	88 (98%)	16 (94%)	0.41
Only inpatient or outpatient	2 (2%)	1 (6%)	
Years in practice, median (IQR)	11 (5–19.5)	15 (10–24)	0.09
Number of pediatric patients discharged annually on invasive ventilation, median (IQR)	15 (10–25)	4 (3–10)	< 0.0001
Geographic location	South 41.1%	Canada 29.4%	Not applicable
	Midwest 23.3%	Australia 17.6%	
	Northeast 21.1%	Europe 17.6%	
	West 14.4%	Israel 11.8%	

Note: Surveys from US involve the following states: Alabama, Washington, Wisconsin, New York, Virginia, California, Minnesota, Ohio, North Carolina, Louisiana, Montana, Texas, Kentucky, Tennessee, Pennsylvania, Michigan, Missouri, Kansas, Georgia, Nevada, Florida, Indiana, Colorado, South Carolina, Oregon, Illinois, Utah, New Jersey, Arizona, Nebraska, Arkansas and Massachusetts.

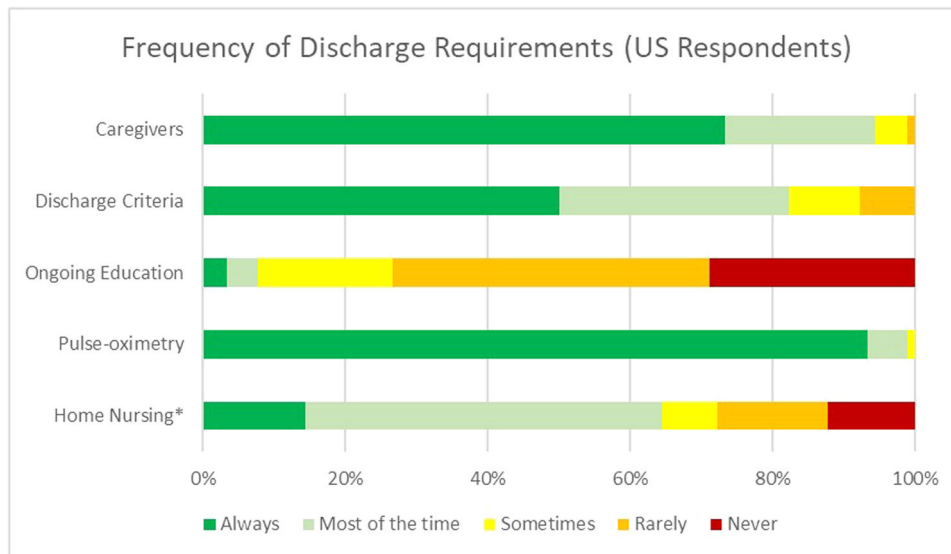


FIGURE 1 | U.S. Centers responses for five of the ATS guideline recommendations, frequency of responses based on adherence frequency from always to never. The requirement of two trained caregivers, having standardized criteria and routine prescription of pulse-oximetry were among the ones most frequently reported as always used. [Color figure can be viewed at [wileyonlinelibrary.com](https://onlinelibrary.wiley.com)]

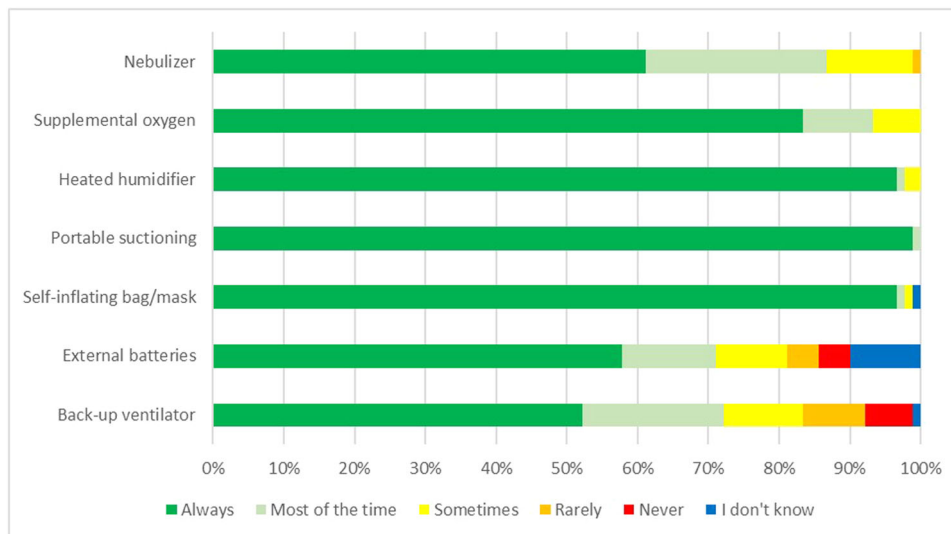


FIGURE 2 | U.S. Centers responses for frequency of prescription of commonly used home equipment. Although the ATS guidelines do not recommend routinely using every one of these equipment, most centers report always prescribing these at discharge. [Color figure can be viewed at [wileyonlinelibrary.com](https://onlinelibrary.wiley.com)]

Overall, less variability was noted between respondents regarding recommended medical equipment (Figure 2), although this was specific to each medical device. Self-inflating bag and mask, portable suctioning, and heated humidification were nearly always supplied to patients at discharge (97%, 99%, and 97%, respectively). Supplemental oxygen was also frequently (83%) prescribed to patients at discharge. There were larger variations in the response to “always” providing back-up ventilators (52%), external batteries (58%), and nebulizers (61%).

reported transferring patients to a long-term care facility before discharge to home and were excluded from the group-based analyses. The pulmonary and ICU groups included 30 and 31 respondents, respectively (Table 2).

There was a significant difference in the median (IQR) number of patients discharged annually on PCHIV by the pulmonary group [23.5 (15–30)] and ICU group [8 (3.5–15), $p < 0.001$].

3.3 | Subgroup Analysis

Categorization of respondents into the 2 groups—pulmonary and ICU—is described in Figure 3. Thirteen respondents

3.3.1 | Caregivers

There was no significant difference between the Pulmonary and ICU groups pertaining to the requirement of two trained family caregivers before discharge ($p = 1.0$). Most respondents in both

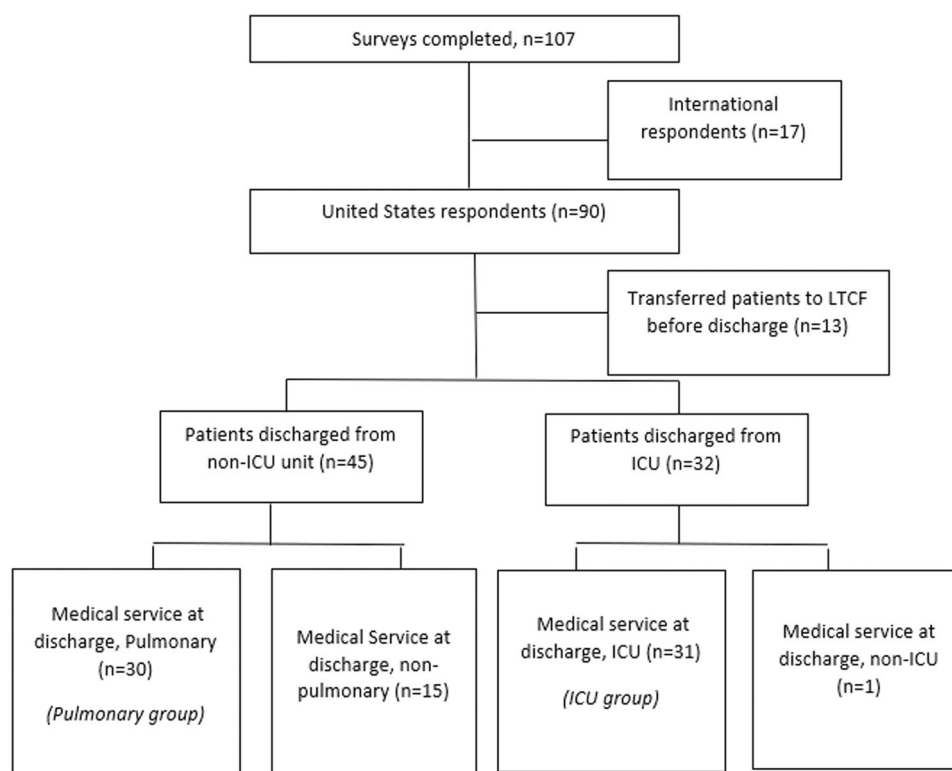


FIGURE 3 | Flowchart of completed surveys and subgroups classification based on discharge unit and discharge specialty team. Pulmonary and ICU groups were used for subgroup analysis.

groups (pulmonary: 70% and ICU: 71%) indicated that two trained family caregivers was always a requirement before discharge.

3.3.2 | Medical Home

The medical home model for coordination of care was widely adopted with 91% of respondents reporting its availability. However, there was no significant difference between the groups regarding the medical home being directed by pulmonary or by ICU/other service ($p = 0.08$).

3.3.3 | Discharge Criteria

While most respondents (82%) reported using standardized discharge criteria “always or most of the time”, a significant difference was noted with the pulmonary group’s utilization of standardized discharge criteria (93%) compared to the ICU group (71%, $p = 0.04$).

3.3.4 | Ongoing Education

The ATS guideline recommends to acquire, reinforce, and augment skills with ongoing education provided to both the family and professional caregivers of these population. Although there is no clear criteria on what encompasses ongoing education, there were no significant differences between the pulmonary and ICU groups for the provision of ongoing family caregiver education across the spectrum of always to never ($p = 1.0$). Ongoing education was

“never” offered by 17% of the pulmonary group and 33% of the ICU group.

3.3.5 | Pulse-Oximetry

Most respondents (93%) recommended outpatient pulse oximetry monitoring; however, there were no significant differences between the groups regarding always utilizing outpatient pulse oximetry ($p = 0.67$).

3.3.6 | Length of Training

Respondents in the ICU group (68%) reported a significantly shorter duration of caregiver training (< 6 weeks) compared to the pulmonary group (37%, $p = 0.003$). Caregiver training lasting more than 9 weeks was reported by almost half of the pulmonary group (43%) in contrast to only 6% of the ICU group.

3.3.7 | Home Nursing

There was no significant difference between the pulmonary (67%) and ICU (59%) groups mandating home healthcare nursing with or without exceptions for discharge ($p = 0.95$).

3.3.8 | Follow Up

Outpatient pulmonary follow-up appointments were scheduled within 1 month and 3 months of discharge in 91% and 100% of

TABLE 2 | ATS guideline adherence and discharge questions survey results.

Question Domain	Responses	Total <i>n</i> = 90	Pulmonary Subgroup <i>n</i> = 30	ICU Subgroup <i>n</i> = 31	<i>p</i> value*
Caregivers	Always	66 (73%)	21 (70%)	22 (71%)	1.00
	Most of the time	19 (21%)	8 (27%)	7 (23%)	
	Sometimes or rarely	5 (6%)	1 (3%)	2 (6%)	
Medical home	Not available	8 (9%)	4 (13%)	2 (6%)	0.08
	Directed by pulmonary	56 (62%)	23 (77%)	19 (61%)	
	Directed by ICU/other	26 (29%)	3 (1%)	10 (32%)	
Discharge criteria	Always or most of the time	74 (82%)	28 (93%)	22 (71%)	0.04
	Sometimes or rarely	16 (18%)	2 (7%)	9 (29%)	
Ongoing education	Always or most of the time	7 (8%)	3 (10%)	2 (6%)	1.00
	Sometimes or rarely	57 (63%)	22 (73%)	23 (61%)	
	Never	26 (29%)	5 (17%)	6 (33%)	
Pulse-oximetry	Always	84 (93%)	28 (93%)	27 (87%)	0.67
	Most of the time or sometimes	6 (7%)	2 (7%)	4 (13%)	
Length of training	0–6 weeks	50 (56%)	11 (37%)	21 (68%)	0.003
	6–9 weeks	20 (22%)	6 (20%)	8 (26%)	
	Over 9 weeks	20 (22%)	13 (43%)	2 (6%)	
Home nursing	Always	13 (14%)	3 (10%)	3 (9%)	0.95
	Rare exceptions are made	45 (50%)	17 (57%)	15 (50%)	
	Required in half or few cases	21 (23%)	7 (23%)	10 (32%)	
	Never	11 (12%)	3 (10%)	3 (9%)	
Follow up	Within 1 month	82 (91%)	25 (83%)	29 (94%)	0.26
	After 1 and within 3 months	8 (9%)	5 (17%)	2 (6%)	

*Fisher exact used to compare distribution of responses between pulmonary and ICU subgroups.

the respondents, respectively. No significant differences were noted between the groups for pulmonary follow-up appointments occurring within 1 or 3 months of discharge ($p = 0.26$).

3.3.9 | Other Equipment

Due to the low number of respondents in each response option for required medical equipment at discharge, 2 responses groups were created for analysis by combining the responses in the “always” and “most of the time” responses and “sometimes”, “rarely”, and “never” responses.

There were no significant differences between the pulmonary and ICU groups regarding required medical equipment at discharge. Both groups reported that self-inflating bags, suctioning equipment, heated humidifiers, and supplemental oxygen were routinely prescribed at discharge with decreased rates demonstrated for back-up ventilators and external batteries. Airway clearance devices were prescribed less routinely, with surveys

reporting “always” or “most of the time” in 50% of the pulmonary group and 42% of the ICU group.

3.4 | International Surveys

Of the 17 international surveys completed, 13 were completed by pediatric pulmonologists and 4 by respiratory therapists. Sixteen respondents were involved in both inpatient and outpatient clinical care. The median (IQR) number of patients under 18 years of age discharged annually [4 (3–10)] was much lower than those reported by U.S. respondents ($p < 0.001$).

The requirement of training two family caregivers was “always” or “most of the time” required for discharge in 58.8% and 41.2% of the respondents, respectively. Availability of a medical home was reported by only 70.1% of respondents that comprised 25% medical homes directed by pediatric pulmonology. Standardized discharge criteria were used “most of the time” in 52.9% or “always” in 29.4% of the respondents. Ongoing skills education

was recommended “rarely” or “never” by 52.9% of respondents. Pulse-oximetry was always recommended by 64.7% of respondents. The training duration for family caregivers was reported to be less than 6 weeks by 41% of the respondents and longer than 9 weeks by other 41% of respondents. Only 2 respondents “always” required home nursing before discharge (6%) with nursing only required “in a few cases” or “never” most of the time (53%).

4 | Discussion

This international cross-sectional questionnaire study aimed to characterize discharge practices and deviations from the ATS PCHIV clinical practice guidelines based on the inpatient medical unit and the primary medical service at the time of discharge. We identified heterogeneous practice patterns pertaining to six ATS clinical practice guidelines recommendations, and in three other common practices not included in the ATS guidelines such as the requirement of home healthcare nursing, duration of family caregiver training, and duration to first pulmonology outpatient follow-up appointment. We identified two groups that represent the practice in most centers — patients managed by an ICU team in an ICU unit until discharge and patients managed by pediatric pulmonologists in a non-ICU unit at time of discharge. Variations in practice patterns and discharge requirements were noted between these two groups.

Overall, we found variable adherence to the ATS guidelines, with notably low adherence to the recommendation on ongoing caregiver skills education and the recommendation for standardized discharge criteria. Although caregiver education is often emphasized during the initial hospitalization, families often encounter unanticipated challenges at home that were not identified or predicted in inpatient training programs [14]. Additionally, studies have reported that both family caregivers and home healthcare nurses have knowledge deficits in the management of tracheostomy and home ventilator emergency care emphasizing the importance of ongoing caregiver education to potentially prevent adverse outcomes [15]. While a wide variety of training programs have been created and introduced across institutions, only a few report an emphasis on continued caregiver training and education following the initial hospital discharge [16]. We suspect the low percentage of reported ‘ongoing education’ refers to formal education provided by the hospital staff, as we believe informal education is generally a part of routine care in this population and as valuable as formal education. Standardized discharge processes have decreased length of stay and hospitalization cost for ventilator-dependent children with decreased readmission rates [17] without increasing adverse outcomes [18]. Considering the benefits of standardized discharge processes, understanding the variability and the barriers to the widespread use of discharge criteria requires investigation to optimize care.

Domains with good adherence to the ATS guidelines included the recommendation for two trained caregivers, availability of a medical home, and the routine use of pulse oximetry. These recommendations are often recognized as standard practice and are vital to ensure patient safety despite the low level of

evidence supporting some of the recommendations. While adherence to ATS guidelines was lower in international respondents, practice patterns could be influenced by healthcare resource availability (such as medical equipment, home healthcare nursing) and availability of nation-specific or institutional guidelines for managing PCHIV [6, 8, 19–21]. Medical equipment prescriptions are probably highly dependent on resources availability, more research is required to understand the challenges encountered by medical teams.

We found that patients discharged from the ICU by intensivists tended to have shorter caregiver training duration and a lower use of standardized criteria for discharge. Although this could be due to limited availability of ICU beds across institutions and even different types of pathology treated in these centers, familiarity with the ATS PCHIV guidelines among intensivists and the level of evidence supporting the recommendations could be contributory. The ICU group had a significantly lower number of patients discharged home annually on invasive ventilation. Apart from institutional practices such as medical unit at the time of discharge, the relatively lower number of annual discharges by the ICU group could potentially impact adherence to some of the ATS guideline recommendations. This lower number of ICU patients also implies a lower number of total patients discharged with lower adherence to the guidelines. These differences highlight that efforts to improve guideline adherence may require multidisciplinary collaboration between ICU and pulmonary teams. Although training in the ICU subgroup could be expedited through enhanced resource utilization to liberate an ICU bed, it is unclear if the quality of discharge education is affected by this shorter duration. The impact of duration of caregiver training and patient-related outcomes such as re-admissions and mortality require further study. Future studies could explore how different centers evaluate caregivers’ readiness for discharge, and if discharge processes include the development of emergency plans, out of hospital trials, or even home visitation.

Regardless of the inpatient medical unit at discharge, these medically complex patients require multidisciplinary care for a successful transition to home. Efforts to identify barriers to guideline adherence and improve discharge practices require granular examination of discharge and training requirements across all disciplines as well as differences in regional and institutional healthcare resources. Although most of the respondents were pediatric pulmonologists, a sizable proportion of patients remained under the care of the intensivists in the ICU before discharge. This highlights the importance of multidisciplinary collaboration with the intensivists when formulating and implementing caregiver training and discharge programs. Optimizing care from Pulmonary Medicine, Otorhinolaryngology, Primary Care - and even other subspecialties in particular cases – greatly benefits this patient population. All specialties could collaboratively design standardized education materials, discharge criteria, and outpatient care models that optimize resource utilization, patient care and procedural coordination.

Prior research by Sabokta et al. predominantly included respondents from the northeastern and Midwest U.S. regions where children are often discharged to other facilities such as

long-term care facilities before going home (79.6%). The reasons for discharging patients to facilities other than home included the need for parent training (62.5%) and the lack of home nursing (60.7%). However, our survey which was comprised of respondents predominantly from the Southern U.S. found that only 14.4% respondents discharged patients to a long-term care facility before going home. Geographical variation in healthcare resources, home health nursing availability, and the availability of long-term care facilities likely contribute to this discrepancy [22]. We found that only 16% of respondents always required home nursing before discharge, while 50% noted that exceptions were made, suggesting that home healthcare nursing shortages could impact the decision regarding the requirement of nursing for discharge [23]. Clinicians are often conflicted with the optimal timing of discharge for patients requiring PCHIV considering the potential for adverse outcomes in the setting of caregiver burnout due to inadequate outpatient resources and the potential benefits of home healthcare nursing on the health of the patient and family caregivers. We acknowledge that this requires further study and advocacy.

4.1 | Strengths and Limitations

Our study has several limitations. One main limitation is that we don't have a registry of all the centers providing care to this patient population, therefore, we could not perform better sampling to accurately represent all available centers. Our method of survey distribution, while spanning several well-known and frequently accessed academic and public workgroups, may not accurately reflect the nationwide landscape. Several distribution platforms favor academic centers; therefore, some community-based and smaller academic institutions may have inadvertently been excluded. Additionally, while most respondents were from academic institutions, the survey did not explicitly inquire about an institution's academic inclinations.

A second limitation is that some centers had more than one respondent. While it is known that individual practice may vary between providers within an institution, this inclusion may have led to an overemphasis on the processes used by certain institutions with multiple respondents. Our study also shows that a significant portion of centers discharge these patients from the ICU, and as we targeted pediatric pulmonologists, the responses in this group could be inaccurate or biased.

Although the design of the survey used an iterative process involving health care professionals from diverse geographical regions and training backgrounds, it was not externally validated. Our survey lacked open-ended responses for some questions, limiting nuanced responses and reducing opportunities for insights into barriers for widespread implementation of the ATS recommendations.

5 | Conclusions

Our study demonstrates variable adherence patterns to expert consensus recommendations outlined by the ATS PCHIV

clinical practice guidelines. A significant proportion of PCHIV patients were discharged directly from the ICU and by ICU teams. Practice variability was evident between institutions and discharging teams; therefore, the identification of barriers to guideline implementation and multidisciplinary collaboration is paramount to optimizing care.

Author Contributions

Guillermo Beltran-Ale: conceptualization, investigation, writing – original draft, methodology, writing – review and editing, formal analysis, data curation, supervision. **Ryne Simpson:** investigation, methodology, writing – review and editing. **Terri Magruder:** investigation, methodology, writing – review and editing. **Ajay. S. Kasi:** conceptualization, investigation, methodology, writing – review and editing, data curation. **Amit Agarwal:** conceptualization, investigation, methodology, writing – review and editing, data curation. **Jake A. Kaslow:** conceptualization, investigation, methodology, writing – review and editing, formal analysis, funding acquisition, writing – original draft, data curation, supervision, resources.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

References

1. R. Amin, P. Sayal, F. Syed, A. Chaves, T. J. Moraes, and I. MacLusky, "Pediatric Long-Term Home Mechanical Ventilation: Twenty Years of Follow-Up From One Canadian Center," *Pediatric Pulmonology* 49 (2014): 816–824.
2. A. M. Nathan, H. Y. Loo, J. A. de Bruyne, et al., "Thirteen Years of Invasive and Noninvasive Home Ventilation for Children in a Developing Country: A Retrospective Study," *Pediatric Pulmonology* 52 (2017): 500–507.
3. R. Amirnovin, S. Aghamohammadi, C. Riley, M. S. Woo, and S. Del Castillo, "Analysis of a Pediatric Home Mechanical Ventilator Population," *Respiratory Care* 63 (2018): 558–564.
4. J. Henningfeld, A. B. Friedrich, G. Flanagan, et al., "Transitioning Children Using Home Invasive Mechanical Ventilation From Hospital to Home: Discharge Criteria, Disparities, and Ethical Considerations," *Pediatric Pulmonology* 59 (2024): 2113–2130.
5. S. A. Sobotka, L. P. Hird-McCorry, and D. M. Goodman, "Identification of Fail Points for Discharging Pediatric Patients With New Tracheostomy and Ventilator," *Hospital Pediatrics* 6 (2016): 552–557.
6. S. Kwak, "Home Mechanical Ventilation in Children With Chronic Respiratory Failure: A Narrative Review," *Journal of Yeungnam Medical Science* 40, no. 2 (April 2023): 123–135, <https://doi.org/10.12701/jyms.2022.00227>.
7. F. Zirek and N. Çobanoğlu, "Caregiver Education Before Hospital Discharge for Children on Home-Invasive Mechanical Ventilation," *Pediatric Pulmonology* 59, no. 8 (August 2024): 2190–2195, <https://doi.org/10.1002/ppul.26803>.
8. A. Torrent-Vernetta, M. M. Soriano, I. Iglesias Serrano, et al., "Arrangement of Residence Before Hospital Discharge for Children on Home-Invasive Mechanical Ventilation," *Pediatric Pulmonology* 59, no. 8 (August 2024): 2080–2088, <https://doi.org/10.1002/ppul.26758>.

9. L. M. Sterni, J. M. Collaco, C. D. Baker, et al., "An Official American Thoracic Society Clinical Practice Guideline: Pediatric Chronic Home Invasive Ventilation," *American Journal of Respiratory and Critical Care Medicine* 193 (2016): e16–e35.
10. S. A. Sobotka, A. Dholakia, R. K. Agrawal, et al., "Discharge Practices for Children With Home Mechanical Ventilation Across the United States. Key-Informant Perspectives," *Annals of the American Thoracic Society* 17 (2020): 1424–1430.
11. S. A. Sobotka, D. S. Gaur, D. M. Goodman, R. K. Agrawal, J. G. Berry, and R. J. Graham, "Pediatric Patients With Home Mechanical Ventilation: The Health Services Landscape," *Pediatric Pulmonology* 54 (2019): 40–46.
12. H. Nayır Büyüksahin and E. Yalcın, "Follow-Up of Children on Home Invasive Mechanical Ventilation After Hospital Discharge," *Pediatric Pulmonology* 59, no. 8 (August 2024): 2145–2148, <https://doi.org/10.1002/ppul.26683>.
13. G. Eysenbach, "Improving the Quality of Web Surveys: The Checklist for Reporting Results of Internet E-Surveys (Cherries)," *Journal of Medical Internet Research* 6 (2004): e34.
14. L. G. Amar-Dolan, M. H. Horn, B. O'Connell, et al., "'This Is How Hard It Is': Family Experience of Hospital-to-Home Transition With a Tracheostomy," *Annals of the American Thoracic Society* 17 (2020): 860–868.
15. S. S. Kun, S. L. Davidson-Ward, L. M. Hulse, and T. G. Keens, "How Much Do Primary Care Givers Know About Tracheostomy and Home Ventilator Emergency Care?," *Pediatric Pulmonology* 45 (2010): 270–274.
16. M. S. High, W. Julion, S. Heigel, A. Fawcett, and S. A. Sobotka, "Parent Education Programs for Children Assisted by Invasive Mechanical Ventilation: A Scoping Review," *Journal of Pediatric Nursing* 66 (2022): 160–170.
17. J. Ellashek, L. Barrios, J. Fredlund, et al., "Determining the Efficacy of a Multidisciplinary Action Plan in Discharge Planning for Pediatric Home Mechanical Ventilation," *American Journal of Respiratory and Critical Care Medicine* 191 (2015): A2224.
18. C. D. Baker, S. Martin, J. Thrasher, et al., "A Standardized Discharge Process Decreases Length of Stay for Ventilator-Dependent Children," *Pediatrics* 137 (2016): e20150637.
19. J. Chawla, E. A. Edwards, A. L. Griffiths, et al., "Ventilatory Support at Home for Children: A Joint Position Paper From the Thoracic Society of Australia and New Zealand/Australasian Sleep Association," *Respirology* 26 (2021): 920–937.
20. R. Amin, I. MacLusky, D. Zielinski, et al., "Pediatric Home Mechanical Ventilation: A Canadian Thoracic Society Clinical Practice Guideline Executive Summary," *Canadian Journal of Respiratory, Critical Care, and Sleep Medicine* 1 (2017): 7–36.
21. E. Jardine and C. Wallis, "Core Guidelines for the Discharge Home of the Child on Long-Term Assisted Ventilation in the United Kingdom," *Thorax* 53 (1998): 762–767.
22. R. Simpson, G. Beltran-Ale, T. Magruder, A. Kasi, A. Agarwal, and J. Kaslow, "Discharge Barriers for Children Requiring Long-Term Invasive Mechanical Ventilation: Practical Experiences From Pediatric Home Ventilation Programs Across the Southeastern United States," *Pediatric Pulmonology* 59 (2024): 2699–2701.
23. S. A. Sobotka, A. Dholakia, J. G. Berry, et al., "Home Nursing for Children With Home Mechanical Ventilation in the United States: Key Informant Perspectives," *Pediatric Pulmonology* 55 (2020): 3465–3476.

Supporting Information

Additional supporting information can be found online in the Supporting Information section.