Rare Pediatric Pulmonary Diseases: Insights from a Survey of Pediatric Pulmonologists in German-Speaking Countries

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Original Article

Rare Pediatric Pulmonary Diseases: Insights from a Survey of Pediatric Pulmonologists in German-Speaking Countries

Seltene pädiatrische Lungenerkrankungen: Erkenntnisse aus einer Umfrage unter deutsch-sprechenden Kinderpneumologen

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ABSTRACT

Background Rare pediatric pulmonary diseases, such as childhood interstitial lung disease and congenital thoracic malformations, pose diagnostic and therapeutic challenges due to their low prevalence and clinical heterogeneity. In contrast to cystic fibrosis and primary ciliary dyskinesia, which are supported by dedicated care networks, many other rare pediatric pulmonary diseases lack structured management pathways. This study aimed to assess pediatric pulmonologists' clinical exposure, confidence, and educational needs related to rare pediatric pulmonary diseases.

Methods A web-based survey was distributed to all 914 members of the German Society for Pediatric Pulmonology. The questionnaire evaluated clinical experience, diagnostic confidence, and preferences for educational contents and formats. Responses were analyzed using descriptive statistics and group comparisons.

Results Among 209 respondents (22.9 % response rate), clinical exposure was low (median: 3 patients/y; interquartile range: 1–5), with 22.5 % treating none. Only 36.7 % of respondents felt confident in suspecting a rare pediatric pulmonary disease, 22.0 % in diagnosis, and 13.3 % in treatment. Educational interest was high (68.8 %), particularly in clinical presentation (70.7 %), treatment (69.8 %), and imaging (59.0 %). Clinicians with < 10 years of experience reported greater interest in clinical presentation than those with ≥ 10 years (84.5 % vs. 57.3 %, $p = 0.0002$). Workshops, webinars, and online discussions were the most preferred learning formats.

Conclusions Despite limited exposure and low reported confidence, pediatric pulmonologists express strong interest in further education on rare pediatric pulmonary diseases. Tailored, accessible educational strategies are essential to improve awareness, diagnosis, and care for children with rare pulmonary conditions.

Keywords Rare disease, questionnaire, congenital thoracic malformation, diffuse parenchymal lung disease, paediatrics

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Introduction

Rare pediatric pulmonary diseases constitute a complex and diverse group of respiratory conditions that, while individually infrequent, collectively represent a significant challenge for clinicians, families, and healthcare systems. A disease is generally considered rare when it affects fewer than 1 in 2,000 individuals (< 0.05 %).[1]

The field of rare pediatric pulmonary diseases is undergoing rapid evolution, driven by expanding research efforts and growing clinical collaboration. Diseases are increasingly recognized as distinct entities requiring specialized diagnostic and therapeutic strategies. In cystic fibrosis (CF), understanding the different functional defects of the CFTR protein has led to the development of small-molecule therapies known as CFTR modulators, designed to correct the underlying molecular defects[2] resulting in substantial improvements in lung function, growth, nutritional status, health-related quality of life and lifetime expectancy.[3–6] For primary ciliary dyskinesia (PCD), the second most common inherited airway disease after CF,[7] the development of clinical networks resulted in improved diagnostic approaches,[8,9] while pre-clinical studies indicated promising new personalized therapy options.[10,11]

In contrast to this, conditions such as childhood interstitial lung disease (chILD), including among other conditions like surfactant metabolism disorders, systemic disease processes affecting the lung parenchyma and exposure related disorders as well as congenital thoracic malformations (CTM), like congenital pulmonary airway malformation, are often not followed in specialized centers and forming multidisciplinary care teams, expanding clinical networks, initiating collaborative research as well as harmonizing clinical care is challenging. These diseases often present with nonspe-

cific symptoms, mimic more common conditions, and require complex diagnostic workups.[12] While recent advances have led to better disease recognition and emerging therapeutic options, diagnostic delays and misclassification remain common, and management frequently relies on extrapolated evidence or expert consensus rather than robust data.[12]

One of the central challenges lies in their inherent rarity. Even within a specialized pediatric pulmonology setting in hospitals, private practice or rehabilitation clinics, the clinical exposure to such patients is often low, leading to diagnostic uncertainty and variable care pathways.

Efforts such as the chILD-EU in Europe (www.childeu.net), RespiRare in France (www.respifil.fr), The Children's Interstitial and Diffuse Lung Disease Research Network (ChILDRN) in the USA (www.child-foundation.org), and chILDRN in Australia and New Zealand (www.lungfoundation.com.au) have contributed significantly to our understanding of the epidemiology, genetic landscape, and clinical course of these conditions. However, these initiatives primarily reflect the perspective of few highly specialized centers. Less is known about how pediatric pulmonologists outside of these academic hubs experience, approach, and perceive the challenges posed by rare pulmonary diseases in children. This information is vital for identifying educational needs, strengthening training programs, and ensuring more uniform care delivery across healthcare settings.

Educational resources focused specifically on rare pediatric lung diseases remain limited. Most currently available materials are in the form of self-directed learning, such as clinical reviews and book chapters, while dedicated educational events like webinars are sparse, although selected international and national conferences occasionally include specialized workshops on these conditions. A selection of educational resources focused specifically on rare pediatric lung diseases is listed in **Table 1**. In this context, understanding how clinicians perceive their own competence and confidence in diagnosing and managing rare pediatric pulmonary diseases is essential. Equally important is uncovering what types of educational contents and delivery formats are most relevant and preferred by clinicians at different stages of their careers. Such data can inform targeted continuing medical education, foster the development of accessible resources, and potentially support broader collaborations or referral structures.

To address this knowledge gap, we conducted a structured survey among members of the *German Society for Pediatric Pneumology (GPP;* https://www.paediatrische-pneumologie.eu/). The aim was to systematically assess clinical exposure to rare pediatric pulmonary diseases at all career stages and different work environments, evaluate self-reported confidence in their diagnosis and treatment, and explore current educational interests and format preferences. The insights derived from this study are intended to guide educational planning and capacity-building strategies in pediatric respiratory care.

Although conditions such as CF and PCD are classified as rare diseases, they were deliberately excluded from this survey as both diseases benefit from well-established diagnostic protocols, structured care pathways, and dedicated national and international networks that support clinical management and continuing education.

Table 1 Selection of educational resources focused specifically on rare pediatric lung diseases

Clinical reviews	▪ Marczak H. et al. An update on diagnosis and treatments of childhood interstitial lung diseases (19) ▪ Seidl E. Childhood interstitial lung disease (20) ▪ Nathan N. et al. Diagnostic workup of childhood interstitial lung disease (21) ▪ Griese M. Chronic interstitial lung disease in children (12)
Book chapters	▪ Seidl E. et al. M. Surfactant dysfunction syndromes and pulmonary alveolar proteinosis in ERS Handbook of paediatric respiratory medicine (22) ▪ Griese M. and Nicolai T. Praktische Pneumologie in der Pädiatrie – Therapie (23) ▪ Griese M. and Nicolai T. Praktische Pneumologie in der Pädiatrie – Diagnostik (24)
International and national conferences	▪ Annual meeting of the German Society for Pediatric Pneumology (GPP) https://www.paediatrische-pneumologie.eu ▪ Annual meeting of the European Respiratory Society (ERS). https://www.ersnet.org/ ▪ Annual meeting of the American Thoracic Society (ATS). https://site.thoracic.org/
Webinars	▪ chILD case discussion, organized by the chILD EU network, https://childeu.net/childeu
Research networks	▪ chILD-EU, Europe, https://www.childeu.net/childeu ▪ RespiRare, France, https://respifil.fr/ ▪ ChILDRN, USA, https://child-foundation.org/ ▪ chILDRN, Australia and New Zealand, www.lungfoundation.com.au

Methods

Study design

This study employed a cross-sectional survey design to assess clinical experience, confidence, and educational needs regarding rare pediatric pulmonary diseases. The questionnaire was provided in German among members of the GPP (**Supplementary Fig. 1a–d, available in the online version only**).

Data collection methods

Data were collected using a structured, web-based questionnaire created and distributed via REDCap (Research Electronic Data Capture), a secure web platform for building and managing online databases and surveys.[13] The survey consisted of both closed and multiple-choice questions covering demographics, clinical interest, diagnostic practices, and educational preferences.

Sample characteristics

Participants included pediatric pulmonologists and physicians in related specialties practicing in Germany, Austria, and Switzerland. Respondents represented a range of healthcare settings including university hospitals, community hospitals, academic teaching hospitals, private practices, and rehabilitation centers, and held varying levels of professional seniority and specialization.

Survey administration

The questionnaire was distributed via email to all members of the GPP. Respondents were given 2 weeks to complete the survey, followed by a reminder and an additional 1-week extension to optimize response rates.

Study preparation

A survey instrument was developed based on the expert input to capture relevant clinical and educational dimensions of rare pediatric pulmonary diseases, excluding well-characterized conditions such as cystic fibrosis and primary ciliary dyskinesia.

Ethical considerations

Participation was voluntary and anonymous. No personal identifiers were collected. The study complied with national data protection regulations. Ethical approval was sought or waived in accordance with institutional and national guidelines for anonymous survey research.

Statistical analysis

Continuous variables were presented as medians with interquartile ranges (IQRs), and categorical variables as counts and percentages. Comparisons between independent groups were performed using the Mann–Whitney *U* test, and paired data were analyzed with the Wilcoxon signed-rank test. For comparisons across more than two related groups, the Friedman test was used. Associations between categorical variables were assessed using the chi-squared test. Responses collected on five-point Likert-type scales were recoded into three ordinal categories representing (1–2 = low, 3 = moderate, and 4–5 = high) in order to reduce sparsity and improve interpretability. All analyses were conducted using a complete-case approach for the variables involved in each specific calculation. No data imputation was performed. Where applicable, *p*-values were adjusted for multiple comparisons using the Benjamini–Hochberg false discovery rate (FDR) correction. All analyses were conducted using R statistical software, version 4.5.0. A two-sided p-value < 0.05 was considered statistically significant unless otherwise specified.

Results

The survey was distributed to all 914 members of the GPP. A total of 209 participants (22.9 %) responded. The characteristics of the respondent cohort are presented in **Table 2**. Most respondents were based in Germany (87.8 %), followed by Switzerland (7.3 %) and Austria (4.9 %). This distribution closely mirrors that of the GPP, with 90.4 % of its members practicing in Germany, 5.1 % in Switzerland, and 4.4 % in Austria. Gender distribution was equal (female 50.7 % and male 47.8 %) and most frequent work environments were university hospitals (31.7 %) or private practice (27.5 %). Respondents reported less than 10 years of experience vs. 10 years or more in both 49.3 %.

The median annual number of patients with rare pulmonary diseases treated per respondent was 3 (IQR: 1–5; range: 0–200), with 22.5 % reporting not seeing such children. Consistent with this limited clinical exposure, only 36.7 % of respondents reported feeling confident suspecting a rare pulmonary disease, 22.0 % in establishing a diagnosis, and 13.3 % in managing rare pulmonary diseases in children (**Fig. 1**). While most respondents both indicated and performed CT-scans (66.8 %), bronchoscopy (59.5 %), and genetic testing (57.7 %) at their own institutions, the majority (66.8 %) referred patients for lung biopsy to another center.

Overall, high interest in learning formats was reported for workshops (82.2 %), followed by webinars (79.1 %), online discussions (75.0 %), and conferences (71.6 %). In contrast, lower levels of interest were indicated for educational videos (62.8 %), podcasts (59.4 %), and written materials (41.2 %). Interestingly, when comparing clinicians with < 10 years and those with ≥ 10 years of experience, less experienced clinicians showed a statistically significant preference for podcasts being helpful (70.3 % vs. 49.0 %, Mann–Whitney *U* test, and FDR adjusted $p = 0.0063$), followed by video formats (72.8 % vs. 54.0 %, Mann–Whitney *U* test, and FDR adjusted $p = 0.0089$; **Fig. 2**). No topic-specific educational interests were associated with perceived usefulness of the different educational

Table 2 Baseline characteristics of the cohort

Characteristic	Value
Respondents, *n*	209
Age (y), median (range)	47 (25–80)
Sex, *n* (%)	
Female	106 (50.7)
Male	100 (47.8)
Prefer not to say	3 (1.4)
Country, *n* (%)	
Germany	184 (88.0)
Switzerland	15 (7.2)
Austria	9 (4.3)
Other country	1 (0.5)
Center, *n* (%)	
University hospital	76 (31.7)
Private practice	66 (27.5)
Academic teaching hospital	49 (20.4)
Municipal hospital	10 (4.2)
Rehabilitation clinic	7 (2.9)
Not reported	1 (0.4)
Position, *n* (%)	
Senior pediatric pulmonologist	74 (35.4)
Specialist	48 (23.0)
Non-senior pediatric pulmonologist	45 (21.5)
Other	25 (12.0)
Resident	16 (7.7)
Not reported	1 (0.5)
Clinical experience in pediatric pulmonology[a], *n* (%)	
10 y and more	103 (49.3)
Less than 10 y	103 (49.3)
Not reported	3 (1.4)

[a]Years of clinical experience were categorized into two groups based on a 10-year cutoff to improve interpretability and ensure balanced group sizes.

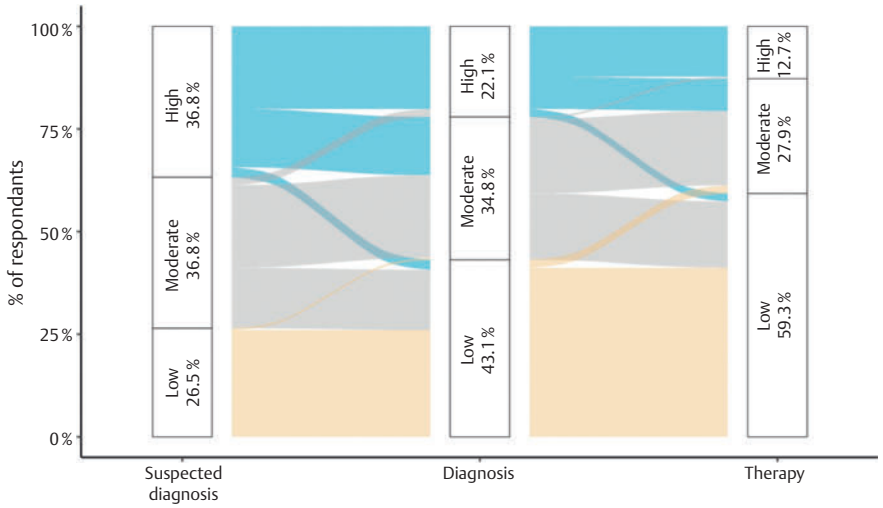

Fig. 1 Confidence ratings across three stages: provisional diagnosis, diagnosis, and therapy (from left to right). Each vertical column represents a stage, with stacked blocks indicating grouped confidence levels (low = 1 and 2, moderate = 3, and high = 4 and 5). The height of each block reflects the percentage of respondents at this confidence level. Flows between blocks represent individual respondents and how their confidence levels changed across stages. The trend was statistically significant (Friedman test, χ^2 (2) = 146.09, $p < 0.0001$). Post hoc comparisons confirmed significant pairwise differences between all stages (Conover test, all FDR adjusted $p < 0.0001$).

formats (**Supplementary Fig. 2, available in the online version only**).

Most respondents (68.8 %) expressed strong interest in further education on rare pulmonary diseases, particularly in areas such as clinical presentation (70.7 %), treatment options (69.8 %), and imaging (59.0 %). This interest was higher compared to lung function diagnostics (48.8 %), genetics (39.0 %), and histology (16.6 %). When asked about specific areas of interest, both congenital thoracic malformations and childhood interstitial lung diseases showed similarly high levels of interest, with no significant difference in distribution (Wilcoxon signed-rank test, $p = 0.28$; **Supplementary Fig. 3, available in the online version only**). There was no significant difference in overall educational interest between clinicians with < 10 years and those with ≥ 10 years of experience (Mann–Whitney *U* test: $p = 0.52$; **Fig. 3a**). However, clinicians with less than 10 years of experience reported significantly greater interest in the topic of clinical presentation (84.5 %) compared to those with ≥ 10 years of experience (57.3 %; chi-square test, $\chi^2(1) = 17.14$, FDR adjusted $p = 0.0002$; **Fig. 3b**).

Discussion

This survey across pediatric pulmonologists in German-speaking countries highlights a marked discrepancy between clinical exposure to rare pediatric pulmonary diseases and interest in further education. While most respondents reported treating none or only a small number of patients annually, they expressed high interest in further training, particularly in areas such as clinical presentation, diagnostics, and treatment. It is plausible that individuals with a particular interest in rare pediatric pulmonary diseases were more inclined to respond. In contrast to this, non-responders may have had even lower self-reported confidence levels. Consequently, our findings are more likely to overestimate than underestimate the overall confidence in this field. Furthermore, interest in further education was high across the diverse cohort, regardless of the participants' professional background, institutional setting, or clinical experience, suggesting a broad and shared demand for enhanced training in the field of rare pediatric pulmonary diseases. Confidence levels in managing rare diseases were low across diagnostic and therapeutic stages, aligning with the limited hands-on experience reported.

These findings are consistent with previous literature emphasizing that rare disease management is often hampered by a lack of familiarity and resources among clinicians.[14,15] Our results reinforce this, showing both the underexposure to and under-confidence in handling rare pulmonary diseases, even among specialists. Unlike previous studies that typically focus on specific diseases or expert centers, this survey captures a broader and more representative picture of real-world pediatric pulmonology practice across diverse healthcare settings.

The high levels of reported educational interest, including both experienced and early career clinicians, indicate a clear opportunity to improve care through targeted educational interventions. Our data suggest that such initiatives should prioritize clinically relevant topics (e.g., disease presentation and treatment strategies) and use interactive or accessible formats such as workshops, webinars, and online discussions. Interestingly, such formats that are scheduled at distinct timepoints, are preferred over formats where the content can be accessed at any time point such as videos, podcasts, or written formats. Hence, in daily clinical practice, it may be easier for physicians to commit to pre-scheduled sessions rather than relying on the on-demand content, which, despite its

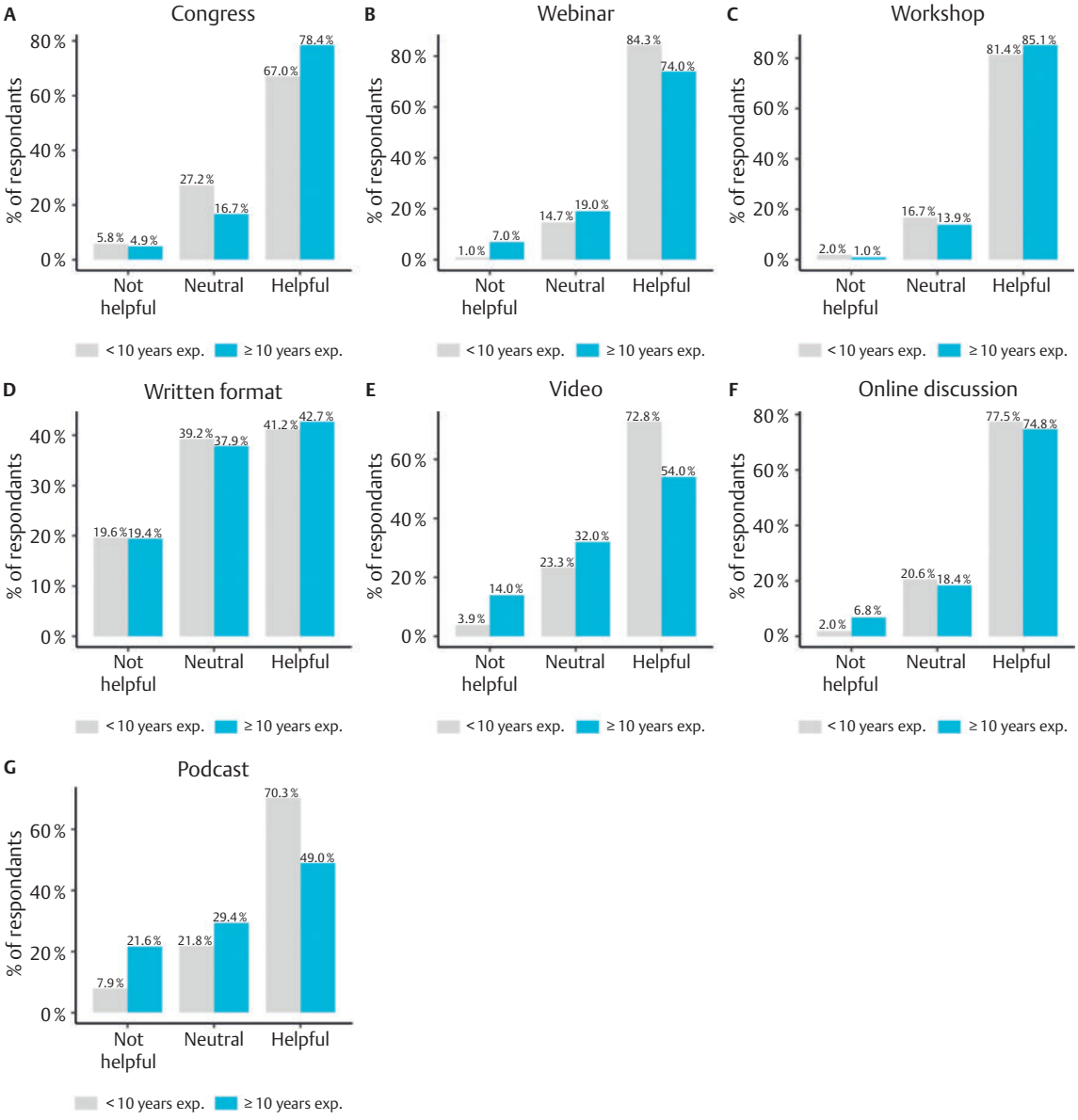

Fig. 2 Percentages of respondents rating each educational format as "Helpful," "Neutral," or "Not helpful," stratified by clinical experience (less than 10 y vs. 10 or more years of experience).

flexibility, is more likely to be postponed or overlooked amid the demands of routine clinical duties. Notably, less experienced clinicians showed a preference for digital formats like podcasts and videos which may inform strategies for designing the effective, experience-tailored educational content.

On a European level, efforts by the European Union to support education for health care providers and patients for rare diseases are funded through initiatives (European Reference Network on Rare Respiratory Diseases, ERN-Lung) and the European Respiratory Society developed a syllabus and examinations to harmonize education for both adult and pediatric pulmonologists in training.[16] A survey among European respiratory specialists initiated by the ERN-Lung demonstrated a high priority on education (not specific to pediatrics) among the respondents, also supporting a variety of formats such as workshops, online courses and webinars as in our survey.[17]

This study has several limitations. The response rate, while comparable to similar surveys,[18] was relatively low (22.9 %), which may introduce response bias. Participants self-selected into the study, possibly leading to overrepresentation of clinicians already interested in rare diseases. However, the geographic distribution of respondents closely reflected the overall distribution of pediatric pulmonologists within the GPP. This suggests that the sample is likely representative of the broader professional group. Additionally, self-reported confidence and interest may not reflect actual clinical

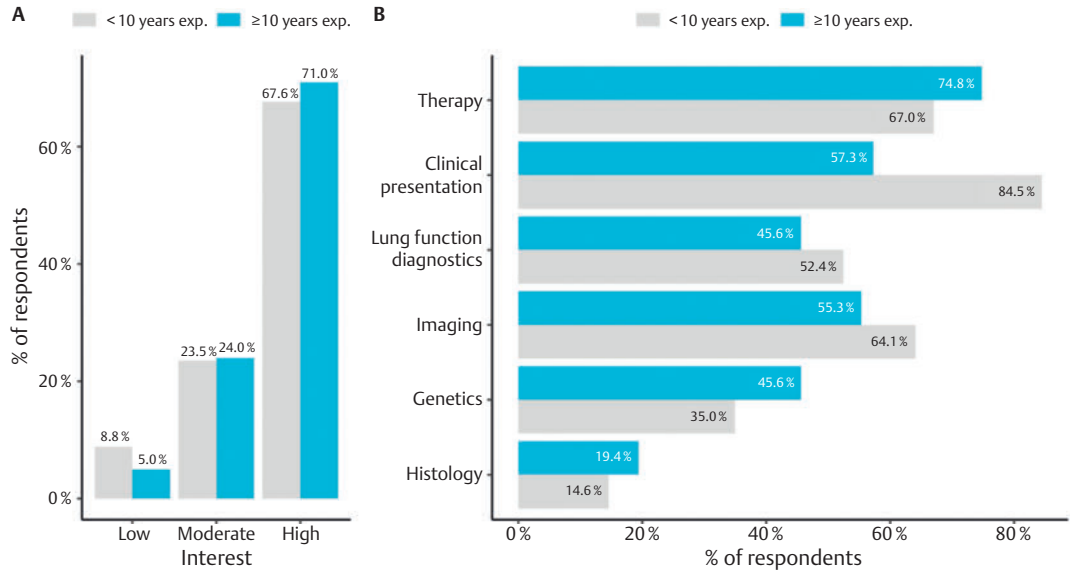

Fig. 3 Educational interest by experience levels. (**a**) Distributions of educational interest (low, moderate, and high) stratified by experience groups. (**b**) Percentage of respondents interested in specific educational areas, stratified by experience groups. Blue bars represent respondents with 10 or more years of experience, and grey bars represent those with less than 10 years.

competencies or engagement. The cross-sectional design also limits its causal interpretation of the observed associations.

Future research should explore how educational interventions impact clinician confidence and patient outcomes over time. Qualitative studies could further elucidate specific barriers to care and training. Expanding the survey to include international participants could provide a more comprehensive understanding of global educational needs and inform the development of harmonized training frameworks.

To meet the expressed needs and preferences of clinicians and to establish sustainable educational structures, clinical workshops and case discussions should be more prominently integrated into conferences, while interactive formats such as webinars, online discussions, and podcasts should be made broadly accessible to participants of all career stages and levels of experience.

Overall, the results of this survey demonstrate that exposure to children with rare pulmonary diseases even within different settings of the specialized pediatric pulmonology community is low and interest in further education is high both for clinicians with fewer or more than 10 years of work experience.

ZUSAMMENFASSUNG

Hintergrund Seltene pädiatrische Lungenerkrankungen, wie interstitielle Lungenerkrankungen im Kindesalter oder kongenitale thorakale Malformationen, sind aufgrund niedriger Prävalenz und klinischer Heterogenität diagnostisch und therapeutisch herausfordernd. Im Gegensatz zur Cystischen Fibrose oder Primärer Ciliärer Dyskinesie fehlen für viele andere Erkrankungen strukturierte Versorgungsansätze. Ziel dieser Studie war es, Expertise, diagnostische Sicherheit und Weiterbildungsbedarf von pädiatrischen PneumologINNen zu erfassen.

Methoden Eine webbasierte Umfrage wurde an 914 Mitglieder der Gesellschaft für Pädiatrische Pneumologie verschickt. Erfragt wurden Expertise, diagnostische Sicherheit und Präferenzen zu Lerninhalten und -formaten. Die Auswertung erfolgte deskriptiv und mit Gruppenvergleichen.

Ergebnisse Von 209 Teilnehmenden (Rücklauf 22,9 %) behandelten 22,5 % keine Patienten mit seltenen Lungenerkrankungen (Median 3/Jahr). Nur 36,7 % fühlten sich sicher im Erkennen eines Verdachts, 22,0 % in der Diagnostik und 13,3 % in der Therapie. Das Interesse an Fortbildung war hoch (68,8 %), besonders zu klinischer Präsentation (70,7 %), Therapie (69,8 %) und Bildgebung (59,0 %). Ärzte mit <10 Jahren Berufserfahrung zeigten größeres Interesse an klinischer Präsentation als solchemit ≥10 Jahren (84,5 % vs. 57,3 %, p = 0,0002). Workshops, Webinare und Online-Diskussionen wurden bevorzugt.

Schlussfolgerung Trotz geringer Fallzahlen besteht großes Interesse an strukturierter Weiterbildung zu seltenenpädiatrischen Lungenerkrankungen.

Schlüsselwörter seltene Lungenerkrankung, Fragebogen, kongenitale thorakale Malformation, diffus parenchymatöse Lungenerkrankung, Pädiatrie

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Statements and additional information

Conflict of Interest The authors declare that they have no conflict of interest.

Data availability Data were made available upon reasonable request from the authors.

Contributors' Statement Julia Carlens: conceptualization, investigation, project administration, and writing—review and editing. Srdjan Micic: conceptualization, data curation, formal analysis, methodology, software, and writing—review and editing. Nicolaus Schwerk: supervision, validation, and writing—review and editing.

Matthias Griese: supervision and writing—review and editing. Alexander Moeller: resources, supervision, and writing—review and editing. Elias Seidl: conceptualization, formal analysis, investigation, methodology, project administration, software, writing—original draft, and writing—review and editing.

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Supplemental Figure 1: Questionnaire on Rare Pediatric Pulmonary Diseases distributed via REDCap to members of the German Society for Pediatric Pneumology.

Confidential

Umfrage zu seltenen Lungenerkrangungen

Sehr geehrte Teilnehmerinnen und Teilnehmer,

herzlich willkommen zu unserer Umfrage über seltene Lungenerkrankungen.

Ihre Einschätzungen sind von grosser Bedeutung, um die Versorgung und Weiterbildung in diesem Bereich gezielt zu verbessern.

Für diese Umfrage verstehen wir unter seltenen Lungenerkrankungen insbesondere interstitielle Lungenerkrankungen im Kindesalter (chILD) sowie angeborene Fehlbildungen. Erkrankungen wie die Cystische Fibrose (Mukoviszidose) oder die Primäre Ziliäre Dyskinesie (PCD) sind nicht Teil dieser Auswertung.

Die Beantwortung der Fragen dauert nur wenige Minuten. Ihre Angaben bleiben selbstverständlich anonym.

Vielen Dank für Ihre Unterstützung!

Hintergrundsifromationen	
Wie alt sind Sie?	_____
Was ist Ihr Geschlecht?	◯ Weiblich ◯ Männlich ◯ Divers ◯ Keine Angabe
An welchem Zentrum arbeiteten Sie?	◯ Praxis ◯ Akademische Lehrkrankenhaus ◯ Kommunales Krankenhaus ◯ Universitätsklinik ◯ Rehaklinik
In welchem Land befindet sich Ihr Zentrum?	◯ Deutschalnd ◯ Österrich ◯ Schweiz ◯ Anderes Land
In welcher Funktion arbeiten Sie?	◯ Assistenzarzt ◯ Facharzt ◯ Kinderpneumologe, aber kein Oberarzt ◯ Oberarzt Kinder-Pneumologie ◯ Andere
Andere Fukntion als oben gelistet	_____
Spezialisierung (Pneumologie oder andere, z.B. Intensivmedizin, Neonatologie)?	◯ Keine Weiterbildung ◯ In Weiterbildung Pneumologie ◯ Abgeschlossene Weiterbildung Pneumologie ◯ Andere abgeschlossene Weiterbildung
Andere Spezialisierung als oben gelistet	_____

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Supplemental Figure 1: Questionnaire on Rare Pediatric Pulmonary Diseases distributed via REDCap to members of the German Society for Pediatric Pneumology.

Confidential

Page 2

An welchen Erkrnakungsgruppen haben Sie persönlich das meiste klinische Interesse?	☐ Asthma ☐ Lungentransplantation ☐ Neuromuskuläre Erkrnakungen ☐ Schlaf- und Beatmung ☐ Seltene Lungenerkrankungen ☐ Infektiologie ☐ Andere
Andere Erkrangungsgruppe als oben gelistet	_____
Wie gross ist Ihr Interesse an interstitellen Lungenerkrankungen im Kindesalter (chILD)	◯ Kein Interesse ◯ Geringes Interesse ◯ Mittleres Interesse ◯ Hohes Interesse ◯ Sehr hohes Interesse
Wie gross ist Ihr Interesse an angeborenen Fehlbildungen	◯ Kein Interesse ◯ Geringes Interesse ◯ Mittleres Interesse ◯ Hohes Interesse ◯ Sehr hohes Interesse
Klinische Erfahrung mit seltenen Lungenerkrankung bei Kindern	
Wie viele Jahre Berufserfahrung in der "Kinder-Pneumologie" haben Sie?	◯ Weniger als 2 Jahre ◯ Mehr als 2 und weniger als 5 Jahre ◯ Mehr als 5 und weniger als 10 Jahre ◯ Mehr als 10 Jahre
Wie viele Patienten mit seltenen Lungenerkrangungen haben Sie in den letzten Jahren pro Jahr ca. gesehen?	_____
Wie viele Patienten mit seltenen Lungenerkrangungen haben Sie in den letzten Jahren pro Jahr ca. direkt betreut?	_____
Wie sicher sind Sie, die Verdachtsdiagnose einer seltenen Lungenerkrangung zu stellen?	◯ Gar nicht sicher ◯ Wenig sicher ◯ Mittel sicher ◯ Ziemlich sicher ◯ Sehr sicher
Wie sicher sind Sie, eine seltene Lungenerkrangung zu diagnostizieren?	◯ Gar nicht sicher ◯ Wenig sicher ◯ Mittel sicher ◯ Ziemlich sicher ◯ Sehr sicher
Wie sicher sind Sie, eine seltene Lungenerkrangung zu therapieren?	◯ Gar nicht sicher ◯ Wenig sicher ◯ Mittel sicher ◯ Ziemlich sicher ◯ Sehr sicher

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Bei Verdacht auf eine seltene Lungenerkrankung, welche Diagnostik würden Sie selber durchführen und wofür weiterverweisen bzw. einweisen?	
CT Thorax	◯ Selber indizieren/im eigenen Haus durchführen ◯ Weiterverweisen
Bronchoskopie/BAL	◯ Selber indizieren/im eigenen Haus durchführen ◯ Weiterverweisen
Lungenbiopsie	◯ Selber indizieren/im eigenen Haus durchführen ◯ Weiterverweisen
Genetik	◯ Selber indizieren/im eigenen Haus durchführen ◯ Weiterverweisen
Weiterbildung und Trainings	
Wie hoch ist Ihr Interesse an einer Weiterbildung für seltene Lungenerkrangungen?	◯ Kein Interesse ◯ Geringes Interesse ◯ Mittleres Interesse ◯ Hohes Interesse ◯ Sehr hohes Interesse
Gibt es einen oder mehrere Teilbereiche, die Sie besonders interessieren?	☐ Bildgebung ☐ Genetik ☐ Histologie ☐ Klinische Präsentation ☐ Lungenfunktionsdiagnostik ☐ Therapie
Wie hilfreich als Weiterbildungstool schätzen Sie folgende Formate ein?	
Kongress	◯ Überhaupt nicht hilfreich ◯ Wenig hilfreich ◯ Teils/teils ◯ Hilfreich ◯ Sehr hilfreich
Webinar	◯ Überhaupt nicht hilfreich ◯ Wenig hilfreich ◯ Teils/teils ◯ Hilfreich ◯ Sehr hilfreich
Workshop	◯ Überhaupt nicht hilfreich ◯ Wenig hilfreich ◯ Teils/teils ◯ Hilfreich ◯ Sehr hilfreich
Schriftliche Fortbildung	◯ Überhaupt nicht hilfreich ◯ Wenig hilfreich ◯ Teils/teils ◯ Hilfreich ◯ Sehr hilfreich

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Video	◯ Überhaupt nicht hilfreich ◯ Wenig hilfreich ◯ Teils/teils ◯ Hilfreich ◯ Sehr hilfreich
Online Falldiksussionen	◯ Überhaupt nicht hilfreich ◯ Wenig hilfreich ◯ Teils/teils ◯ Hilfreich ◯ Sehr hilfreich
Podcast	◯ Überhaupt nicht hilfreich ◯ Wenig hilfreich ◯ Teils/teils ◯ Hilfreich ◯ Sehr hilfreich

Haben Sie abschliessend noch Anmerkungen oder Kommentare?

Kommentar _____

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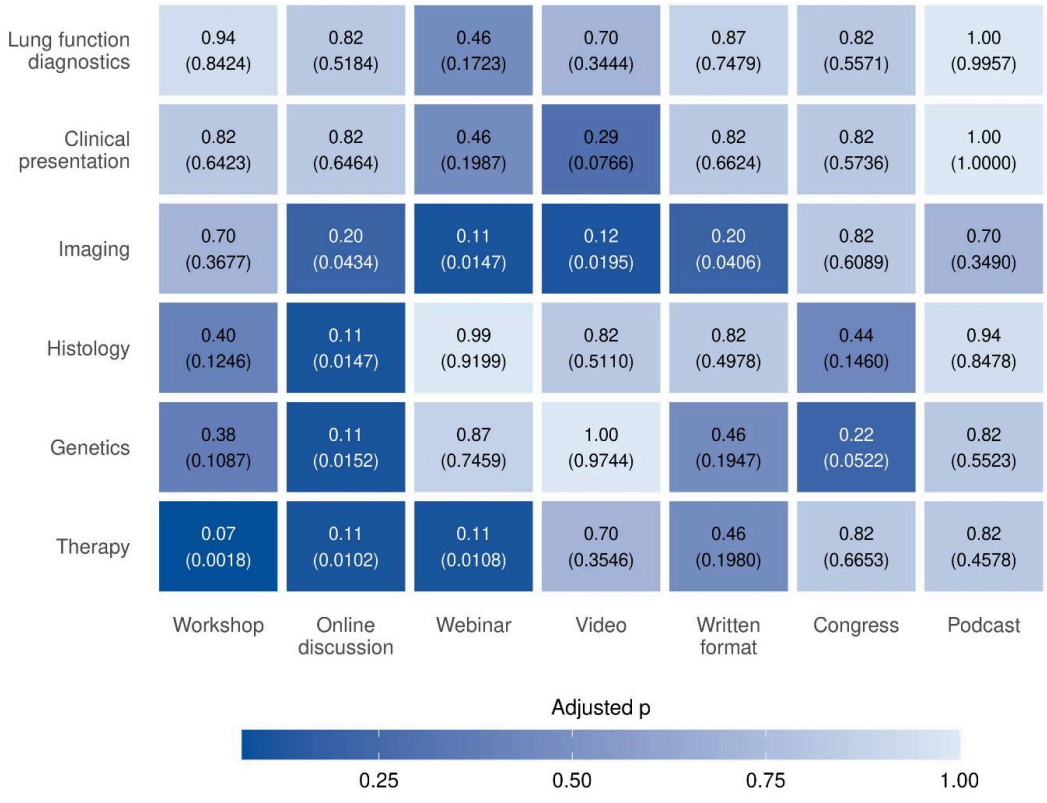
Supplemental Figure 2: Forty-two comparisons were conducted using Mann–Whitney U tests to examine whether topic-specific educational interests were associated with perceived usefulness of educational formats. After adjustment for multiple testing, no associations remained statistically significant (all FDR adjusted p-values > 0.05).



Supplemental Figure 3: Distribution of self-reported interest levels in Childhood Interstitial Lung Disease (gray bars) and Congenital Thoracic Malformations (blue bars). Responses were originally collected on a 5-point ordinal scale and subsequently grouped into three categories (low, moderate, high).