

Challenges and Barriers in Pediatric to Adult Transition in Chronic Pulmonary Diseases in Italy: A Nationwide Survey

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Keywords

Lung diseases · Continuity of patient care · Adolescent health services

Abstract

Introduction: Advances in medical research, early diagnosis, and therapeutic strategies have significantly improved survival among children with chronic pulmonary diseases (CPDs), leading to a growing population of adolescents and young adults transitioning to adult care. Despite this demographic shift, healthcare systems, including Italy's, remain inadequately equipped to manage the evolving needs of these patients. This study aims to identify key barriers and

unmet needs within the Italian healthcare system regarding the transition from pediatric to adult care for individuals with CPDs. **Methods:** A nationwide survey was conducted among members of IPRS (Italian Pediatric Respiratory Society) through a questionnaire consisting of 13 questions. The survey was sent between June and August 2023, with responses collected until July 2024. **Results:** A total of fifty-one responses were collected from pulmonologists, hospital-based pediatricians, primary care pediatricians, and adult pulmonologists from 14 Italian regions. Of

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these, 64.7% reported the absence of a structured transition program within their institutions. Where programs existed, they primarily targeted severe asthma (60.6%) and PCD or non-CF bronchiectasis (24.2%). Only 15.7% of respondents consistently addressed transition with patients and families, and 13.8% of centers had dedicated transition clinics. Proposed improvements included the establishment of specialized clinics (76.5%) and targeted professional training (72.5%). **Conclusions:** The transition of CPDs patients in Italy is currently fragmented and underdeveloped. Standardized protocols, dedicated transition services, interdisciplinary collaboration, continuous education, and involvement of patient associations are essential to ensure continuity of care and optimize long-term health outcomes.

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Plain Language Summary

Children and adolescents with chronic lung diseases, such as severe asthma, primary ciliary dyskinesia, bronchiectasis, and chronic respiratory failure, are now living longer thanks to advances in diagnosis and treatment. As a result, many of these young patients need to move from pediatric care to adult care when they reach adolescence or early adulthood. This important process is called “transition of care,” which refers to the ongoing support of adolescents and young adults over time, helping them develop the skills, knowledge, and confidence to manage their own health. This is distinct from “transfer,” which specifically refers to the coordination between pediatric and adult care teams to ensure continuity of care. In Italy, the way this transition is organized is still very variable and often incomplete. To understand the situation better, we conducted a national survey among pediatric and adult lung specialists who are members of the Italian Pediatric Respiratory Society (IPRS). Our results show that most hospitals and clinics do not have structured programs to support patients during this transition. Only a minority of centers offer dedicated clinics or formal pathways. Many professionals believe that improvements are needed, such as creating specialized transition clinics, preparing personalized medical summaries for patients, and offering training courses for doctors. This study highlights the urgent need for more organized and consistent transition pathways in Italy. Better planning and collaboration between pediatric and adult specialists could help young people with chronic lung diseases move more safely into adult care, improve their quality of life, and reduce the risk of losing follow-up or worsening their health condition.

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Introduction

Survival rates of children with chronic diseases and special healthcare needs have significantly improved in recent decades, thanks to advances in research and technology in medicine. It is estimated that up to 1 in 10 adolescents suffer from chronic illnesses or disabilities and that the number of Adolescents and Young Adults (AYA) living with chronic pulmonary diseases (CPDs) has progressively increased [1]. This is why modern healthcare professionals must deal with a major challenge: guiding AYAs affected by CPDs such as severe asthma, cystic and non-cystic fibrosis (CF), primary ciliary dyskinesia (PCD), bronchiectasis, neuromuscular diseases, respiratory sleep disorders, congenital lung malformations, bronchopulmonary dysplasia (BPD), and other rare diseases through the transition process from pediatric to adult healthcare.

Adolescent Medicine

Despite the World Health Organization defined adolescence as the period between ages 10 and 19 [2], there is currently a lack of uniformity in the definition of adolescence across countries. Various health services often define adolescence differently, with age limits set at 16 or 18. This is particularly true in Italy, where the age threshold for healthcare responsibility between pediatric and adult medicine varies from region to region and between individual hospitals. In Italy, the upper age limit for pediatric care is typically set at 18 years. In contrast, it is worth noting that the English National Health Service recognizes the importance of supporting individuals up to the age of 25, acknowledging the extended nature of adolescence [1].

Transition in Chronic Diseases

Transition often overlaps with key developmental milestones, such as autonomy, identity formation, and preparation for adulthood, requiring both medical and psychological support [3]. AYAs with CPDs must adapt to the chronic nature of their illness while facing risks of marginalization and peer comparison [4]. Although patient empowerment may positively influence transition, research remains limited for socioeconomically disadvantaged and minority groups [5]. Additionally, AYAs with chronic diseases engage in risky behaviors at rates comparable to or higher than their healthy peers, with greater potential for adverse outcomes [6]. This is linked to

poor treatment adherence, shifting current focus toward fostering self-management and promoting patient autonomy [7, 8].

Planning Transition in CPDs

Proper planning and guidance are crucial to support young patients in managing CPDs while fostering empowerment and self-efficacy. Since transition occurs during adolescence, it should be approached as a structured process rather than a one-time event [9]. In Italy, this process is often hindered by the absence of structured pathways, with significant regional variability. Key challenges include.

- a. Continuity of care: pediatric teams are deeply familiar with patients and their families. Transitioning to adult care can introduce unfamiliar providers, risking care gaps [10].
- b. Complex management: CPDs require advanced, ongoing treatment. Adult systems often lack pediatric expertise, making care more difficult [9].
- c. Care coordination: adults with CPDs frequently see multiple specialists, increasing the risk of fragmented care, inconsistent treatments, and poor adherence.
- d. Healthcare system issues: transition is further hindered by access difficulties, financial constraints, and a lack of specialized adult centers, especially in remote areas [11].

Effective Transition Components

There is evidence that a structured transition is associated with positive health outcomes, but scientific studies often lack a detailed description of the transition process and present methodological limitations such as a small size and the absence of a control group [12].

Most research favors a holistic approach, fostering independence, supporting the adolescent's unique needs, and considering the broader social and cultural context to ensure a successful transition to adulthood [10].

Therefore, the components of an effective transition should include.

- a. Self-Determination: the ability of adolescents to make informed healthcare decisions, promoting independence in disease management [5, 13].
- b. Accountability: shared responsibility between adolescents and healthcare providers, supported by transition tools such as goal setting, reminders, and regular check-ins [14].
- c. Acknowledgment of individual differences and complexities
- d. Recognition of vulnerabilities and the influence of culture and socioeconomic status

- e. Early preparation and caregiver support: empowering adolescents early and involving caregivers supports autonomy and a smoother transition [15, 16].

The purpose of this nationwide survey is to delve into the barriers existing in Italy regarding pediatric to adult transition in CPDs, to identify the key points from which we could improve the current healthcare offer for these patients regarding transition.

Methods

We designed a survey questionnaire aimed at exploring the transition from pediatric to adult care for patients with CPDs in Italy. The survey was conducted using an online questionnaire, which was distributed electronically to all current members of IPRS (Italian Pediatric Respiratory Society), a scientific society representing a diverse network of healthcare professionals dedicated to pediatric respiratory health. IPRS includes specialists from tertiary-level pediatric hospitals, general pediatric departments, specialized pediatric outpatient clinics, pediatric pulmonology units, and primary care pediatricians, ensuring broad national coverage and representation across various levels of care. The survey was developed to investigate current practices, challenges, and strategies related to the transition process. Members were encouraged to forward the questionnaire to other specialized centers and Italian primary care pediatricians to achieve wider data collection and more comprehensive insights. Questionnaires were sent by email to all IPRS members between June 2023 and August 2023, and the answers were collected until the end of July 2024. Approximately 1,000 physicians registered with IPRS received the questionnaire, and to encourage responses, 3 follow-up reminders were sent over several months.

Questionnaire

The questionnaire was written in Italian and consisted of thirteen structured questions designed to collect detailed information.

1. To report the Italian region they worked in;
2. To report their work setting, whether they worked in a Children's Hospital, a Pediatrics outpatient clinic, Primary Care Pediatrics, or Adult Pulmonology;
3. To indicate the number of patients with CPDs in care and specify in which age group: <14 years, 14–18 years, and 18–25 years;
4. To indicate if there was a transition pathway for CPDs patients in their working environment;

5. To indicate if a transition pathway existed, for which specific disease it was applied;
6. To describe the figures involved in the existing transition pathway;
7. To describe how the transition was structured in their work setting;
8. To indicate if there was a transition dedicated ambulatory in each hospital/center;
9. To estimate how often the topic of transition was discussed with patients or their parents;
10. To list what strategies were considered most useful to facilitate transition;
11. To express an opinion on whether training courses on transition from pediatric to adult care are necessary;
12. To say whether in their own personal experience patient associations have had a role in the transition process;
13. Further comments or suggestions.

The survey questions and answer options have been compiled and can be consulted in Table 1.

Analysis

This is a descriptive study utilizing data obtained from the questionnaire sent to IPRS members. The survey was published on the official IPRS website to ensure broader participation and visibility. The collected data were anonymized and entered into a centralized database. In this survey, there is no disclosure of sensitive data from individual patients; therefore, no formal approval from the Ethical Committees was requested.

Results

A total of 51 physicians from 14 Italian regions responded to the survey, including hospital-based pediatricians, pediatric pulmonologists, primary care pediatricians, and adult pulmonologists. Since the questionnaires were sent to approximately 1,000 IPRS members, a response rate of around 5.1% was achieved. Most respondents worked in children's hospitals (76.5%, $n = 39$), followed by pediatric outpatient clinics, primary care settings, and adult pulmonology units, as shown in Table 2. Overall, the age distribution of patients with chronic pulmonary diseases (CPDs) reported by the respondents showed that 55% were younger than 14 years, 29.7% were aged 14–18 years, and 20% were between 18 and 25 years (Table 2).

The majority of participants (64.7%, $n = 33$) reported the absence of a structured transition program from

pediatric to adult care within their institution. Among centers where a transition pathway was available (35.3%, $n = 18$), the transition program was directed toward patients with severe asthma (77.7% of responses, $n = 14$), primary ciliary dyskinesia or non-cystic fibrosis (CF) bronchiectasis (33.3%, $n = 6$), chronic respiratory failure (33.3%, $n = 6$) and respiratory sleep disorders (22.2%, $n = 4$) (Table 2). Other conditions, including neuromuscular diseases, congenital lung malformations, bronchopulmonary dysplasia, and mild-to-moderate asthma, were less frequently included in structured transition pathways.

Regarding the organization of transition care, pediatricians were involved in most responses (84.3%, $n = 43$), while adult pulmonologists participated in 60.7% of responses ($n = 31$). The involvement of other healthcare professionals was less consistent, with physiotherapists involved in 35.3% of responses ($n = 18$), nurses in 23.5% ($n = 12$), and psychologists in only 17.6% of responses ($n = 9$). In terms of transition modalities, 25.5% ($n = 13$) of respondents reported joint outpatient visits involving both pediatric and adult specialists, and 19.6% ($n = 10$) provided patients with a personalized medical summary, while 7.8% ($n = 4$) referred their patients to their primary care physicians. However, in 58.8% of responses ($n = 30$), no specific transition strategy was in place. Furthermore, 86.3% of respondents reported the absence of dedicated transition clinics within their centers ($n = 44$) (Table 2).

Communication about transition with patients and families was reported as inconsistent. Only 15.7% ($n = 8$) of physicians stated that they always discussed the transition to adult care, while 35.3% did so often ($n = 18$), and 41.2% ($n = 21$) only occasionally (Table 2).

When asked about strategies to improve the transition process, most respondents identified the creation of dedicated pediatric-to-adult transition clinics as the most effective intervention (76.5%, $n = 39$). Additional proposed strategies included the use of personalized medical summaries (45.1%, $n = 23$), greater involvement of Primary care services (37.3%, $n = 19$), and prolonged shared care for complex patients (25.5%, $n = 13$). A large proportion of participants (72.5%, $n = 37$) also emphasized the need for specific training programs focused on transition. Finally, patient associations were considered to play a relevant role in the transition process by 51% of respondents ($n = 26$) (Table 2).

It is important to note that the results of the survey reflect estimates provided by the respondents. All percentages reported in the results section refer to the proportion of survey respondents who selected a given answer and do not represent direct clinical observations of individual patients.

Table 1. CPDs transition survey questionnaire

Questions	Response options
1. In which region do you practice?	Free-text response
2. In which setting do you practice your professional activity? (Check all that apply)	- Children's hospital - Pediatrics outpatient clinic - Primary care Pediatrics - Adult pulmonologists
3. How many patients with chronic respiratory disease are you currently managing, and in which age groups (<14 years of age, 14–18 years of age, 18–25 years of age)?	Free-text response
4. Is a transition pathway established in your clinical practice/department?	Yes/No
5. If yes, for which conditions?	Free-text response
6. Which healthcare professionals are involved in the transition process? (Check all that apply)	- Pediatrician - Adult pulmonologist - Nurse - Physiotherapist - Psychologist
7. How is the transition pathway structured? (Check all that apply)	- Joint outpatient visits involving both pediatric and adult specialists - Release of a personalized medical summary to the patient (care plan) - Referral to primary care physician - No transition strategy is in place in my center
8. Is there a dedicated transition clinic in your hospital/center?	Yes/No
9. How often have you addressed the topic of transition with your patients or their parents?	- Always - Frequently - Sometimes - Never
10. Which strategies do you consider most useful to facilitate the transition? (Check all that apply)	- Creation of dedicated pediatric-to-adult transition clinics - Release of personalized medical summaries - Greater involvement of primary care services - Prolonged shared care between pediatric and adult specialists for complex patients
11. Do you consider training courses on the transition from pediatric to adult care to be necessary?	- Very necessary - Moderately necessary - Not necessary
12. In your experience, do patient associations play a role in the transition process?	Yes/No
13. Do you have any additional comments or suggestions?	Free-text response

Discussion

We analyzed data on pediatric to adult transition for CPDs obtained from 51 IPRS members and pediatricians between June 2023 and July 2024. Our study aimed to assess how widespread the transition process for children with CPDs was among Italian pediatric centers and to identify the main barriers to

the implementation of structured transition pathways. Modern healthcare providers must recognize that transition is a complex, multifactorial process requiring careful evaluation of patients' characteristics (age, disease severity, comorbidities, psychosocial, and cognitive development), family factors (social support, education, coping skills), and healthcare system elements (availability of structured pathways,

Table 2. Chronic pulmonary diseases transition survey summary

Category	Details
Total responses	51 responses from IPRS (Italian Pediatric Respiratory Society) members
Regions represented	14 out of 20 Italian regions (Lazio, Puglia, Toscana, Lombardia, Friuli Venezia Giulia, Trentino-Alto Adige, Sicilia, Veneto, Campania, Emilia Romagna, Marche, Umbria, Piemonte, Liguria)
Work settings	39 in children's hospital 5 in Pediatrics outpatient clinic 5 in primary care pediatrics 7 Adult pulmonologists 2 responses included dual settings
Patient age distribution	55% <14 years of age 29.7% 14–18 years of age 20% 18–25 years of age
Transition program availability	64.7% no transition program ($n = 33$) 35.3% with a transition program ($n = 18$)
Transition program focus	77.7% Severe asthma ($n = 14$) 33.3% Primary ciliary dyskinesia/non-CF bronchiectasis ($n = 6$) 33.3% Respiratory chronic failure ($n = 6$) 22.2% Respiratory sleep disorders ($n = 4$)
Conditions less represented in transition programs	16.6% Neuromuscular diseases ($n = 3$) 11.1% Bronchopulmonary dysplasia ($n = 2$) 5.5% Congenital lung malformations ($n = 1$)
Figures involved in transition	60.7% Adult pulmonologists ($n = 31$) 84.3% Pediatricians ($n = 43$) 35.3% Physiotherapists ($n = 18$) 23.5% Nurses ($n = 12$) 17% Psychologists ($n = 9$)
Components of transition to adult care programs	25.5% outpatient visit with both specialists 19.6% personalized medical sheet 7.8% referral to primary care physicians, 58.8% no specific transition program
Presence of dedicated transition clinics	86.3% lack dedicated transition clinics
Frequency of discussing transition with patients/parents	15.7% always 35.3% often 41.2% sometimes
Preferred strategies for facilitating transition	76.5% want a dedicated CPDs transition clinic 45.1% want personalized medical sheet 37.3% want greater primary care involvement 25.5% propose prolonged care 72.5% support training courses
Importance of patient associations in transition	51% believe patient associations are important

provider skills, and education) [1]. We focused on this survey as literature shows an increasing number of CPDs patients reaching adulthood and requiring transitional care [9], yet Italian pediatric centers still lack structured pathways and dedicated specialists to support them.

Key Results and Brief Analysis

From the data analyzed in our survey, we found that the majority of surveyed physicians (64.7%) reported the absence of a structured transition pathway, and 86.3% lacked dedicated transition clinics. Only 15.7% consistently discussed transition with their patients. These findings are

consistent with reports from other European healthcare systems, suggesting that the lack of structured transition models represents a widespread challenge rather than an isolated national issue [17]. Moreover, the issue was not limited to the lack of structured transition pathways within healthcare facilities, but also extended to limited communication with patients, suggesting that the problem originated not only from the healthcare system but also from individual physicians' limited awareness and sensitivity on the subject. Looking at responses where a transition program existed, the figures involved in our sample are mainly pediatricians (84.3%), adult pneumologists (60%) and, to a lesser extent, psychologists (37.2%), physiotherapists (35%), and nurses (23.5%). These healthcare professionals participated with an important relevance still but their presence is not to be considered discretionary, as an effective transition pathway should include a multidisciplinary assessment, providing in-depth patient's evaluation [18]. This cooperation aims to ensure quality and continuity of care, promoting 2 fundamental ethical principles in modern medicine: patient empowerment and patient autonomy in disease management. Patient empowerment is the process that aims to make patients active participants in their own care, providing them with the knowledge, skills, and support necessary to effectively and independently manage their condition. Patient autonomy is the ability to make informed decisions and manage one's health with self-determination. These are not only ethical principles, since a poor and unplanned transition leads to loss at follow-up, negatively affecting clinical outcomes and healthcare costs [19, 20]. Transition can be a period of great stress and anxiety for patients with CPDs, their families, and caregivers, but mental health often receives insufficient attention during the transition process [21]. According to our data, existing transition programs especially included an outpatient visit (25.5%), and a personalized medical sheet (19.6%), so this may be a starting point to expand protocols in accordance with the collaboration of physicians already implementing transition in CPDs. The lack of a standardized process may be the crucial hurdle in establishing a widespread effective transition medicine. We also questioned physicians about which strategies they considered to be the most appropriate for organizing a transition process. They suggested that the establishment of dedicated pediatric-to-adult transition clinics and the design of personal medical sheets could be useful. In total, 72.5% of them also suggested organizing training courses for transition, which could be functional both to raise awareness among healthcare professionals, and to create spaces where we could breed ideas to develop specific transition protocols based on what patients need on a practical level [16, 22]. Otherwise, there seemed to be no

clear trend of opinion about the importance of patients' associations' role in transition, since 51% of physicians considered them important in the process. Nevertheless, we might expect that creating informative content about transition and discussing the topic with patients in advance could be a fruitful way to bring caregivers and CPDs patients themselves closer to the world of transition. This could be the first step to autonomy for some of these patients. Although we believe that the support of patient associations, particularly during the transition phase, can be beneficial in assisting families throughout this process, it may also play a crucial role in preventing them from feeling isolated during this period of change. These data could raise consciousness in the community on how important it is to improve transition pathways, and they could be the starting point for the development of dedicated protocols for patients with chronic respiratory disease who need to transition from pediatric to adult care. Our future goal was to delve into more specific geographic and social factors influencing transition in order to plan targeted interventions and to establish an effective model procedure that promotes successful transition, gathering information from existing transition clinics. After optimizing transition pathways for Italian children and adolescents with CPDs, the next step would be to evaluate the impact of transition pathways on quality of life, health outcomes, and healthcare costs of patients with CPDs.

Transition across Different CPDs

Most physicians practicing in centers where a structured transition pathway existed reported that the transition pathway was mainly dedicated to patients with severe asthma (77.7% of responses), primary ciliary dyskinesia or non-CF bronchiectasis (33.3%), and chronic respiratory failure (33.3%). These findings are consistent with the international literature, as studies on transition pathways mainly focus on the same conditions reported by our participants" [23–25]. Specifically, in our survey, severe asthma was the most frequently reported CPD requiring transition to adult care. This finding aligns with existing literature, which identifies asthma as a condition particularly vulnerable to discontinuity of care during adolescence [26]. Our data suggest that, despite the high prevalence of asthma, structured transition pathways remain inconsistently implemented. This is noteworthy given that early initiation of transition discussions and patient-centered education can improve care continuity and long-term disease control [27, 28]. The limited representation of rarer conditions in our survey responses underscores the risk that patients with less common diseases may be disproportionately

disadvantaged by the absence of standardized transition frameworks. These findings support the need for flexible transition models that can be adapted to disease complexity while maintaining a shared core structure.

System-Level Challenges and Geographical Disparities

Territorial discrepancies emerged from the survey, with several Italian regions not represented (Table 2). These gaps may reflect unequal access to structured transition programs and regional differences in health-care organization. International evidence suggests that geographical disparities can negatively affect health outcomes in chronic diseases, emphasizing the need for national strategies to ensure equitable access to transition care [29].

Another relevant challenge concerns adult care settings. Adult specialists may lack specific training in pediatric-onset chronic respiratory diseases, potentially contributing to fragmentation of care after transfer [30]. Moreover, the involvement of pediatric and adult physicians may not occur simultaneously or continuously, depending on local organizational models, the availability of structured transition pathways, and patient-related factors such as timing of referral and adherence. Consequently, during certain phases of the transition, clinical care may be provided by only one of the 2 professionals. The lack of overlapping involvement between pediatric and adult providers during these phases of transition further increases the risk of discontinuity in care.

Study Limitations

One of the limitations of this study is that out of the 20 regions in Italy, only 6 regions responded to the survey. This may be due to the absence of transition centers, a low number of patients with chronic respiratory diseases, or the exclusion of centers not affiliated with IPRS. Another major limitation was the limited involvement of adult pulmonologists, as IPRS is a pediatric scientific society. A broader, multidisciplinary approach is recommended for future studies.

Conclusion

Transitional medicine is still a challenge for the Italian healthcare system; it must mandatorily include standardized pathways to transition CPDs patients from pediatric to adult medicine to ensure continuity of care for this fragile population, which is essential for their overall health and quality of life. Pediatricians and adult pneumologists are tasked with

conversing with primary care physicians and other key medical professionals to successfully guarantee the transition from pediatric to adult care. Structures dedicated to transition need to be created or implemented, as well as specific protocols that will serve as a guide to physicians and patients. With the aim of scientific associations, we should also develop transition courses and strategies to transfer more accurately CPDs patients' information to different physicians who will take care of them, such as the creation of specific medical sheets, to make the transition process more uniform across several settings.

Statement of Ethics

This study was performed in accordance with the Declaration of Helsinki. Ethics approval for this human study was waived by Comitato etico territoriale campania 1 – approval: 25/11/2025. Parent, guardian, or next of kin consent was not required for the minors because informed consent was not required because this was a survey study; no patients were directly involved, and all data were collected anonymously. Adult participant consent was not required because Informed consent was not required because this was a survey study; no patients were directly involved, and all data were collected anonymously.

Conflict of Interest Statement

The authors have no conflicts of interest to declare.

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Author Contributions

A.A. and M.M. have designed the survey, collected patient data, performed the statistical analysis and the interpretation of data, and wrote the first draft of the paper. J.A.D., M.B., A.O., M.G.P., C.M., L.T., V.T., C.I., R.A., and P.V. collected patient data, were involved in the statistical analysis and the interpretation of data, contributed to the first draft of the paper and to review the paper. All authors have read and approved the final manuscript.

Data Availability Statement

The data that support the findings of this study are not publicly available due to privacy reasons but are available from the corresponding author upon request.

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