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ORIGINAL RESEARCH ARTICLE

The real-life experience of a general pulmonary transition clinic

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ABSTRACT

Background: Paediatric-to-adult transition represents an unmet need in many chronic conditions. Data and outcomes on pulmonary transition clinics (PTC) are limited.

Methods: We report the structure, organization, and patients' characteristics of a multidisciplinary outpatient PTC started in 2022 by two secondary level academic hospitals in Milan, Italy. Consecutive adult patients (≥18 years old) that entered the PTC from January 2022 until January 2023 and completed ≥2 follow-up visits were asked to answer a custom designed, anonymized, online questionnaire to test improvement in disease perception, self-confidence, and evaluate their experience with the clinic.

Results: Out of thirty-three patients, twenty-one completed the survey (62% males, median age 19 years). The most common diagnoses included asthma (57%) and bronchiectasis (19%). The disease control rate was optimal, only <2% of visits were unscheduled emergency visits. 100% of patients rated the presence of a dedicated service, a direct relationship with the treating physician and the possibility to improve self-management extremely useful.

Conclusions: Our questionnaire revealed that transitioning from caregiver-based disease management to patient-based disease management was perceived as more arduous. PTCs are an impactful resource for patients transitioning to adult care, but our knowledge on disease specific management strategies in transitioning patients remains limited.

Key words: pulmonary transition clinic, doctor-patient relationship, self-management, asthma, bronchiectasis

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Introduction

The incidence and prevalence of chronic conditions with onset in early life is globally rising. The proportion of hospital admissions among paediatric patients with one or more complex chronic conditions in United States reached 10.1% in 2006, increasing by 10% in ten years since 1997 [1]. Compared with patients with non-chronic conditions, paediatric patients with complex chronic conditions are at higher risk of intensive care unit admission, higher length of stay and increased mortality [2]. Globally, it has been estimated that more than 10% of adolescents live with a chronic disease that in 90% of cases will require continuing care into adulthood [3].

Since early 1990s, studies have emphasized the importance of a successful transition from paediatric to adult care to ensure long-term positive outcomes. The risks and consequences of an inadequate transition include a reduction in treatment adherence and follow-up attendance, leading to poor disease control, increased rates of unscheduled emergency visits and hospitalizations, and subsequent impaired academic performance or dropout from studies [3,4].

However, among chronic paediatric patients, rates of transfer preparedness are low; in fact, only 20% of them receive adequate services for transition to adult care [5,6].

Numerous issues related to a successful transition have been identified, which can affect patients, their families, or healthcare providers. Anxiety for the upcoming changes during adolescence (potentially different therapies in adult health care, lack of information), concerns about loss of information about the disease, and nonspecific anxieties about adult health care stand out as some of the most significant barriers recognized for the success of the transition [7].

It should also be considered that patients and parents are often accustomed to a strong relationship with their treating physicians and to the possibility of frequent or as-needed visits through direct contact and differences in how the services are accessed, organized, and managed can result in a lack of confidence in adult services. Furthermore, the adult healthcare provider may not be accustomed to interacting with and meeting the needs of young patients.

The final element to consider is that not all adolescents are the same, the transition process depends on various factors, including the specific disease and the individual attributes of each patient (maturity, cognitive abilities, psychological status, readiness for transition, disease awareness) [8].

Awareness of the importance and role of a structured and planned Health Care Transition (HCT) process has markedly increased over the years [9, 10], however, guidelines and recommendations on HCTs are lacking in most countries [10]. A Delphi consensus indicated that indicators for a successful healthcare transition include population health-related outcomes (e.g., disease-specific control indicators, hospitalization rate and medication adherence), subjective outcomes (e.g., quality of life (QoL) and patients/family satisfaction rate) and health service-related outcomes (e.g., timing of visits and regular attendance at medical appointments) [11].

To date, various transition clinic models have been proposed mainly focused on inflammatory bowel disease, diabetes, or cystic fibrosis [12-14].

Real-life data on general pulmonary transition clinics (PTC) are currently missing.

The aim of the present study was to describe the structure, organization, and patients' satisfaction after 18 months from the establishment of a general pulmonary transition clinic of our academic hospital.

Methods

In January 2022 the Division of Respiratory Diseases of the Luigi Sacco University Hospital in conjunction with the Buzzi Children's Hospital in Milan (Italy) started a PTC for young adults with complex and non-complex chronic lung diseases.

PTC structure

The PTC was developed based on a previously published model [14], including a multidisciplinary team consisting of paediatric and adult pulmonologists, paediatric and adult radiologists, rheumatologists, and thoracic surgeons.

The target population consisted of patients ≥ 18 years old with chronic diseases of the respiratory system other than cystic fibrosis, that required clinical, radiological, and functional long-term follow-up.

Before transferring the patient to the PTC, a detailed and comprehensive collegial handover was conducted, covering the clinical needs, reviewing radiological, clinical, and pharmacological histories, and addressing the outstanding issues of each patient.

The first transition visit had a flexible duration to ensure the comfort of patients and caregivers and to facilitate the necessary adjustment to the new setting. At this stage the medical history was reviewed with particular focus on previous medical treatments, medication adherence, and the patient's awareness of the importance of the previously prescribed pharmacological therapy; future treatment, clinical and behavioural goals were established using a person-centred approach, including patient's education, and coaching on disease and therapy management.

A personalized follow up plan was scheduled, according to the patient's clinical and school/work needs and direct communication with the PTC was assured by a dedicated email address.

Each follow-up visit includes clinical evaluation, therapy assessment, patient education, and coaching on disease management to enhance disease knowledge and improve self-management of therapies and disease control. Each disease was managed according to current international guidelines.

Disease control was assessed by integrating physical examination, disease-specific questionnaires (when available), secondary and tertiary level pulmonary function testing (plethysmography, nitrogen washout, exhaled nitric oxide, cardiopulmonary exercise testing, gas exchange), chest ultrasonography, need of relieve therapy. Videos and action plans were provided to improve adherence and compliance. Inhaler e-devices were used, if needed, to accurately assess proper adherence to pharmacological therapy.

Patients' satisfaction and questionnaire

Considering the assumption that transition readiness and general self-efficacy are strong predictors of increased adherence to follow-up appointments and reduced reliance on emergency visits or access to the emergency room, and that a positive care experience reduces anxiety, leading to improved disease control and quality of life [15], we created a custom-designed questionnaire based on NICE guidelines [8] and on recognized outcomes' indicators for a successful healthcare transition.

The questionnaire included the following questions:

1. *How useful do you think our PTC is?*
2. *How important do you believe it is to have an outpatient clinic that ensures continuity with the paediatric care journey you have previously undertaken?*
3. *Does it reassure you/bring you relief to know that there is a dedicated service to take care of your disease outside of the paediatric care?*
4. *How important is in your opinion the possibility of having a direct contact with the treating physicians (visits conducted consistently by the same doctors, the ability to contact them directly*

via email, scheduling appointments, addressing any doubts)?

5. *Do you believe PTC helps you in making your disease more stable/controllable, thus reducing its complications?*
6. *Do you think this service helps you in improving the self-management of your disease? Did you change any attitude toward the disease since entering the PTC?*
7. *Do you think this type of clinic can make you more responsible and confident in managing your illness even in the absence of your usual accompanying family members?*

The possible answers to the questionnaire were: *not at all, a little, moderately, extremely.*

All consecutive patients referred to the PTC from January 2022 to January 2023 that performed at least two visits, were asked to complete this custom-designed, anonymized, online questionnaire to test improvement in disease perception and self-confidence, and to evaluate their experience with the clinic.

The data were reviewed retrospectively in accordance with the principles outlined in the 2008 revision of the Declaration of Helsinki. Ethical committee approval was deemed unnecessary based on the General Authorization to Process Personal Data for Scientific Research Purposes (Authorization no. 9/2014). This authorization specifies that ethical approval is not required for retrospective archival studies employing ID codes, as these codes prevent direct identification of the individuals. The confidentiality of the information collected was maintained in compliance with the GDPR (Regulation (EU) 2016/679) and Legislative Decree No. 101/2018.

Results

Patients' characteristics

By January 2023, 33 patients have been referred to the PTC, of which 12, not yet ready for transition, underwent only advanced pathophysiology testing and were not included in the analysis.

Twenty-one patients completed the survey. The patients' characteristics are shown in Table 1.

Table 1. Patients' characteristics at pulmonary transition clinic entry. Data are presented as frequencies and prevalence.

Characteristic		**All patients N = 33**
Sex, n (%)	Male	13 (62)
	Female	8 (38)
Age group, n (%)	< 20	16 (76)
	20-22	4 (19)
	> 22	1 (5)
Smoking, n (%)	Non-smoker	15 (72)
	Active smoker	4 (19)
	Former smoker	2 (9)
Occupation, n (%)	Student	17 (81)
	Worker	3 (14)
	Unemployed	1 (5)
Disease, n (%)	Asthma	12 (57)
	Bronchiectasis	4 (19)
	Pulmonary agenesis	1 (5)
	ILNEB syndrome	1 (5)
	Restrictive disease	3 (14)

Patients were predominately male (62%) with a median (IQR) age of 19 (18-19) years.

Of the included cohort, 71% were never smokers, 81% were students, 14% were workers while only 5% were unemployed. The most common diagnose was asthma (n = 12), 67% with allergic T2-high phenotype, followed by bronchiectasis (n=4) and restrictive syndrome (n=3) including in-uterus pneumonectomy/lobectomy.

Our PTC also included patients suffering from rare diseases, including Nephrotic syndrome and Epidermolysis Bullosa (ILNEB syndrome, n=1) and pulmonary agenesis (n=1). Furthermore, 29% of patients had undergone paediatric cardio-pulmonary procedures.

Disease control

Regarding the assessment of disease control, based on specific guidelines for the management of each disease, we observed an excellent control rate. Most patients attended only scheduled follow-up visits without requiring emergency visits or therapy changes due to acute events. Only <2% of visits were

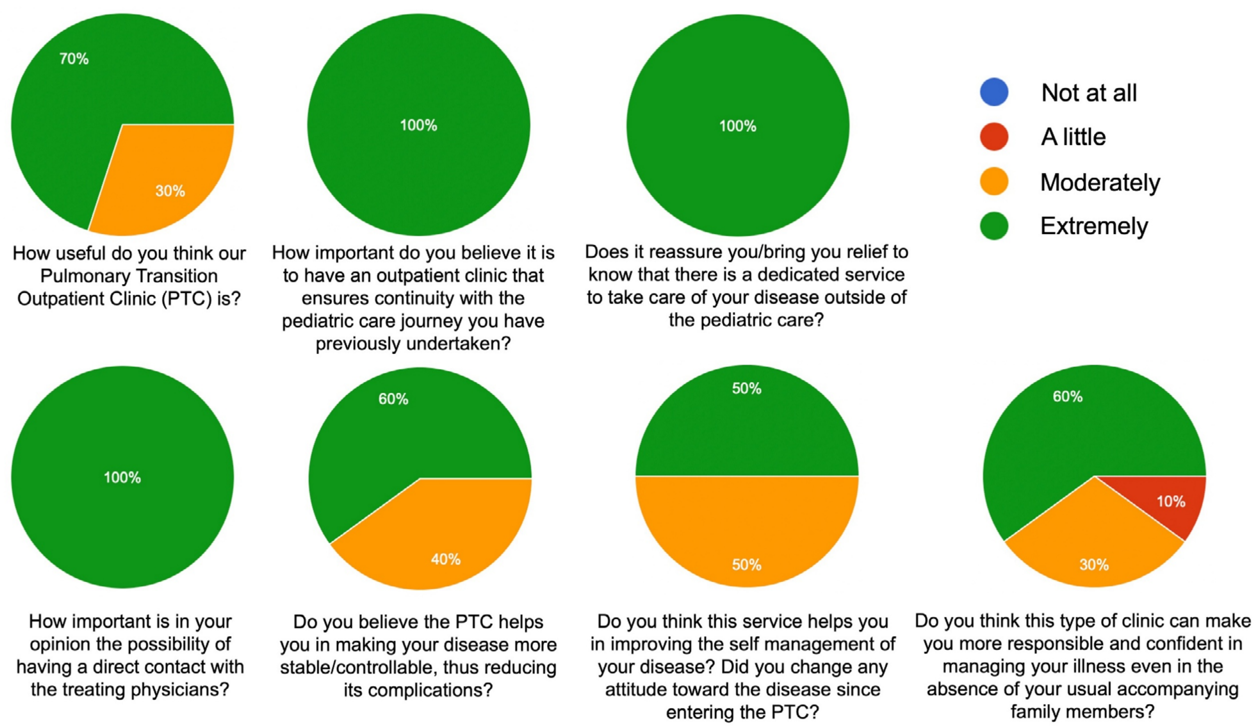

Figure 1. Results of a questionnaire assessing patient perceptions of the Pulmonary Transition Outpatient Clinic (PTC).

unscheduled emergency visits, performed due to specific patient needs or inadequate disease control.

Questionnaire results

Survey's results are reported in Figure 1. The PTC service was rated extremely useful by 70% of respondeers. The continuity from the paediatric clinic, the presence of a dedicated service and a direct relationship with the treating physician was rated extremely important by 100% of patients. The role of the PTC for disease control and the possibility to improve self-management was rated moderately to extremely important by all patients. The promotion from a parent-centred to a patient-centred management scheme was rated extremely positive by 60% of respondents, while 10% rated this possibility poorly achievable.

Discussion

This study first confirms that many patients with chronic paediatric conditions require ongoing follow-up into adulthood, as extensively documented in the literature. Additionally, it presents for the first-time real-life data from a pulmonary transition outpatient clinic.

In contrast to what is reported in the literature, our PTC does not focus exclusively on the transition process itself or on specific diseases. Instead, it addresses various respiratory conditions while simultaneously emphasizing the success of transition and disease control in this specific age group. Of peculiar interest, the PTC encompasses multiple chronic diseases of the lung and the chest wall, including, but not limited to, moderate-to severe asthma or restrictive diseases secondary to thoracic surgery or chest wall deformities.

The analysis of our *ad-hoc* questionnaire in terms of disease control rate, showed that following intervention and potential therapeutic adjustments, most patients attended visits exclusively for scheduled check-ups. Unscheduled emergency visits accounted for less than 2% of total visits, emphasizing that direct access, continuous therapy optimization, and an effective patient-provider relationship can improve clinical outcomes.

Regarding the transition process, our experience confirms the importance of an intermediate phase during which patients are guided from the paediatric care system to the adult care system.

The response obtained from the anonymous online questionnaire appear to support the alignment of our PTC's objective with those outlined in the NICE guidelines and with recognized outcomes' indicators for a successful healthcare transition [8]. 100% of the patients found important and reassuring to have the opportunity provided by our PTC to receive a care service that ensures continuity with the paediatric care journey previously undertaken. This point turns out to be crucial considering that anxiety and concern regarding disease management prove to be a factor negatively influencing short and long-term outcomes. Being consistently followed by the same team and the possibility of having a direct relationship with them also appears to be a winning factor, it allows a gradual detachment from the paediatric care system, facilitating and encouraging the progressive handling of communications by the adolescent patient, increasing their direct involvement, and gradually reducing the involvement of caregivers.

The last key element highlighted by the questionnaire administered to patients is the role our PTC plays in the process of building independence. The questionnaire results reveal that 100% of patients believe our transition outpatient clinic can assist them in becoming more self-reliant and independent in managing their illness, while 90% consider that this type of clinic can enhance their responsibility and confidence in handling both their illness and their relationship with doctors.

These outcomes are achievable through the adoption of a person-centred and developmentally appropriate model. In the person-centred approach, young patients are viewed as equal partners in the transition process, prioritizing their perspectives and needs. This model encourages young patients to make decisions autonomously and gain confidence in managing all aspects related to their disease-condition.

Hypotheses have also been formulated that transitional readiness and general self-efficacy are strong predictors of increased adherence to follow-up appointments and reduced reliance on unscheduled emergency visits or access to the emergency room. Additionally, a positive care experience reduces anxiety, leading to improved disease control and quality of life [15].

Our Transition Outpatient Clinic still faces some limitations, largely attributable to its relatively short history of operation. The first limitation is the small patient sample currently available, and the second is the lack of long-term success data since we haven't had patients reaching the transfer stage yet. These limitations will undoubtedly be overcome as our PTC gains more operational experience.

As the first pneumological Transition Outpatient Clinic, another noteworthy aspect we plan to delve into in the future is the management and control rate of specific lung diseases in this age group. Additionally, a promising avenue for future development, as our interaction with the paediatric care system solidifies, is the gradual advancement of patient care initiation, aiming to achieve transfer before the age of 20. Notably, one of the main areas of potential improvement is also represented by the lack of allied healthcare professionals within the current PTC structure. These figures have already proven their pivotal role in the management of CF and non-CF bronchiectasis, or in patients with genetic disorders and neuromuscular diseases [10]. Indeed, implementing the clinic structure with the support of physiotherapists, trained nurses, dietitians, psychologists, and a counselling service dedicated to sexual and reproductive health, represents a bundle of crucial future steps when seeking optimized and integrated care in a respiratory transition service.

Conclusions

In conclusion, this is the first report to present real-life evidence of the structure and patients' perspective of a general PTC in Italy. PTCs still represent an unmet need in pulmonary medicine. Our knowledge on disease specific treatment plans, different educational interventions, and management strategies in transitioning patients is still limited. The impact of PTCs goes beyond the management of the disease, affecting healthcare and public resources. Reference centers should be aware of the value of PTCs and improve access to transition in pediatric patients with chronic respiratory diseases.

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