

Transition from paediatric to adult health care in Poland – current problems and future challenges. Analysis of issues faced by patients with inborn errors of immunity

System przekazywania pacjentów przewlekle chorych z opieki pediatrycznej do opieki dla dorosłych w Polsce – aktualne problemy i przyszłe wyzwania. Analiza problemów pacjentów z wrodzonymi błędami odporności

¹ Department of Paediatrics, Paediatric Nephrology and Allergology, Military Institute of Medicine – National Research Institute, Warsaw, Poland

² Department of Internal Medicine, Pneumology and Allergology, Military Institute of Medicine – National Research Institute, Warsaw, Poland

Correspondence: Agata Będzichowska, Department of Paediatrics, Paediatric Nephrology and Allergology, Military Institute of Medicine – National Research Institute, Szaserów, 04-141 Warsaw, Poland, e-mail: abedzichowska@wim.mil.pl

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ORCID iDs

1. Agata Będzichowska <https://orcid.org/0000-0002-1756-7316>

2. Ewa Więsik-Szewczyk <https://orcid.org/0000-0001-8509-4453>

Abstract

The health care system in Poland provides treatment for patients up to 18 years of age in paediatric health care facilities, whereas adult patients are treated in specialist health care facilities for adults. A critical moment for the continuity of permanent treatment for all people with chronic disease is the transition from paediatric care to adult care. Organisational, psychological, and social problems can disrupt this process, posing the risk of health deterioration, and in extreme cases, discontinuation of therapy and premature mortality among young adults. In Poland, there is no universal, coordinated, efficient, and successful model for patient transition. This article highlights potential factors contributing to the lack of fluidity in the transition process and the associated risks. Examples of models ensuring optimal transition of a paediatric patient to adult care are also presented. It seems that creating systematic, uniform patient transfer programmes is the only way to eliminate potential threats. The crucial elements in this process are postulated to include: 1) advance planning of the transition process, 2) efficient transfer of information about the patient's condition and treatment between paediatric and adult centres, 3) patient awareness of their new role in the decision-making process. The article focus on patients with inborn errors of immunity, highlighting the current experience and potential reasons for failures in the patient transition process.

Keywords: transition, adolescent health care, chronic health conditions, disabilities, inborn errors of immunity

Streszczenie

System organizacji opieki zdrowotnej w Polsce zakłada leczenie pacjentów do 18. roku życia w poradniach pediatrycznych, a pacjentów pełnoletnich w poradniach specjalistycznych dla dorosłych. Momentem krytycznym dla ciągłości leczenia osób przewlekle chorych jest moment przejścia spod opieki pediatry pod opiekę lekarza specjalisty leczącego chorych dorosłych. Czynniki organizacyjne, psychologiczne i społeczne sprawiają, że proces ten nie zawsze przebiega płynnie, niosąc za sobą ryzyko pogorszenia stanu zdrowia, a w skrajnych przypadkach – zaprzestania terapii i przedwczesnej umieralności młodych dorosłych. W Polsce praktycznie nie istnieją programy efektywnego, skoordynowanego przekazywania pacjentów. W artykule zwrócono uwagę na potencjalne przyczyny powodujące brak płynności procesu przekazywania oraz zagrożenia z tym związane. Przedstawiono również przykładowe modele optymalnego przejścia pacjenta pediatrycznego do poradni dla dorosłych. Wydaje się, że tylko stworzenie usystematyzowanych, jednolitych dla danej specjalności programów przekazywania pacjentów daje szansę na wyeliminowanie potencjalnych zagrożeń. Za kluczowe elementy w tym procesie można uznać: 1) planowanie z wyprzedzeniem procesu przekazania pacjenta, 2) przepływ informacji o chorobie pacjenta i dotychczasowym leczeniu między ośrodkami, 3) świadomość pacjenta o jego nowej roli w procesie podejmowania decyzji. W artykule szczegółowo opisano także problemy pacjentów z wrodzonymi błędami odporności, zwracając uwagę na obecne

doświadczenia i potencjalne przyczyny niepowodzeń w procesie ich przekazywania z ośrodków pediatrycznych pod opiekę poradni immunologicznych dla dorosłych.

Słowa kluczowe: proces przekazania, opieka przejściowa, choroby przewlekłe, niepełnosprawność, wrodzone błędy odporności

INTRODUCTION

One of the common definitions of a chronic disease is: a chronic health-related condition that has one or more of the following characteristics: it is long-term or permanent; it leaves a residual disability; its causes, natural course, and treatment are ambiguous; it is degenerative; it requires special training of the patient for rehabilitation; and it requires long-term supervision⁽¹⁾.

Advances in medical care over the past few decades have significantly extended the lives of children with chronic diseases and disabilities. According to Statistics Poland, children with chronic diseases currently make up approximately 30% of the total paediatric population in Poland⁽²⁾.

Adolescents and young adults (AYA) with chronic diseases represent a group of patients that poses a particular challenge to the health care system. The term refers to patients up to 25–30 years of age. A critical moment of their treatment is the transition from paediatric care to adult treatment centres. The process takes place during a period which is crucial for personality development of young individuals^(3,4).

The Society for Adolescent Health and Medicine defines “transition” as purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health care systems. The process should address the medical, psychosocial, and educational needs of adolescents with chronic diseases. It might be universal across all branches of medicine, regardless of the type, duration, and severity of the condition. The transition involves not only the patient but also their legal guardians. Potential barriers to successful transition may be related to the patient, their family, and the health care system institutions⁽⁵⁾. An ideal transition model should ensure full cooperation between paediatric and adult treatment centres in the transfer of medical information about the patient condition and treatment. It should also focus on the medical education and psychological support of patients⁽³⁾. Most key elements of transitional care are universal.

In Poland there is no single universal, coordinated, efficient, and successful model for patient transition⁽³⁾. In this review, we would like to raise awareness and promote importance of transition care, with a focus on inborn errors of immunity (IEs).

POTENTIAL BARRIERS TO SUCCESSFUL TRANSITION FROM PAEDIATRIC TO ADULT-ORIENTED HEALTHCARE SYSTEMS

Adolescence is a time when important biological, psychological, and social changes take place in human life^(3,6). This

period involves making important life decisions, such as starting a family, choosing further education or a career path. It is also a critical period for shaping young people’s personality. Adolescents with chronic diseases and disabilities also face other challenges. Their defects or limitations may cause them additional anxiety and uncertainty. These can also lead to depression, low self-esteem, and difficulties in interpersonal contacts^(3,7–11).

In addition, studies on brain development during adolescence have shown that between adolescence and early adulthood people may, for structural reasons, not be able to fully understand the nature of their disease and predict its consequences. This explains why adolescents can be irrational about their health and treatment⁽⁶⁾. A possible consequence is noncompliance with therapeutic recommendations. Another difficulty in caring for adolescent patients is the “hormonal storm” causing mood swings and communication problems. While paediatricians are used to considering these natural aspects of the maturation process, this is not so obvious in adult healthcare settings. Therefore, many adult-oriented specialists may perceive adolescents as difficult, uncooperative, and defiant patients. This attitude discourages doctors from engaging with teenage and young adult patients. On the other hand, these behaviours also intensify the sense of loss and fear of the unknown experienced by a chronically ill patient during the transition to adult care^(3,7).

The transition also involves a modification of approach to the patient from a care-based model to one that emphasises patient autonomy. A patient aged 18 has certain habits acquired during paediatric care. Appointments in children’s outpatient clinics usually take place without long waits, and the staff try to make every diagnostic and therapeutic procedure as easy, pleasant, and painless as possible. However, in internal medicine care, it becomes a daily reality that patients must wait, make decisions on their own, and receive less personalised attention from the staff. This can cause discouragement, frustration, and even discontinuation of treatment⁽⁴⁾.

The role of the patient’s parents and caregivers in the transition process should be also discussed and emphasised. When the patient reaches the age of majority, the guardian should accept their full autonomy in making decisions. However, support and help from the family are crucial and indispensable for adjustment to the new situation. However, in many cases, overprotectiveness from parents is observed. Parents, fearing the loss of control over their child, often do not want to give them an opportunity to make independent decisions^(4,5).

Factors contributing to difficulties in transition	
Patient-dependent factors	<ul style="list-style-type: none"> • Complex medical conditions • Terminal phase of chronic diseases • Lack of personal responsibility for health • Lack of personal support systems • Lack of trust in adult care providers
Family-dependent factors	<ul style="list-style-type: none"> • Over-protectiveness • Intrusive parenthood • Fear of loss of control • Emotional dependency on child • Lack of trust in adult care providers • Financial benefits for parents due to the diagnosis of their child's chronic disease
Paediatric centre-dependent factors	<ul style="list-style-type: none"> • Ambivalence about transition event • Emotional bonds with patient/family • Expertise in underlying disease • Lack of trust in adult care provider
Adult centre-dependent factors	<ul style="list-style-type: none"> • Insufficient knowledge and experience with transitional care and underlying conditions • No existing emotional bond with patient/family • Burden of assuming care for unfamiliar, occasionally complex patients
Healthcare system-dependent factors	<ul style="list-style-type: none"> • Lack of referral networks linking paediatric and adult providers • No systematic training opportunities in transitional care • Discontinuous health insurance coverage from paediatric to adult programmes • Lack of robust quality indicators • Lack of data for optimal cost-effective strategies

Tab. 1. Potential obstacles to successful transition from paediatric to adult-oriented health care systems (based on⁽⁵⁾)

The problems related to the lack of systemic legal regulations for the process of patient transfer in Poland are equally important. The current health care system has not created uniform protocols for the transition process yet. There is no single, consistent model of patient transition in Poland. Such a model should ensure full cooperation between paediatric and adult health care centres in the field of medical information transfer, patient education, fostering self-awareness of their condition. It should also include psychological support for the whole family^(3,4).

Different medical centres dealing with various chronic diseases are trying to regulate the issues associated with transferring patients who reach the age of majority on an individual basis. However, the lack of shared protocols and experience generates several unintended oversights resulting in the deterioration of chronic disease control. Another difficulty in maintaining the continuity of medical care in Poland is the significant disparity in therapeutic protocols and drug programmes for paediatric and adult patients^(4,6,12-14).

Potential difficulties associated with the process of patient transition from paediatric to adult health care are summarised in Tab. 1⁽⁵⁾.

RECOMMENDATIONS

Universal consensus of the European Academy of Paediatrics

Understanding the complexity of the problem, the Adolescent Health and Medicine Working Group of the European Academy of Paediatrics (EAP) has developed a consensus that highlights the most important elements ensuring an optimal patient transition⁽³⁾.

Planning

The transition process should start as early as possible. It is the paediatrician's responsibility to prepare the whole family for the transition. The timing of the transition should be individualised. Active participation of young people and their parents or guardians in the transition process should be encouraged. It is recommended to create a transition plan as early as possible, ideally before the 14 or at least one year prior to the actual transfer. Each time, the degree to which the patient has acquired the ability to make independent decisions should be considered. The patient's expectations regarding their continued treatment are no less important^(3,15-20).

An important aspect in the care of adolescents with chronic diseases is adequate staff sensitisation to their specific needs. It should be remembered that these patients face problems that extend beyond treating their condition. These include, for example, issues related to contraception and prevention of sexually transmitted infections, the use of legal and illegal psychoactive substances, nutritional concerns, practicing sports adapted to their health, and career counselling⁽²¹⁾. Moreover, mental disorders, especially anxiety, depression, and psychosomatic symptoms, are common comorbidities in adolescents^(7,8). It is important that these problems are dealt with by an interdisciplinary team, which should include doctors, nurses, social workers, educational therapists, and psychologists^(3,7,8,15).

Uniform guidelines and consistent transparent documentation

Uniform protocols ensure continuity of care and prevent errors. Clearly defined procedures give both doctors and patients a sense of security. It is also essential to prepare a written, up-to-date summary of medical records in advance, including key elements such as diagnosis, treatment history, and therapeutic options. Follow-up assessments

should also be carried out to allow healthcare professionals to assess the success of transition, and to track and assist patients dropping out of the healthcare system⁽³⁾.

Financing

People with chronic diseases should have uninterrupted access to services funded from the public healthcare budget⁽³⁾.

Transition protocols models

Over the past few years, several concepts for the optimal transition of paediatric patients to the care of specialists for adult patients have been developed. Among them, the following can be distinguished.

Direct transition model

This model involves the independent transfer of young patients with chronic diseases to adult health care services. Due to the lack of systemic control, this model poses some dangers, such as discontinuation of specialist care resulting in discontinuation of treatment, deterioration of health, and even premature mortality. In addition, there is the aspect of long waiting list and delays for the first visit to specialist clinics in Poland. To improve this model, a uniform transition summary card could be developed, containing information about the current treatment, recommendations for its continuation, and contact details of the current health care centre. Such medical information cards are already successfully used, for example, in diabetology⁽⁴⁾.

Model of joint adolescence medicine department/centre

It is a healthcare system enabling a smooth transition of patients from paediatric centres to an adult health care facilities, based on the functioning of the ward for adolescents, where treatment is carried out under the supervision of both a paediatrician and an internist. Such centres could operate in the form of an outpatient clinic or mini-clinic, where young people aged 16–22 would be gradually introduced to the adult care system. The optimal solution would involve a cooperating team of specialists from various fields, including paediatricians, internists, psychologists, social workers, and nurses. This model is commonly used in Great Britain⁽⁴⁾.

Sequential transition model

The model of gradual (evolutionary) transition takes into account the level of emotional development of young people. Its assumption is based on an individualised approach ensuring the transition of young people at the most optimal time. Depending on the country in Europe, this process typically occurs between the ages of 14 and 22⁽⁴⁾.

Consultation transition model

This health care system assumes that from the age of 16, a paediatric patient will consult with a doctor from the centre at least 4 times a year. The physician will continue

the patient's treatment after the age of 18. This transition model ensures the continuation of treatment and the transfer of information about the patient while reducing the patient's discomfort related to the new situation. This model is widely practiced in Sweden and in the Netherlands⁽⁴⁾.

The disadvantages of the last three models include increased direct medical care costs and the need to reorganise the logistics of health care⁽⁴⁾.

Characteristics of transition difficulties depending on the type of chronic disease

Oncology and haematology

Considering the clinical course and specific treatment requirements of childhood cancers, efforts are being made to extend the care of adolescents and young adults in paediatric units. Usually, the National Health Fund agrees to continue the treatment of patients beyond the age of 18 in paediatric centres. However, such extensions always require individual arrangements between the payer and the service provider⁽⁴⁾.

In an analysis conducted among paediatric oncology and haematology centres, only five out of 17 centres reported the commencement of the procedure of transition after completed oncological treatment to adult care within six months to a year before the planned final transition. In other centres, the process is more of a direct transfer rather than a gradual transition after the patient reaches adulthood. In 41% of centres, convalescents are referred for further care by a specialist if complications are likely, and in 59% only if complications were found during the treatment. Eleven out of 17 health care facilities declare the follow-up of convalescents after they have been transferred to adult care. Five centres organise regular meetings with adult convalescents⁽²²⁾.

Diabetology

The Polish Diabetes Society has prepared recommendations for the transition of patients with type 1 diabetes and has created an information card for paediatric diabetes care⁽²³⁾. Nevertheless, according to some studies, 20–25% of patients may abandon specialist care within 2–4 years of the end of treatment in their paediatric centre. It is also estimated that 11–24% of adolescents with type 1 diabetes fail to be managed in the adult health care system. Following their transition to adult health care facilities, young diabetics tend to have higher haemoglobin A1C levels, are more frequently hospitalised, and face more complications and comorbidities. Long-term clinical follow-up of young type 1 diabetic patients shows higher rates of obesity, smoking, and alcohol use within eight years post-transition. During this period, almost 20% of patients developed retinopathy or nephropathy^(12,13).

Rheumatology

Juvenile idiopathic arthritis and other rare juvenile-onset rheumatic and musculoskeletal diseases present in several clinical forms. A certain percentage of patients experience

persistent disease activity into adulthood. Juvenile forms of the disease often turn into chronic arthritis, which falls under adult rheumatology. However, some of the undifferentiated forms remain undifferentiated. In Poland, the lack of officially accepted protocols for transferring paediatric patients to adult rheumatology centres means that each centre has developed its own procedures. The biggest problem seems to be the lack of continuity of treatment programmes used in children and adults. Strict restrictions concerning drug therapies for arthritis in adults make it difficult to continue treatment after reaching adulthood⁽¹⁴⁾.

In 2017, the European League Against Rheumatism (EULAR) developed standards and recommendations for transitional care for young people (YP) with juvenile-onset rheumatic and musculoskeletal diseases. The experts stratified the recommendations into “essential” and “ideal” components, with “essential” defined as the minimum standards below which care would be deemed unacceptable⁽²⁴⁾. The essential components include having a coordinator who can appropriately assist with transition issues; as a minimum, there should be at least two “direct” contacts (by telephone or e-mail) between the paediatric and adult rheumatology team (and documented in written communication); one before and one after the transfer. The existence of a transitional care process should be documented in medical records. As a minimum, a transition policy must be established, with documents should be updated at least every five years. The transfer document should include, as a minimum, a medical summary with the diagnosis, comorbidities, vaccinations, any complications of the disease or treatments, professionals involved in care, and current and previous treatments (with reasons for changing treatments and any adverse events). The team engaged in transition should receive training on adolescent health and the process of transition⁽²⁴⁾. It is essential that funding for biological and other therapies should continue if clinically indicated, irrespective of patient age and transfer to adult care.

Clinical immunology

Childhood clinical immunology focuses on IEs, previously known as primary immunodeficiencies (PID). As medicine advances, patients with IEs who previously died in childhood are now reaching adulthood. Inborn errors of immunity are rare and ultrarare diseases, and the care of these patients must be managed in tertiary referral centres. These patients, due to the specificity of their disease, the wide range of possible complications, and numerous comorbidities, often require long-life extensive multidisciplinary care. The heterogeneity in the clinical course of these diseases makes it very difficult to create a uniform protocol for care and follow-up. On the other hand, the lack of an established transitional programme results in the loss of some patients from follow-up, which may lead to higher rates of non-compliance, lack of continuity in immunoglobulin replacement therapy, inadequate anti-infection prophylaxis in combined immune deficiencies, and hesitancy regarding

prophylactic vaccinations, ultimately leading to increased hospitalisation rates, morbidity, and mortality⁽²⁵⁾.

Based on the literature and our own experience, we propose highlighting certain clinical scenarios/categories that clinicians encounter during the transition process. Two main categories regarding transition in IEs were proposed in 2016⁽²⁶⁾. The first category includes AYA with diagnosed lifelong conditions that require long-term medical treatment. The majority of them are patients with various forms of primary antibody deficiency who require lifelong immunoglobulin replacement therapy (IgRT). Over the last past decade in Poland, reimbursements for IgRT become available and are now covered by national health care, including home therapy for adults as well as children. The introduction of a special drug programme for adult patients in 2014 was an achievement of the clinical immunologist community in Poland and opened the way for home IgRT for adults with documented success⁽²⁷⁾. However, adult centres are obliged to verify the inclusion criteria for long-term IgRT as patients transition to adulthood. The process of transition at this point is not structured but mainly based on informal, personal cooperation between the paediatric and adult medical teams.

The second category of AYA in clinical immunology includes patients who have undergone allogeneic haematopoietic cell transplantation (HCT)⁽²⁶⁾. It is recommended that these individuals are provided with long-term monitoring. Some are fully immune reconstituted and lead normal, healthy lives, requiring only annual check-ups and routine blood tests. Others remain on long-term IgRT. However, a significant number in this group have ongoing medical and/or psychological issues. Patients report significantly greater impairments in their work, home, and social life due to health reasons – everyday problems which have to be addressed⁽²⁸⁾. In adult centres, we expect a growing number of patients who have undergone HCT due to IEI and will face medical issues that extend significantly beyond IgRT. A recently published detailed assessment of very long-term outcomes in adulthood have revealed that 30% of these patients experience ongoing complications⁽²⁹⁾. Medical complications include infections, chronic graft-versus-host disease (GvHD), and late-onset autoimmune complications. Sometimes infections are specific; for example, all patients with gamma chain or JAK3 SCID developed warts at a median of 15.7 years post-HCT (range: 8–20 years) which have proven refractory to topical treatments and surgical intervention. Three patients (4%) of the analysed group developed late-onset moderate/severe renal or hepatic sequelae (chronic kidney disease and liver failure)⁽²⁹⁾. Two patients from this cohort died⁽²⁹⁾.

In our adult centre, we also identify a third group of AYA with IEs: those patients who, because of their diagnosis, are currently recommended to be treated by HCT, but who did not undergo the procedure during childhood. The reasons might be delayed final genetic diagnosis, progress and changes in recommendations, and previous parental lack of

consent for treatment. Qualifying these patients for HCT is a challenge and raises many clinical dilemmas⁽³⁰⁾.

The fourth scenario involves adolescents with unspecified conditions who were followed in paediatric centres but remained undiagnosed. It seems reasonable that they should not leave the paediatric facility without thorough updates and diagnostic reevaluations⁽²⁵⁾.

A unique subgroup are AYA with monogenic autoinflammatory diseases (AID). In Poland, care for this group is managed by paediatric and adult clinical immunologists. Due to the rarity of these conditions and the limited number of referral centres, the transfer process is smooth, although it is mainly based on personal communication between specialists. The National Health Care in Poland supports continuous treatment with anakinra, an interleukin-1 blocker, for patients referred from paediatric to adult care. In 2020, the Italian Primary Immunodeficiency Network centres prepared recommendations for the transition of patients with IEs from paediatric to adult health care services. Consensus was achieved based on the Delphi methodology⁽²⁵⁾. The authors presented general principles of care and underscored the importance of reproductive genetic counselling, which should begin in adolescence. While experts raised the question of contraindications for transition, no consensus was achieved in this field, and the topic should be further explored. Beyond overarching principles applicable to AYA with IEs, the authors identified six categories that group patients based on shared medical issues in the transition phase⁽²⁵⁾. These are: (1) humoral defects, (2) DiGeorge syndrome spectrum diseases, (3) combined immune deficiencies, (4) innate immunity defects, (5) inborn errors with malignancy and DNA-repair defects, and (6) patients with severe forms of IEs after HCT or gene therapy. For each group, the authors identified special aspects which should be covered during the transition of care.

A survey of current practices and transition pathways in IEs and AIDs was published in 2023; however, only two centres from Poland were approached, and only one responded⁽³¹⁾. The results showed that the transition process in the majority of centres involved 10 or fewer patients per year (in 91% of AID centres and 75% of PID centres),

which illustrates the rarity of these diseases. The process was based on schedules created by cooperating referral centres (75% of centres), given the lack of formal national recommendations (86% responders from PID centres). The common practice is to hold at least one joint appointment involving paediatric and adult services prior to the transfer of care, incorporating physicians, nurses, psychologists, and specialists from other medical teams. Full integration of records across paediatric and adult services was available in over 70% of centres; unfortunately, this is not the case in Poland. Lack of time to prepare the documents and/or inadequate funding are among the main reported obstacles to a smooth transition pointed out by responders.

CONCLUSIONS

The transition of patients with chronic diseases from paediatric to adult health care systems is a difficult and multifactorial process. It is essential to address the expectations and psychological needs of both patients and their families throughout this transition. Current experiences show significant challenges in creating transition programmes for IEs worldwide. IEs are rare and heterogenous in their course, and they often need multidisciplinary care. Our goal for the future is to establish realistic recommendations addressing the needs of medical staff and patients for optimal transition in these unique conditions. In our opinion, it is important to assess real-world practices in transition care in IEs in Poland, identifying the number of patients who are transferred, the expectations of adult centres, and the obstacles faced by teams in both paediatric and adult services.

Conflict of interest

The authors do not report any financial or personal connections with other persons or organisations which might negatively affect the content of this publication and/or claim authorship rights to this publication.

Author contribution

Original concept of study; critical review of manuscript; final approval of manuscript: EWS. Collection, recording and/or compilation of data; analysis and interpretation of data; writing of manuscript: AB.

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