

The value of the health care transition in the treatment of patients with rare diseases - highlights for clinicians

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Abstract

Advances in medical science, the development of diagnostics and modern treatments have contributed to prolonging the survival of patients with chronic diseases and/or disabilities. The adolescence stage is a crucial period in everyone's life and, in the case of patients with disabilities, it is also a challenging period. It is at this stage that social problems or difficulties associated with adolescence become apparent. A change in the form of healthcare provision also takes place at this stage. A properly planned process affects not only the patients' health needs, but also their social development. The transition of adolescents with chronic diseases and/or disabilities from paediatric to dedicated adult care is a complex process that requires appropriate coordination to ensure continuity of highly specialised healthcare. The quality of the transition process depends on the commitment of physicians, but also of patients and their caregivers. Despite the medical community's awareness of the benefits of a properly organised transition process, there is still a lack of standardised recommendations and standards for this process. Few adolescents with chronic diseases receive any support during this period. Understanding the challenges of the transition process is key to providing holistic care for patients and their caregivers. This article searches the available literature on the topic of transition to present current knowledge in this area. Barriers and challenges to the transition process are identified, but also the steps of a properly structured transition process from paediatric to adult care, as proposed by *GotTransition*, are presented.

Purpose

The purpose of this article was to indicate the legitimacy of organizing an effective and caring process of transferring patients with special health problems, as well as to

present the model and related elements that could be an inspiration in facilitating the transition process in Poland.

Introduction

The progress in medical sciences, growing number of clinical trials, and increasingly easier access to modern technologies and innovative drug therapy have significantly influenced the issue of life expectancy in patients with special medical issues. The problems faced by teenagers and young adults who suffer from chronic diseases or disabilities are more and more often becoming the subjects of research in the field of medical sciences. With the development of diagnostic techniques and the modernisation of the treatment process, the lives of numerous patients who require access to multi-specialty health care and individual care for their whole lives have become subject to increasing scrutiny.^[1] Currently, as over 85% of children with chronic diseases, including genetic diseases, reach adult age, the moment of transition from paediatric care to healthcare dedicated to adults seems to become a major challenge among multiple aspects of medical care.^[2]

The responsibility for the care of a teenage patient after he or she becomes an adult is transferred from the paediatric clinic to adult healthcare. However, many patients still remain in the care of paediatric facilities, although they have already turned 18. So far, the healthcare system has not provided a realistic healthcare path for those who suffer e.g., from microsomia or intellectual disability, for whom the stay at ambulatory or hospital facilities involves severe stress, but also difficulties in access to medical equipment (e.g., for densitometry, gastroscopy or spirometry) at internal medicine units for adult patients who have the anthropometric parameters of a child.

An increasing number of young adults are faced with problems, barriers, and multiple issues concerning transitional care. Most young people do not have sufficient access to services and supporting measures in the transition period. An example may be the patients who have been diagnosed with metabolic disorders, such as *phenylketonuria* (PKU). At most healthcare facilities, persons with this diagnosis are treated at paediatric centres, while special emphasis is put on the specialist care dedicated to those patients due to the specificity of their disorder (including reproductive aspects that may be significant for their children).^[3] In Poland, a consensus was finally reached, so that adult patients with this disorder are treated by physicians who specialise in metabolic paediatric medicine, in cooperation with gynaecologists and internal medicine specialists.

Many diseases that used to be considered to be childhood diseases, e.g. cystic fibrosis and some life-threatening metabolic disorders should now be treated as disorders that start in childhood and then continue in adult life.^[4] The extended survival period of this group of patients even more strongly emphasises the legitimacy of organising an effective and care-oriented process of transition. At the same time, it is one of the main challenges faced by the healthcare system in the upcoming century.^[5]

The importance of the transition process

Already as early as 30 years ago, scientists were aware of the existence of the problem of transition from paediatric to adult healthcare. The transition process was first mentioned in a study by Robert Blum in 1993^[6], where transition was defined as a purposeful, planned movement of teenagers and young adults with chronic medical and physical diseases from the system of healthcare that focuses on children to the healthcare system that is dedicated to adults. This definition remains valid today, and it is currently promoted by the *American Society for Adolescent Medicine*.^[7] According to this study, transition is a complex process that requires the involvement, skills, and coordination of multiple parties, including the patients, their families, physicians and healthcare decision makers, in order to function properly.

Specialists from numerous countries see the need to create specialist facilities for adult patients with special health-related needs and emphasise the importance of the coordination of the process of transition from paediatric healthcare to healthcare dedicated to adults.^[3] However, a review of the relevant research demonstrates that the issues related to the transition from paediatric to adult healthcare are somewhat of a niche category in the healthcare policies of various states. At the same time, although there are only a few healthcare documents available that touch upon the *transition* issue, there is still insufficient empirical evidence that would allow us to implement tested, realistic principles in clinical practice, including in Poland.^[8,9] Currently, most states do not use any guidelines that would describe a correctly planned process of transition of patients from paediatric to adult healthcare, which means that such processes should be developed in the future.

The main aim of a well-planned transition process is to ensure the continuity of multi-specialty care over patients with chronic diseases, as well as to offer them a chance to obtain more independence and autonomy in adult life.^[10] This process involves certain risks, as the stage of tran-

sition from paediatric care to healthcare that focuses on adults is a period of increased risk of deterioration of the health outcomes of the patients and of lower satisfaction with the received specialist care, as well as the risks connected to the potential deterioration of the quality of life of patients. Sometimes, young adults, after leaving their homes and taking over full responsibility for their treatment, tend to avoid doctors and do not make prophylactic or follow-up appointments. Literature reveals that the rate of patients who fall out of specialist care after the transition from paediatric to internal medicine facilities is high. For example, for Congenital Adrenal Hyperplasia (CAH), it is as many as 50% of patients^[10], and for the Turner syndrome 30% of adult patients.^[11] Those young people often contact specialists again in cases of emergency or crisis that might not have occurred if they had maintained regular contact and the appropriate prophylactic measures.

Lack of transformation process and its consequences

Currently, neither Poland nor multiple other countries offer a developed medical care dedicated to adults who suffer from rare diseases.^[8,13] Patients from this group are currently “transferred” to adult healthcare without any special preparation or coordination or, on the contrary, they remain in the care of paediatricians although they have reached adult age. The presented solutions generate numerous difficulties. A specialist who takes over a patient with a rare disease does not have access to information about previous treatment, which complicates the chances for the implementation of adequate therapy in potential emergency and health/life-threatening situations, due to the lack of knowledge about the given patient.^[14] In the second situation, i.e. if the patient remains in paediatric healthcare, the arising difficulties result from different methods of treatment depending on age (e.g. in cases of hypertension). The absence of a coordinated healthcare system based on the transition of patients from paediatric care to adult facilities may have a significant influence on both the efficiency of the treatment process and on the quality of life of those patients. This means that it is justified to explore the subject of *transition* while at the same time emphasising its importance for patients with rare diseases and their families.^[15-17]

The transition from paediatric healthcare to healthcare dedicated to adults is an event that may determine the further appropriate functioning of patients, so the correct management of the transition process should become

a fundamental element of the so-called good practices in medicine. Ideally, the goal of the discussed transition process is to provide continuous, coordinated healthcare that will be appropriately and comprehensively organised in both its formal and social aspects.^[18]

Basic principles of transition

In the last 20 years, numerous policy documents aimed at improving transitional care have been published, mainly in the UK, Germany, the USA, and Australia.^[19] One of the more popular guidelines concerning transitional care are the guidelines proposed by the American Academy of Pediatrics, developed by a professional association of doctors and focusing on the strategies of transition between different forms of healthcare.^[20] Even though many countries have expressed their desire to attempt to solve the problems related to *transition*, only the UK and Australia published documents that provided a detailed description of the transition strategies supported, additionally, by the given state.

The concepts of the fundamental principles of the transition system are usually consistent in all policy areas presented by various states. All of them emphasise the difficulties with which healthcare workers are confronted, and some of them provide practical guidelines on the organisation of the process of preparing the care over patients in the period of transition from paediatric to adult healthcare and point out the importance of the involvement of children, their parents, and doctors in this process. Unfortunately, the developed guidelines are often insufficient to lead to significant changes, and they remain in the theoretical sphere, without being applied in clinical practice. Although the needs related to the transition process are relatively well described, the most important link, i.e., the recipe stating “how to do it” is still missing. The medical database contains documents that describe what a correctly planned *transition* process should look like.^[8, 9] The structure of the process is described, among others, in the guidelines of NICE of 2016^[21], American Academy of Pediatrics^[22], Canadian Association of Paediatric Health Centres^[23] or by the *Got Transition* center.^[24]

Got Transition Centre

The description of a perfectly structured transition process should start with the *Got Transition* center and the *Six Core Elements*.^[24, 25] *Got Transition* is a national centre that conducts research on *health care transition* (HCT). The center is financed by the federal government, and its aim is to

improve the process of transition from paediatric to adult healthcare by means of using evidence-based strategies for the stakeholders of the healthcare system, including the doctors, the funder of the healthcare, and the patients and their parents or legal guardians.

Got Transition developed the *Six Core Elements* approach, which is also referenced in the guidelines of the *American Academy of Pediatrics 2018*, the *American Academy of Family Physicians*, and the *American College of Physicians*. The six elements refer to the main components of a correctly structured transition process. Moreover, the center has developed tools dedicated to each of the individual elements, which may be helpful in making the whole process more efficient. The elements proposed by *Got Transition* cover three main sections: planning, transition, and integration of care. As with any other solution, this also has its main objectives. These include:

1. Improving the ability of adolescents and young adults with special healthcare needs to manage their own healthcare and use the healthcare services efficiently.
2. Ensuring an organised process in the paediatric and internal medicine healthcare systems in order to facilitate the transition and transfer of care.

The *Six Core Elements* from *Got Transition* represent a structured approach to healthcare transition for adolescents and young adults with special healthcare needs including patients with rare diseases also. These elements have gained recognition and support for being a best practise in healthcare transition due to several reasons which include:

- Evidence-Based approach: The Six Core Elements are based on research. It provides a structured frameworks that ensures a comprehensive and evidence-based approach to organizing transition care for patients with various diseases.
- Patients-Centered perspective: The model places a strong emphasis on the needs and preferences of adolescents or young adults. It recognizes the importance of individualized care and supports their active involvement in the transition process.
- Interdisciplinary Collaboration: Healthcare transition often involves multiple healthcare providers, specialists and support services. The Six Core Elements promote collaboration among different healthcare providers, including pediatric and adult healthcare teams, to ensure a coordinated transition plan.
- Quality Improvement: The Six Core Elements offer a systematic approach that encourages continuous quality improvement in healthcare transition services. By setting clear standards and monitoring progress, healthcare providers can continually enhance the transition process.

- **Measurable Outcomes:** The model includes specific, measurable outcomes to assess the success of the transition process. This allows healthcare providers to track progress and make necessary adjustments to improve the experience for the young adults and their families.
- **American Recognition:** Got Transition, the organization behind the Six Core Elements, has received recognition and support from national healthcare organizations and government agencies, including the American Academy of Pediatrics, the American Academy of Family Physician. This recognition lends credibility to the approach and encourages its adoption by healthcare providers.

Six Core Elements

According to the guidelines provided by Got Transition, a correctly planned transition process should consist of six “events”. The illustration below presents the subsequent steps taken by paediatricians, general physicians, and patients.

Stage I: POLICY/GUIDE

At the first stage of the process, it is recommended to prepare a guide, i.e. a certain type of guidelines, concerning the transition from one form of care to another. The developed document should contain the characteristics of the role played by every person involved in the process, from the adolescents and their parents to the physicians providing care for the patient. The final version of the document should be adapted to the given centre and the recipients of the transition process. A policy developed in this way should provide a description of the transition practice used as well as an explanation of the approach to the care provided by doctors who take care of adults. It is essential to address the issue of the patient’s privacy, to present the previously taken medical actions in detail, as well as all consents required for the transfer of care.

Stage II: TRACKING AND MONITORING

The next step consists of tracking and monitoring the process. This phase should involve the development of the criteria and the process of identifying patients (adolescents) at the age of transition who should start the process of preparing for transition. The guidelines of *Got Transition* recommend developing a dedicated process of tracking the level of reception of the six described elements of transition and integrating such data (as far as possible) with the patient’s medical documentation.

Stage III: READINESS

Measuring readiness for transition among the target group to whom the process applies is a crucial element of the whole process. Regularly conducted assessment of the readiness for transition, starting from the age of 14 to the age of 16, enables those responsible to identify and discuss the emerging problems of young people and their parents/guardians and their needs related to self-care and using healthcare services at an early stage. In order to assess readiness for transition, *Got Transition* proposed a questionnaire entitled *Sample Transition Readiness Assessment for Youth*, which may be used to check how well the patient handles the main issues related to organising their own self-care. Additionally, apart from the tool developed by *Got Transition*, there is also a questionnaire entitled *Transition Readiness Assessment Questionnaire*. Its aim is to assess the readiness of adolescents to start the transition process. The questionnaire has been translated into 9 languages (at the time of preparing this article, the Polish language version was unavailable). At this stage, education should also be provided for patients and their families, at a level adapted to the results achieved during the assessment of the readiness for transition.

Stage IV: PLANNING

Planning and organisation of the process constitute the fourth of the six core elements of transition. Appropriate

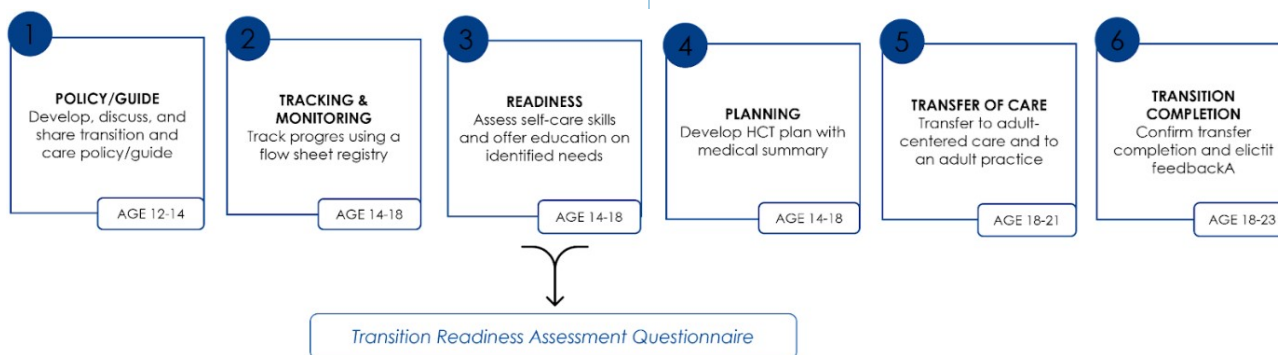


Figure 1. Six Core Elements – Got Transition

planning of the transition from paediatric care to care dedicated to adults should take place in cooperation both with the young people (patients) and their parents/legal guardians. This process should start at the early stage of adolescence, and it should be continued until the patient is released from paediatric care. Planning and organisation of *transition* include several continuous elements whose aim is to build health awareness, the ability to manage their own treatment process, the ability to provide independent self-care, preparation for the changes that occur at the age of 18, as well as managing the transition and choosing a new service provider for adults.

Stage V: TRANSFER OF CARE

Developing a dedicated and coordinated method of transferring care to adult clinical practitioners ensures the performance of key actions that are necessary to guarantee continuity of care. One of the elements of the fifth stage of the process consists of informing patients and their parents/legal guardians about the form of transfer of care and of medical information concerning the process of treatment so far. Another important element is communication and coordination of care between paediatricians and specialists who provide care for adults. It is recommended that the patients should be transferred before 22 years of age.

Stage VI: TRANSITION COMPLETION

The completion of the transition process with optional verification of the continuation care of the patient in adult care includes verification of the completion of the process, offering paediatric consultations (if necessary), and an evaluation of the experience of patients, their parents/legal guardians, and physicians, related to the completed process of transfer of care. An important element of this stage is closing the process by verifying that the patient whom it concerned receives care in clinics dedicated to the treatment of adults.

The stages of the organisation of the transition process proposed by *Got Transition* may constitute a model and inspiration for the development and implementation of actions in various healthcare systems, including the Polish system. The cooperation between different specialists in shaping the policy of the transition of patients is a topic that is addressed by healthcare experts in the context of its implementation in the system of coordinated care. Although coordinated care is a wider structure than the *transition* process, it is certain that this process, whose aim is to ensure the continuity of highly specialised care for young patients suffering from chronic diseases, encompasses the essence of coordinated care. On the other hand, coordinated care is aimed at improving the accessibility, quality, and efficiency of care, including the quality

of life and satisfaction of patients. An integrated system of providing services means “close relations between various forms of the provision of benefits/services”; therefore, implementing dedicated and planned transition processes for paediatric patients in the healthcare system would be an excellent example of coordinated care, and, at the same time, it would constitute *Value Based Healthcare* (VBHC).^[26]

Challenges for the Polish health care system

Even though the practical use of the developed processes of transition of patients from paediatric care to adult care is scarcely discussed in academic literature, the need to create such processes, as well as their potential significance and the resulting benefits, are increasingly often emphasised in the international arena, both by physicians, patients, and representatives of healthcare administration bodies.^[14, 27-30] The transition process seems to be a necessity during the treatment of patients with special healthcare needs. Due to that, the challenge, in the form of developing and practical implementation of structured guidelines concerning the transition process, should be tackled as soon as possible, in order to provide patients with continuous, highly specialised care, in compliance with the highest standards of medical practices, including in the conditions of the Polish healthcare system.

An opportunity to improve the current situation of patients with rare diseases has been provided in the *National Plan for Rare Diseases* (NPCR), whose aim is to ensure continuous realisation of healthcare, that focuses on the needs of patients diagnosed with rare diseases. The plan introduces systemic solutions for health problems in this group of patients. The tasks of the Plan include, among others: improving access to diagnostics and highly specialised medical care as well as the development of information, science, and education related to the treatment of rare diseases. The proposed tool is a novelty in the Polish healthcare system and offers a potential chance to improve the current state of care of patients with rare diseases, among others, by means of designating reference centres and creating a healthcare network.

Although the growing interest in the theoretical aspect of the *transition* area is becoming increasingly noticeable, there is still insufficient research that would provide practical conclusions for the purposes of applications in this field. In the Polish healthcare system, the subject of the transition process is still a niche topic, which means that it should be further explored to improve the efficiency of the process of diagnosis and treatment of patients with rare diseases. The authors of this study are undertaking further research to develop the transition area in Polish conditions.

Limitations

This review has several limitations. First and foremost, the literature review may not have captured all the publications in the topic under discussion. In addition, all the studies included in this review were written in English, so a bias regarding the language of the study was possible. Moreover, the authors were limited to the area of rare diseases only, and the current literature in the field of transition in these conditions is still limited. Besides, the article presents only one approach to organizing transition care, proposed by Got Transition, which, although it is the most widely used and recommended by scientific societies, could be supplemented with other solutions. Despite these limitations, this review highlights important recommendations for streamlining the transition from pediatric to adult care, which is a huge challenge for health systems and structuring it in Poland would help ensure continuity of highly specialized care for patients with rare diseases, which would affect their level of comfort and quality of life.

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