

Experience with the transition process of adolescents with chronic diseases from pediatric to adult care in a general hospital

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ABSTRACT

Introduction. The continuity of care from pediatrics to adult medicine is key to optimal health care.

Objective. To describe the experience of the transition process of adolescent patients with chronic diseases from pediatric to adult care in a general hospital.

Population and methods. Cross-sectional study of patients aged 16–24 years with a history of liver transplantation, kidney transplantation, endocrine, metabolic, rheumatic diseases, and myelomeningocele seen at a tertiary care teaching general hospital between 2015 and 2019 during the transition process. The process of health care and transition success were assessed. The Transition Readiness Assessment Questionnaire (TRAQ) was used.

Results. A total of 372 patients were included. The myelomeningocele clinic, the kidney transplant and the liver transplant teams were the most common specialties. Thirty-seven percent of participants were involved in the transition process. The mean duration of follow-up by pediatrics until transition initiation was 9 years. The mean age at the beginning of transition was 19 years, and the mean age at the end, 21 years. The joint clinic transition strategy was the most frequent, used in 96% of cases.

The median value of the ordinal TRAQ was 4; of these, 32% had already seen adult care physicians. A successful transition was achieved by 32.7%.

Conclusions. The continuity of care during transition is a process that took almost 2 years; more than one third of the patients had a successful transition.

Key words: transition to adult care, adolescence, chronic disease, adult.

<http://dx.doi.org/10.5546/aap.2022.eng.398>

To cite: Vainman S, Heller False Speiser MM, Posadas Martínez ML, Pérez L, et al. Experience with the transition process of adolescents with chronic diseases from pediatric to adult care in a general hospital. *Arch Argent Pediatr* 2022;120(6):398-404.

INTRODUCTION

Optimal health care is achieved when each individual throughout their life receives appropriate medical care. A key element is the continuity of that care at different stages of development and, in particular, when going into adult care.

This is applicable to all individuals, both healthy and chronically ill. The goal of a planned health care transition is to maximize the functional potential and well-being of youth with or without special health care requirements.

According to a report by the United States Department of Health from October 2008, 90% of children and adolescents with chronic conditions requiring special care reach adulthood. Such change in the survival of patients with complex diseases, who were previously cared for only in the pediatric setting, presents a different health care picture.^{1,2}

In the face of this reality, a gap has been observed in the continuity of health care for these young people with special needs when they must transition to the adult health care system.³

The transition should be progressive; it is not an event, but a planned process over time for the detection of educational, medical, and health care resources of adult services. The coordination of the treating services (pediatric and adult) is critical for the patient to learn to function independently as an adult in society.⁴

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Funding:
None.

Conflict of interest:
None.

Received: 12-17-2021
Accepted: 3-18-2022

The general picture in Argentina is very disparate: from pediatric hospitals that stop treating children from the age of 14 and others that do so until the age of 18, to general hospitals that have the possibility of accompanying these patients throughout their lives.

Hospital Italiano is a general, tertiary care hospital and an ideal setting –in theory– to implement a transition program that involves an interdisciplinary team of health care providers who can take care of this important group of adolescent patients who are transitioning to adulthood and ensure their continuity of care. Since 2012, we have been working on the transition process through multidisciplinary meetings with pediatrics, adult clinic, nursing, and administrative staff and monthly grand rounds and gatherings to discuss the strategies proposed by each specialty.

OBJECTIVES

General objective

To describe the experience with the transition process of adolescent and youth patients with chronic diseases from pediatric to adult care in a general hospital.

Specific objectives

1. To describe the characteristics of adolescent and youth patients with chronic diseases who are going through transition in health care.
2. To assess their readiness to move to adult care using a validated and cross-culturally adapted questionnaire called Transition Readiness Assessment Questionnaire (TRAQ).
3. To estimate the rate of successful transition.

POPULATION AND METHODS

This was a descriptive, retrospective, cross-sectional study in patients aged 16–24 years with a history of liver transplantation, kidney transplantation, endocrine, metabolic, and rheumatic diseases, and myelomeningocele seen in the 2015–2019 period. The patients who met the following criteria were included: 1) had at least 3 pediatric outpatient consultations; 2) had recorded any of the following problems in the electronic medical record (EMR): transition from pediatric to adult care, myelomeningocele, liver transplantation, kidney transplantation; 3) had at least 2 consultations with pediatric rheumatology, pediatric metabolism, pediatric endocrinology, pediatric liver transplantation, pediatric kidney transplantation, myelomeningocele or joint clinic

transition.

The specialties mentioned above were selected as a pilot test in a group of patients with varying degrees of complexity. The patients whose EMR included the TRAQ were also included, even if they did not meet the above mentioned criteria. The questionnaire was administered to patients who were 16 years and older during the consultation and across different moments of the transition process.

Definitions

The transition process is divided into 3 stages: preparation, planning, and implementation, based on the Got Transition® model.¹

The TRAQ is a tool that is recorded in the EMR and is used to assess transition readiness in our hospital patients. It has been validated locally and adapted to Spanish,⁵ and assesses certain patient skills to determine their level of readiness for transition to the adult health care system. The TRAQ is targeted at patients aged 14 to 26, and is made up of 20 items divided into 5 domains: Managing Medications, Appointment Keeping, Tracking Health Issues, Talking with Providers, and Managing Daily Activities. Each item has 5 response options which are scored 1 to 5: 1 is equivalent to a minimum autonomy level and 5, to a maximum autonomy level.

The joint clinic transition strategy involves providing care to patients in the same office by both pediatric and adult care specialists.

Treatment adherence was defined based on the recording of continuity of treatment in the medical records.

Successful transition was defined if the following 4 criteria were met: the time to the first consultation with adult care was ≤ 6 months, there were no unsuitable consultations with the emergency service, there was adherence to treatment, and patients remained in the adult care area (2 or more consultations).

Data collection

Data were collected through a request made to the Research Information Management Area for the list of patients with sentinel chronic diseases along with administrative data. Medical records were reviewed in a standardized manner to validate data of interest: age at the beginning of the preparation for transition from pediatric care, age at the time of first consultation with the adult care team, consultations with pediatric and adult care specialists, transition strategy,

TRAQ questionnaire score, time from transition initiation to the first consultation with adult care physicians, continuity with the adult care team, number of health care providers consulted until seeing the physician of referral, treatment adherence, and successful transition.

Statistical analysis

Numerical variables were expressed as mean and standard deviation (SD), whereas categorical variables were indicated as percentage and absolute frequency. Rates are described as percentage and its corresponding 95% confidence interval (CI). The t test was used to assess the association of quantitative variables and the χ^2 test or Fisher’s test, for categorical variables. A *p* value < 0.05 was considered statistically significant. The STATA software, version 13, was used.

The study was approved by the Research Protocol Ethics Committee of Hospital Italiano de Buenos Aires under protocol no. 5499.

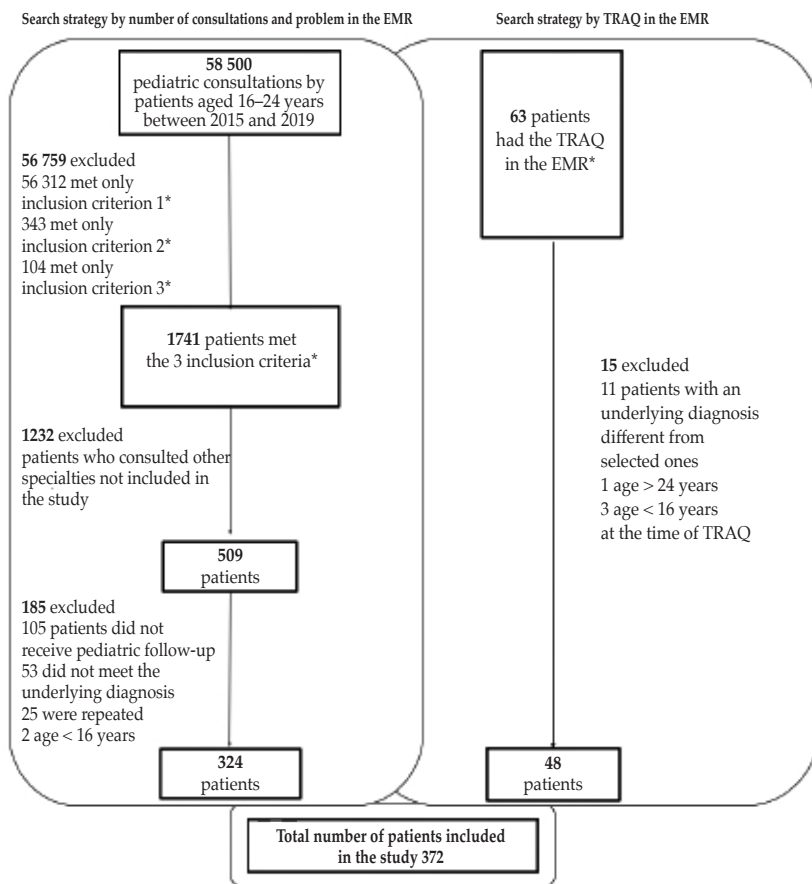
RESULTS

Participants

A total of 372 patients who met the selection criteria during the study period were included. *Figure 1* shows the patient selection flowchart.

The 3 most frequent specialties were myelomeningocele clinic in 42.5% (158), kidney transplant team in 29% (109), and liver transplant team in 13% (48). The 3 most frequent chronic diseases were myelomeningocele in 43% (161), kidney transplant in 28% (106), and liver transplant in 13% (48). *Table 1* shows the characteristics of patients with chronic diseases according to whether or not they participated in the transition process from pediatric to adult care.

FIGURE 1. Flow chart of pediatric patients with chronic diseases



EMR: electronic medical record.

Transition process

In total, 37% (138) (95% CI: 32–42) of the patients had participated in the transition process. The mean follow-up by pediatrics until transition initiation was 9 years (SD: 5). The mean age at the beginning of transition was 19 years (SD: 2.3) and the mean age at the end of transition was 21 years (SD: 2.5).

In 64% (88/138) of the EMRs, the problem “Transition from pediatric to adult care” had been recorded. In 90% (124/138) of the cases, the transition process was recorded in the medical notes of the EMR.

The most frequent transition strategy was the joint clinic transition in 96% (132/138) of the patients. Table 2 shows the characteristics of the patients who were old enough to participate in the transition process.

TRAQ

The TRAQ was included in 44% (61/138) of the EMRs of patients involved in the transition process. The median value of the ordinal TRAQ was 4 (between 3 and 4); of these, 32% (20/61) had consulted an adult care physician. The comparison by group of adult care consultation showed that the median value of the ordinal TRAQ was 4 for those who consulted adult care physicians versus 3.6 for those who did not ($p = 0.11$). These data were obtained from the latest TRAQ administered.

The median ordinal TRAQ value by specialty was 4.5 for metabolism, 4 (between 3.7 and 4.2) for kidney transplant team, 4 (between 3.6 and 4) for endocrinology, 3.65 (between 3 and 4) for myelomeningocele clinic, 3.4 (between 3 and 4) for rheumatology.

Successful transition

In total, 38% (52) of patients (95% CI: 30–46) completed the transition process and consulted adult care physicians.

In our sample, 32.7% (17/52) (95% CI: 20–47) met the 4 criteria for successful transition, 53.8% (28/52) (95% CI: 40–68) met 3 criteria, 11.5% (6/52) (95% CI: 4–23) met 2 criteria, and 2% (1/52) (95% CI: 1–10) met only 1 criterion.

The mean time to the first consultation with adult care physicians was 6 months (8.5); the rate of continuity with the adult care team was 87% (47); there were no unsuitable consultations with the adult care emergency service; and the mean number of health care providers consulted before seeing the physician of referral was 1 (0.67).

DISCUSSION

The formal transition rate was 37% of the patients in the age range for the study period. Although it is a low rate, it has helped us to establish our starting position in order to work on the greater dissemination and implementation of the transition process and its recording in the EMR. The difficulty in achieving implementation and assessing the impact of different transition programs around the world is well known, as described in a systematic review published in 2014.⁶

When assessing transition process notes in the medical records, we found a high rate of description of the process in the text referring to the course of disease in the medical record, with a lower recognition of the burden of the problem “Transition from pediatric to adult care.” It is worth mentioning that, in a study conducted at Hospital Garrahan in Buenos Aires, it was

TABLE 1. Baseline characteristics of patients with chronic diseases and of the care setting by transition group

	Total n = 372		Without transition n = 234		With transition n = 138	
	%	n	%	n	%	n
Females	56	(209)	54	(127)	59	(82)
Specialty						
Myelomeningocele clinic	42.5	(158)	57	(134)	17	(24)
Kidney transplant team	29	(109)	29.5	(69)	29	(40)
Liver transplant team	13	(48)	12.5	(29)	14	(19)
Endocrinology	9.5	(35)	0.5	(1)	24.5	(34)
Rheumatology	5	(19)	0	(0)	14	(19)
Metabolism	1	(3)	0.5	(1)	1.5	(2)

observed that the implementation of the transition process was carried out in 84% of the cases via an informal agreement with another facility, 49% received some form of joint or parallel care, and only 20% had a formal transition plan.⁷

The average age at the beginning of the transition process was 19 years and the average age at the end was 21 years. This demonstrates that we should start the process earlier, if we compare our results with the

NICE recommendations,⁸ although the average age at the end of transition is not so far from that suggested in the bibliography. According to the recommendations in the Anglo-Saxon bibliography, the transition process should start between 13 and 14 years old. However, they clarify that planning should be in accordance with the development, capabilities, and requirements of each individual.

The kidney transplant team completed the

TABLE 2. Characteristics of the transition process

	Total n = 372		Without transition n = 234		With transition n = 138		p
Mean duration (years) of pediatric follow-up by specialty (SD)							
Endocrinology	7	-	5	-	7.1	(3.7)	
Rheumatology	7	(3)	-	-	7	(3)	
Kidney transplant team	8	(4.1)	7.3	(3.8)	9.3	(4.4)	
Myelomeningocele clinic	9.8	(4.9)	9.5	(4.9)	11.1	(4.9)	0.15
Metabolism	11	-	12	-	10.5	(6.4)	
Liver transplant team	11.6	(7.2)	12	(7.2)	11	(7.3)	0.01
Transition strategy,% (n)							
Joint clinic care					95.7%	(132)	
Deferred pediatric-adult care consultations					3.6%	(5)	
Pediatric physician working with an adult care physician					0.7%	(1)	
Mean age at initiation of transition by specialty, years (SD)							
Endocrinology					18.8	(1.7)	
Rheumatology					17	(1.2)	
Kidney transplant team					20.7	(2.4)	
Myelomeningocele clinic					19.7	(1.8)	
Metabolism					17.5	(0.7)	
Liver transplant team					17.5	(1.5)	
Treatment adherence, % (n)	89%	(331)	88%	(206)	91%	(125)	0.45
Consulted adult care physicians, % (n)	32%	(120)	28%	(66)	39%	(54)	0.02
Mean age at end of transition by specialty, years (SD)							
Endocrinology					19.6	(1.6)	
Rheumatology					18	(0.5)	
Kidney transplant team					22	(2.4)	
Myelomeningocele clinic					20.7	(1.7)	
Metabolism					18	(0)	
Liver transplant team					-*	-	
Age at first consultation with adult care, years (SD)				21	(2.5)		
Consultations with adult care physicians (SD)	9.9	(12.7)	11	(12.5)	8.5	(12.9)	0.28
Continuity in adult care, % (n)	87%	(104)	86%	(57)	87%	(47)	0.9
Unsuitable consultations with adult care emergency services, % (n)	1%	(0.8)	1.5%	(1)	0%	(0)	0.36
Number of health care providers (SD)	0.9	(1)	1.1	(1.2)	1	(0.7)	0.02

*No patient with liver transplantation completed the transition; at the time of the study, their mean age was 19 years (SD: 2). SD: standard deviation.

transition later. Patients with rheumatic and metabolic diseases completed the process at 18 years old.

All the specialties included in the study had an average follow-up of 7 to 11 years, both for patients who made the transition and those who did not. It is important to consider the age of chronic disease onset because, if it occurs during middle adolescence, a bond of trust and a therapeutic alliance must be established, and, before starting the transition process, stability of the disease must be achieved.

Regarding the strategy of care during the transition process, the joint care transition (pediatric sub-specialist and adult sub-specialist) was the most frequent in the rheumatology, endocrinology, and nephrology areas. This result is consistent with the patients' perspective when asked about their preferred form of care (patient-oriented, joint clinic).⁹ Referral to an agreed-upon health care provider was most common in the hepatology area. In the metabolism specialty, patients continue with the same pediatric physician for adult care, whereas the myelomeningocele clinic has overlapping strategies according to the patients' needs.

Regarding the preparation process, the TRAQ was included in the medical record as a tool to assess autonomy and knowledge of the disease in 44% of the cases, i.e., almost half of the patients. Among those with a score of 4, one third had already had an adult care consultation. Those with lower scores were patients with myelomeningocele, a group with a greater degree of disability and who require more complex care. However, patients with rheumatic diseases also had values below the mean, a result that is difficult to interpret, which indicates that the TRAQ is a useful tool for assessing readiness, but it should not be the only one.¹⁰

When comparing patients who completed the transition (n = 138) and those who did not (n = 234) by specialty, rheumatology had a 100% transition rate, followed by endocrinology, metabolism, liver transplantation, kidney transplantation, and myelomeningocele.

The main limitations of this study were, firstly, that it was a retrospective study; however, the possibility of recovering information was maximized through the comprehensive and standardized review of the medical record, and when necessary, treating physicians were contacted. Secondly, the definition of successful transition that was used is a construct that has not

yet been validated; it is a way of approximating potential indicators of process success, and should not be used to evaluate the complete success of a program.¹¹

We believe that the results will be scalable to make local improvements, disseminate the proposal, and have a halo effect to all areas of the hospital that are responsible for the care of young patients, as well as other hospitals with similar characteristics.

CONCLUSIONS

The continuity of care during transition is a process that took almost 2 years; more than one third of the patients had a successful transition. ■

Acknowledgments

We would like to thank Claudia Raddavero, Guillermo Alonso, and Soledad Kleppe for allowing us to include their patients in this study.

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