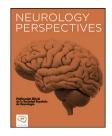


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ORIGINAL

Transition from paediatric to adult neurological care: What do we know?



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Received 15 June 2023; accepted 16 June 2024 Available online 12 October 2024

KEYWORDS

Transition; Transfer; Neurology; Paediatric neurology; Adolescence; Chronicity

Abstract

Introduction: Healthcare advances have allowed an increase in the survival of paediatric patients with neurological diseases. As a result, it is increasingly common to find these patients in adult neurology consultations. The aim of this study is to evaluate the current level of consensus on the transition of neuropaediatric patients among neurology and paediatric professionals in the Balearic Islands.

Material and methods: We conducted an observational, analytical, cross-sectional study through an anonymous questionnaire consisting of 27 questions, which was distributed to neurologists, paediatric neurologists, hospital paediatricians, and primary care paediatricians in the healthcare network of the Balearic Islands. It was developed using Google Forms and distributed by the competent professional societies. Consensus was considered to exist for answers with 70% or more agreement.

Results: Responses were received from 58 professionals; 46.6% were hospital paediatricians, 29.9% were neurologists, 13.8% were paediatric neurologists, and 13.8% were primary care paediatricians. Among other issues, consensus was observed on the need for a transition programme for patients with neurological diseases. No consensus was observed regarding the duration of the transition (P=.029) and how long simultaneous follow-up must last after the transfer (P=.09).

Conclusions: Due to increased survival rates, there is a need to create transition programmes for paediatric patients with neurological diseases. In our study, more than 70% of professionals believed that it would be beneficial to create such programmes.

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PALABRAS CLAVE

Transición; transferencia; Neurología; Neuropediatría; adolescencia; cronicidad

Transición de la edad peditrica a la edad adulta en las enfermedades neurolgicas. ¿Qué sabemos?

Resumen

Introducción: Los avances sanitarios han permitido un aumento de la supervivencia de pacientes pediátricos con enfermedades neurológicas. Por ello, cada vez es más frecuente encontrarlos en consultas de neurología de adultos. El objetivo de este estudio es evaluar el nivel de consenso actual sobre la transición del paciente neuropediátrico entre los profesionales de la neurología y de la pediatría de nuestra comunidad autónoma.

Material y métodos: Estudio observacional, analítico y transversal a través de una encuesta anónima que consta de 27 preguntas realizada a neurólogos, neuropediatras, pediatras hospitalarios y pediatras de atención primaria de la red sanitaria de las Islas Baleares. Se ha llevado a cabo mediante un formulario Google y la difusión se ha realizado a través de las sociedades profesionales correspondientes. Se considera que existe consenso en aquellas respuestas que han obtenido el 70% o más de coincidencia.

Resultados: Han respondido 58 participantes, donde el 46,6% son pediatras hospitalarios, 29,9% neurólogos, 13,8% neuropediatras y 13,8% pediatras de atención primaria. Se ha alcanzado consenso, entre otras cuestiones, en la necesidad de un programa de transición para pacientes con enfermedades neurológicas. No se ha alcanzado en la duración de la transición (p = 0,029) y cuánto tiempo tiene que durar el seguimiento simultáneo tras la transferencia (p = 0,09).

Conclusiones: Debido a la mayor supervivencia de los pacientes pediátricos con enfermedades neurológicas se plantea la necesidad de crear programas de transición para estos pacientes. En nuestro estudio más del 70% de los profesionales cree que sería beneficioso formar programas de transición.

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Introduction

Advances in treatment and medical care have led to improved survival rates among patients with childhood-onset chronic diseases, and particularly neurological diseases. As a result of this, it is increasingly common for these patients to be attended at adult neurology clinics. Neurologists specialising in adult care are often unfamiliar with these childhood-onset disorders, such as autistic spectrum disorders and epileptic encephalopathy. As a result of this, they are not comfortable treating this type of patient, either due to a lack of experience with this type of diseases or because the patients they usually treat require a different type of care.^{1–3}

Paediatric and adult care present certain differences, with the former focusing more on the family, whereas the latter focuses more on the patient and their disease.

The transition from paediatric to adult care must achieve several objectives, which include establishing a good relationship between the physician, the patient, and their family, and empowering the patient and their family.

Although several working groups have developed international guidelines on the transition from paediatric to adult

care, few publications have focused specifically on neurological disease. The great majority of these publications are opinion articles, and there is a lack of controlled clinical trials assessing whether there are differences between the different transition models proposed.

The main objective of the present study is to evaluate the current level of consensus regarding the transition from paediatric to adult neurological care, among neurologists and paediatricians in the public health service of the Balearic Islands, in order to assess the need to create a transition unit within neurology departments.

Material and methods

Study design

We conducted a cross-sectional, analytical, observational study based on an anonymous survey. The survey included 27 questions, with 24 closed-ended and 3 open-ended questions (Appendix 1). The survey was created through a review of the most recent publications and guidelines on this topic. 1–13

Population

The survey was distributed to neurologists, paediatric neurologists, hospital paediatricians, and primary care paediatricians working within the Balearic Islands healthcare system. It was developed using Google Forms, and distributed by the Balearic Society of Neurology, the Balearic Society of Paediatrics, and the Primary Care Paediatrics Association of Islas Baleares.

Consensus or agreement on an issue was defined as the same answer being given by at least 70% of respondents.

Descriptive and statistical analysis

We gathered the following variables:

- total number and percentage of participants among all professionals:
- total number and percentage of participants among paediatric neurologists, adult neurologists, hospital paediatricians, and primary care paediatricians;
- total number and percentage of responses for each item;
- total number and percentage of consensus for each item.

Qualitative variables were compared with the chi-square test. *P*-values < .05 were considered statistically significant.

The study was approved by the research ethics committee of the Balearic Islands.

Results

A total of 452 professionals were contacted: 364 hospital or primary care paediatricians, 18 paediatric neurologists, and 70 adult neurologists. Fifty-nine professionals responded to the survey.

A total of 12.8% of the target population participated in the study. Of all participants, 46.6% were hospital paediatricians, 29.9% were neurologists, 13.8% were paediatric neurologists, and 13.8% were primary care paediatricians.

Regarding the survey questions, 50% of the sample did not know the distinction between transition and transfer. Analysis by professional subgroup identified no significant differences in respondents' understanding of the concept of transition (P=.101). However, 75% of paediatric neurologists and 59.3% of hospital paediatricians did know the difference between transition and transfer, compared to 50% of primary care paediatricians and 33.3% of adult neurologists.

Over 70% of respondents agreed that there was a need for a transition programme.

Regarding the age at which transition should be started, consensus was not observed for any of the age ranges proposed, although 54.1% of participants considered 14–16 years to be the most appropriate option.

We did observe consensus on the question of whether, after the transfer, patients should be followed up jointly by the paediatrician and neurologist, with 81% of respondents supporting this idea. However, there was no consensus on how long the complete transition process should take.

Consensus was observed on the issue of which diseases would benefit from a transition programme, with 96.6%

considering it appropriate for drug-resistant epilepsy, 96.6% for neuromuscular diseases, 89.7% for cerebral palsy, 89.7% for neurometabolic diseases, 84.5% for demyelinating diseases, and 74.1% for cerebrovascular diseases. However, when participants were asked if there was any particular disease for which a specific age should be established for transition, no consensus was apparent for any of the proposed diseases.

Another issue for which consensus was reached was the perceived lack of information provided by paediatric neurologists about such subjects as sexual education and pregnancy (87.9%), contraceptives (79.3%), and school and workplace guidance (77.6%).

Regarding the factors that may delay patient transitions or transfers, there was agreement that families' need for support (70.7%) and greater disease complexity (87.9%) could have this effect.

Regarding structural barriers in the healthcare system that may prevent or hinder the development of transition programmes, respondents agreed that such hurdles included the lack of institutional recognition of this need (72.4%), lack of communication between medical departments (70.3%), and insufficient preparation or training on the diseases with greatest prevalence among adolescents (70.7%).

Regarding barriers to proper transition among healthcare professionals, 75.9% of respondents agreed that there are significant difficulties in coordinating medical services during transition or transfer.

For some questions, there was consensus on all the items presented.

One of these was the question of whether all patients should be taught about their disease (94.8%), about treatment options and adverse reactions (98.3%), and about whether emergency medications are available and how they are used (91.3%). Another was the need to have discussions with the patient about mental health and comorbidities (84.5%), sexual and reproductive health (89.7%), and sudden unexpected death in epilepsy in patients with the disease (70.7%).

Participants also agreed that it is important to ensure proper communication between different members of the healthcare system (87.5%) and provide lifestyle education (93.1%).

Consensus was also observed for all items proposed in the question about the key elements of a good transition programme: prior communication of the transfer (84.5%), perception of the patient and their family that everybody involved is part of the team (84.5%), planning of the transition (89.7%), institutional support (87.9%), and multidisciplinary consultations (82.8%).

To improve the transition from paediatric to adult neurological care, respondents agreed that there is a need for national guidelines/recommendations on the transition (75.4%), that a specific clinical structure should be created to assist with the transition (74.1%), that joint consultations should be held with paediatric and adult neurologists (84.5%), and that courses on the transition should be introduced in neurology and paediatrics training programmes (75.9%).

The comparative analysis between subgroups of specialists yielded the following results.

Table 1 Comparative analysis of different professional subgroups' preferred duration of the transition process (P=.029). Which label best describes What do you consider to be the appropriate duration of the process of transition from your medical practice? paediatric to adult neurological care? 1-3 months 3-6 months 6-8 months >12 months Total NRL O 5 9 15 1 2 2 0 **PEDNRL** 4 8 5 7 27 **HPED** 1 14 **PCPED** 0 1 4 3 8 Total 3 11 18 26 58

HPED: hospital paediatrician; NRL: neurologist; PCPED: primary care paediatrician; PEDNRL: paediatric neurologist.

Statistically significant differences were observed between groups on the preferred duration of the complete transition process, and the duration of simultaneous follow-up or assessment by the paediatrician and the neurologist until completion of the transfer (Tables 1 and 2). Both for the complete process and for joint follow-up, adult neurologists and hospital paediatricians proposed longer timeframes, with durations exceeding 12 months, whereas paediatric neurologists and primary care paediatricians preferred shorter durations, between 3 and 6 months (*P*=.029 and .009, respectively).

No statistically significant differences were observed regarding the ideal age at which transition programmes should begin (P=.474), as mentioned above (Table 3). Although there was no consensus supporting any of the proposed age ranges, the most popular option was 14–16 years.

We also observed no significant differences in respondents' opinions on whether follow-up should be performed after the transfer (P=.715), with 80% of participants considering this to be appropriate (Table 4).

For some questions, consensus was not established for any item. Nonetheless, these corresponded to answers referring to disagreements about the transition. In the light of this, and extrapolating the methodology used in the study, we may conclude that there are discrepancies on various subjects, including not participating in the transition process, not knowing whether transition programmes are in place for other medical specialties at their hospital or whether a transition programme is needed for less severe neurological conditions, and how to begin follow-up by the adult neurology department.

Discussion

As mentioned above, healthcare advances have increased the survival of patients with childhood-onset neurological diseases and, as a result, it is increasingly common for them to be attended at neurology consultations once they reach adulthood. Adult neurologists are frequently unfamiliar with these diseases, which require a different type of care. ^{1–3}

The paediatric care model is centred around the patient and their family. The patient is followed up for several years, beginning at very young ages, and a strong bond is formed with the professional attending them. Furthermore, decisions are made by the patient's parents or legal guardians, who are typically responsible for managing consultations and administering treatments, among other tasks. When the patient reaches adolescence and the time comes for them to transfer to an adult physician, many families resist the change and do not accept the transfer.

Difficulties in the transfer or transition may have a range of causes. As shown by the results of our survey, professionals perceived various barriers to successful transition, including higher disease complexity and families with greater support needs. In addition to these patient-related barriers, other barriers included difficulties in coordination between hospital departments and a lack of clinical guidelines, specific clinical structures, and institutional support. All of these factors may contribute to patients and their families feeling afraid or abandoned after the transfer.

Although the adult care system has undergone changes in recent years, it continues to focus on the disease; consequently, physicians frequently manage the patient and their

Table 2 Comparative analysis of different professional groups' preferred duration of joint follow-up or assessment by the paediatric neurologist after transfer (P=.009).

Which label best describes your medical practice?	If you responded 'yes' to the previous question, for how long after the transfer should joint follow-up be performed?						
	1–3 months	3–6 months	6–8 months	> 12 months	Don't know/no response	Total	
NRL	0	0	2	9	4	15	
PEDNRL	3	4	0	1	0	8	
HPED	2	6	4	12	3	27	
PCPED	1	0	0	6	1	8	
Total	6	10	6	28	8	58	

HPED: hospital paediatrician; NRL: neurologist; PCPED: primary care paediatrician; PEDNRL: paediatric neurologist.

Table 3 Comparative analysis of different professional subgroups' opinion of the appropriate age for beginning transition programmes.

Which label best describes your medical practice?	What do you consider to be the most appropriate age for starting transition programmes for patients with neurological diseases?						
	12-14 years	14–16 years	16–18 years	> 18 years	Total		
NRL	5	6	4	0	15		
PEDNRL	1	5	1	1	8		
HPED	2	15	8	2	27		
PCPED	2	4	1	1	8		
Total	10	30	14	4	58		

HPED: hospital paediatrician; NRL: neurologist; PCPED: primary care paediatrician; PEDNRL: paediatric neurologist.

disease, without taking into account their social and family setting and their potential lack of independence.

In Spain, the age at which paediatric patients are transferred to adult care differs between autonomous communities. In the Balearic Islands, patients are transferred at the age of 14 years, often without prior notice and without a transition process. In the context of chronic disease, it is crucial that patients and their families are offered a good transition process in which they understand and accept the new model, as different patien ts and diseases will need different amounts of time for the transition and/or transfer^{1,3–5}; some patients may not be ready for this change by the age of 14 years.

The concepts of transfer and transition have existed for many years in the medical context, although many healthcare professionals do not know the difference between the 2: half of our respondents did not know the difference before participating in the study.

The term transfer refers to the patient's move from paediatric to adult care at a given point in time. Transition, in turn, refers to the complete process of preparation before, during, and after the patient's transfer. It is a dynamic process, typically involving multiple steps, in which efforts must be made to ensure the involvement of the patient, their family, and the referring and receiving hospital departments at all stages, enabling the process to be tailored to the individual needs of each case. The duration of the process will vary as a function of the patient, their family, and their disease.

Table 4 Comparative analysis of different professional subgroups' opinions of whether patients should be followed up under the paediatric system following transfer to adult care.

Which label best describes your medical practice?	Should patients be followed up under the paediatric system after transfer to the adult system?				
	No	Yes	Total		
NRL	4	11	15		
PEDNRL	2	6	8		
HPED	4	23	27		
PCPED	1	7	8		
Total	11	47	58		

HPED: hospital paediatrician; NRL: neurologist; PCPED: primary care paediatrician; PEDNRL: paediatric neurologist.

In our study, one of the open-ended questions invited respondents to define these concepts in their own words; 50% of participants who claimed to know the difference between transition and transfer were able to describe it accurately.

The transition process seeks to achieve several objectives. One of these is the transfer of all medical and psychosocial information on the patient and their family, which is gathered throughout the patient's childhood, to facilitate their move into the adult healthcare system and prevent the trauma that may occur due to a sudden change in healthcare professional. Furthermore, this shift occurs during adolescence, a moment of life in which patients are more susceptible to change, and may present worsening of their symptoms, denial about their disease, poor treatment adherence, etc.⁵

Another objective of the transition process is to increase the patient's independence, because in adulthood it is the patient who takes the central role and participates in decisions affecting them. We must ensure that the adolescent patient understands and accepts responsibility for their medical condition and treatments. We must counsel patients so that they may gain these skills in order to make decisions independently. This change in role also involves working with families, as parents must understand that it is now their son/ daughter who will begin making the personal decisions for which the family had so far taken responsibility. At this point, there may be differences of opinion between the patient, their family, and the healthcare professional, and the process will be smoother if good transition planning was previously implemented. 1-4 Good planning enables a good relationship between patient, family, and physician, and may be an appropriate use of public resources, as good transitions have been shown to reduce emergency department visits and hospital admissions, among other outcomes.^{3–5}

Transition medicine is an ambitious project that requires different resources, both personal and material. This study demonstrates the need for joint consultations and multidisciplinary teams in the provision of this care. Our survey asked participants whether transition programmes had been developed for other specialties at their hospitals; 37.3% responded that such programmes did exist (Fig. 1). Observing the functioning of these units may be a way to begin this transition project in neurology departments in the Balearic Islands. However, it was noteworthy that more than half of the sample did not know whether such programmes existed (Fig. 2).

Respondents also believed that there was a need for national recommendations or guidelines on transitions to

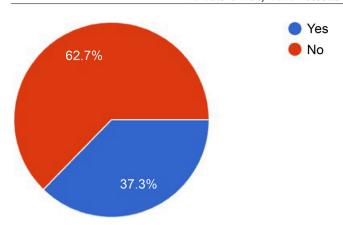


Fig. 1 Pie chart showing responses to question 5: "Do you know if there are transition programmes for adolescents with chronic diseases at your hospital?"

avoid potentially traumatic experiences during the transfer, which may result in the patient having less understanding of their disease, poorer treatment adherence, lack of trust in their neurologist, and more emergency department visits; in short, less efficient use of public resources.^{1–6}

Although several national and international working groups are studying the transition to adult care, there are currently no guidelines, recommendations, or reference units for these transitions. $^{2-14}$

This study is intended to demonstrate that, in the opinions of the professionals involved, there is a need in our region for a transition protocol and transition units for paediatric patients (Fig. 3).

Conclusion

We may conclude that, among healthcare professionals attending patients with childhood-onset neurological diseases, there is consensus on a range of points related to the transition to adult care. Over 70% of respondents to our survey believe it would be beneficial if transition programmes were created for neurological diseases.

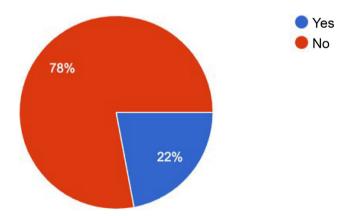


Fig. 2 Pie chart showing responses to question 7: "Do you know if there are transition programmes for adolescents with neurological diseases at other Spanish hospitals?"

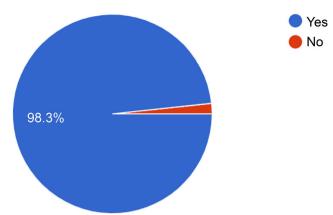


Fig. 3 Pie chart showing responses to question 27: "If no transition programme exists in your centre, do you believe it would be beneficial for families, patients, and medical professionals if there were a liaison role to facilitate the transition of patients with neurological diseases?"

Limitations

A significant limitation of our study was the low rate of responses to the survey; however, it should be noted that the real target population is smaller than that calculated, as many professionals belong to more than one of the participating medical societies.

Furthermore, some hospitals have limited access to web pages and many professionals were unable to open the online survey.

Another limitation was the exclusion of family doctors from the study sample, as we had no appropriate method of distributing the survey to this population.

A further limitation of the study is the method used to define levels of consensus between professionals. Studies using surveys typically follow the Delphi method to establish expert recommendations on a topic. For the present study, we opted not to use this method due to the lack of a panel of experts on the transition of paediatric patients to adult neurological care. Rather, this initial study seeks to establish a basis for the creation of such a committee in the future, and for the development of new studies and recommendations.

Funding

This study received no funding from any public or private entity.

Patient informed consent

No informed consent was obtained as no patients participated in this study.

Ethical considerations

We consider this project not to present any ethical limitations. Survey responses were anonymous and cannot be linked to respondents in any way.

We also took the following measures to guarantee anonymity:

- The individual responsible for distributing the survey by email was not the lead researcher, who therefore did not have access to respondents' e-mail addresses. As explained above, the survey was distributed by the Balearic Society of Neurology, the Balearic Society of Paediatrics, and the Primary Care Paediatrics Association of Islas Baleares.
- In Google Forms, we deactivated the option for respondents to provide their e-mail addresses; thus, responses are only identified by participant numbers, with no biographical data.

Members of the research team participated voluntarily, and received no financial compensation. The authors have no conflicts of interest related to this study.

The study was conducted in compliance with Spanish Organic Law 3/2018 of 5 December, on personal data protection and digital rights, and Regulation (EU) 2016/679 of the European Parliament and of the Council on data protection (GDPR).

We observed the requirements of Spanish Law 14/2007 of 3 July, on biomedical research, and the principles of the Declaration of Helsinki on medical research involving human subjects.

The database was created anonymously, ensuring the confidentiality of the participants. All parties will maintain the confidentiality of the information provided and created, and will be vigilant in the treatment of the results.

Declaration of competing interest

The authors have no conflicts of interest to declare.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.neurop.2024.100174.

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