Available online at www.medicinescience.org

ORIGINAL ARTICLE

Medicine Science 2022;11(2):639-44

Medicine Science International Medical Journal

Transition clinic in pediatric onset multiple sclerosis: Opinions of pediatric neurologists and neurologists

Ismail Solmaz

University of Health Sciences, Faculty of Medicine, Dr Sami Ulus Maternity Child Health and Diseases Training and Research Hospital, Department of Pediatric Neurology, Ankara, Turkey

Received 31 January 2022; Accepted 19 February 2022
Available online 09.03.2022 with doi: 10.5455/medscience.2022.01.026

Abstract

Multiple sclerosis (MS) is rare in children compared to adults. The management of pediatric onset MS (POMS) differs from adult disease, and the appraoch of pediatric neurologists and neurologists can also diverge in practice.We conducted a survey among pediatric neurologists and neurologists to identify the problems experienced in the transition period of POMS patients to adulthood, and to collect suggestions about a transitional clinic for these patients. Questionnaires were prepared by the Delphi method with a group of specialists and sent via e-mail to pediatric neurologists and neurologists through national associations. Statistical analysis was performed on the answers received. Participants included 31 pediatric neurologists (48.4%) and 33 neurologists (51.6%). The majority of pediatric neurologists (n=22, 71%) had been involved in central nervous system demyelinating diseases for 0-9 years. Among neurologists, the largest group 17 (n=17, 51.5%) was those who had been caring for these patients for 10-19 years. Pediatric neurologists were more interested in a transition procedure for POMS patients than adult neurologists: 26 (89.7%) vs.18 (56.3%) respectively (p=0.004). The preferred method for transferring the patient was face to face, realized more by pediatric neurologists (15/31) than neurologists (8/33) (p=0.044). Satisfaction with the transition process was not at the desired level in both groups of physicians. Transferring patients through a joint meeting and writing a detailed consultation note were frequent recommendations. Most contacted physicians were in favor of a national system for the transfer of POMS patients to neurology care, and suggested specialized transitional clinics. Applicable and agreeable procedures need to be implemented for both patients' and physicians' advantage.

Key words: Transition, pediatric, multiple sclerosis, adulthood, demyelinating

Introduction

Health policies are being developed in many countries for an optimal transfer of patients from pediatric to adult clinics. British, Canadian, and American pediatric societies have recommendations for transition to facilitate maintenance of well-being and continuous health care in adulthood [1-3]. Studies on transition clinics are scarce in neurological diseases [4] but exist in pediatric-onset diabetes mellitus [5-8] and cystic fibrosis [9-11]. Life-long neurological conditions such as demyelinating disorders can affect several aspects of adult life like pregnancy, employment, social life and autonomy. These problems should be anticipated and adequate expertise and assistance provided [12]. Unlike some neurological disorders that begin and end in young ages or persist in stable condition into adulthood, those like pediatric onset multiple sclerosis (POMS) begin in childhood and continue onto adult age with a static, relapsing or even progressive course.

POMS is less common in childhood than cerebral palsy, epilepsy, vision loss, and hearing loss [13]. Therefore, there is almost no study on transition clinics in POMS. Awareness about the diagnosis of multiple sclerosis (MS), increasing use of magnetic resonance imaging (MRI) in clinical practice, establishment of diagnostic criteria for children, and expansion of clinical and basic science studies led to an augmentation of POMS diagnoses in the last two decades.Targeted therapies developed in recent years are only available off-label in the pediatric age group; this often complicates the treatment of POMS patients in adult clinics. As in many countries, POMS is followed-up in pediatric clinics in our country and transferred to adult clinics after a 18 years.

***Corresponding Author:** Ismail Solmaz, University of Health Sciences, Faculty of Medicine, Dr Sami Ulus Maternity Child Health and Diseases Training and Research Hospital, Department of Pediatric Neurology, Ankara, Turkey
E-mail: isolmaz68@gmail.com

We planned this study in order to explore factors affecting the adaptation of POMS patients to the adult clinic. We also intended to understand the level of communication between pediatric neurologists and neurologists. We administered a questionnaire to pediatric neurologists and neurologists and analyzed similaritites and differences between these two groups' answers in order to point out at any factors to work on.

Materials and Methods

This questionnaire-based study was designed to learn the opinion of physicians about the transition clinic. The questionnaire was prepared by a Delphi procedure conducted among 6 neurologists and pediatric neurologists with 3-20 years of practice in demyelinating diseases. After finalization, the questionnaire (available in the supplement file) was sent via electronic mail through neurology/ pediatric neurology working groups. Ethical compatibility of the study was approved by Hacettepe University Ethics Committee (Project number GO 21/416, Desicion number 2021 /07-58).

Statistical analysis

Statistical analyzes were performed using a package program called SPSS (IBM SPSS Statistics 24). Frequency tables and descriptive statistics were used to interpret the findings. Responses from neurologists and pediatric neurologists were analyzed statistically. Pearson-χ 2 cross tables were used to analyze the relations between two qualitative variables, significance set at $p<0.05$.

Results

The questionnaire was sent to 103 pediatric neurologists and 62 neurologists but answers received by 31 and 33 respectively. The age range of the groups was similar: most pediatric neurologists (n=13, 41,9%) were 30-39 years old and most neurologists (n=20, 60,6%) were 40-49 years old. The duration of clinical interest in central nervous system (CNS) demyelinating diseases was mostly 0-9 years in pediatric neurologists (n=22, 71%) and 10-19 years (n=17, 51,5%) in neurologists. The majority (64% for both groups) of the participating physicians were working at university hospitals where both pediatric and adult neurology clinics co-existed. The majority could work with neuroradiologists in their own hospitals (67,8% of pediatric neurologists, 69,7% of neurologists), find enough laboratory opportunities in their own hospitals (45,1% of pediatric neurologists, 63,6% of neurologists), have enough hospitalization facilities (74,2% of pediatric neurologists, 75,8% of neurologists) and could manage and care for most MS patients (77,4% of pediatric neurologists, 87,9% of neurologists). Access to intensive care units for serious patients was easier for pediatric neurologists compared to neurologists (64.5 vs. 39.5%). Both physician groups had facilities to administer intravenous methylprednisolone, intravenous immunoglobulin, and plasma exchange therapies in their institution. The majority of pediatric neurologists were following up their patients until the age of 18 years, and neurologists generally started to follow up MS patients after that age. Information including demographic data, physicians' working places and working opportunities are given in Table 1. There was no statistical difference between the groups.

Table 1. Demographic data, physicians' workplace and characteristics

	Pediatric neurologists (n=31, 48.4%)	**Neurologists (n=33, 51.6 %)**
Age group*	30-39 age, 41.9% (n=13)	40-49 age, 60.6% (n=20)
Duration of interest in CNS demyelinating disease*	0-9 years, 71%, n= 22	10-19 years, 51.5%, n= 17
Workplace*	University hospital (64%, n= 20)	University hospital (64%, n=21)
Both physicians exist in the same hospital	83.9%, n=26	54.5%, n=18
Practices diagnosis, treatment and follow-up MS patients	77.4%, n= 26	87.9%, n= 29
Age of follow-up patients*	Until 18, 87%, n=27	After 18, 60.6%, n=20
Neuroradiologist in the same hospital for consultation	67.8%, n= 21	69.7%, n=23
Adequate hospitalization facilities	74.2%, n=23	75.8%, n=25
Adequate intensive care unit	64.5%, n=20	39.5%, n=13
Treatment methods during the attack period*	IVMP 100%, n= 31	IVMP 100%, n=33
	IVIG 71%, n=22	IVIG 63%, n=21
	PLEX 70%, n=21	PLEX 64%, n=22
Laboratory facilities for CSF analyzes, OLB, and IgG index *	Facilities in the institution 45.1%, n= 14	Facilities in the institution 63.6%, n=21
	Paid by families in private laboratories 45.1%, n=14	Paid by families in private laboratories 30.4%, n=10

*Most frequent choice
Abbreviations: CNS: central nervous system, CSF: cerebro spinal fluid, OLB: Oligoclonal band, IVMP: intravenous methylprednisolone, IVIG: intravenous immunoglobulin, PLEX: plasma exchange, MS: multiple sclerosis

A significant difference was found between pediatric neurologists and neurologists in the transition process ($\chi2$=8.445; p=0.004). Transition procedures were predominantly used by pediatric neurologists: 26 pediatric neurologists (89,7%) transferred patients to neurologists while 18 neurologists (56,3%) did transfer patients from pediatric neurologists. The selected method differed: the largest group of child neurologists (n=15, 48.4%) preferred face-to-face, while 25/33 (75.8%) adult neurologists did not use this method ($\chi2$=4,047; p=0.044) but consultation forms (n=19, 45.2%) (Table 2). Both groups of physicians were thinking a joint meeting would make the transition more effective (Table 2). Pediatric neurologists' satisfaction with the transition procedure was mostly "no, could be better" (38%), "yes, a little" (30%), similar to neurologists: "yes, a little" (34%) and "no, could be better" (30%).

Factors creating the necessity of transitioning POMS patients to the adult clinics were legal responsibility due to the age of the patient (71%), insurance payment of some drugs over 18 years of age (65%), and pregnancy plans (61%) according to pediatric neurologists. Factors reducing the possibility of transitioning POMS patients to the adult clinics were bonding of patients and parents to the pediatric neurologist and not wanting to leave (81%), neurologists spending less time with patients (68%), communication difficulties with a neurologist (42%) and patients not wanting to be in the same clinic with adult patients (32%) (Table 3). According to neurologists, factors affecting the need for transitioning were: administration of more effective immunotherapy and reducing the possibility of future disability in the adult clinic (64%), desire to follow-up POMS patients (48%) and the thought of pediatric neurologists not having enough experience in MS (39%). On the other hand, the following reasons reduced the possibility of transitioning POMS patients to adult clinics: reluctance/lack of information of pediatric neurologists for newer disease-modifying treatment agents (48%), excess of patients in adult clinics (42%), and difficulties communicating with parents (36%) (Table 3).

Both groups of physicians agreed a specialized unit would better adapt the patients to the transition period, that the transition process could be easier with a physiotherapist, daily treatment units, and specially trained nurses available. Presence of sufficient number of neurologists in the patient's area of residence was important. Transfer with joint meetings of neurologists and pediatric neurologists, writing detailed and official transfer notes and establishing a national system for the transition of MS patients would improve the process (Table 3).

Table 2. Management of transition procedure

	Pediatric neurologists (n=31)	Neurologists (n=33)	Statistical analysis*
Have you ever been involved in the transition procedure of multiple sclerosis patients?			
Yes	n=26, 89.7%	n=18, 56.3%	$\chi2$=8.445
No	n=3, 10.3%	n=14, 43.7%	**p=0.004**
Have you used face to face transition method?			
Yes	n=15, 48.4%	n=8, 24.2%	$\chi2$=4,047
No	n=16, 51.6%	n=25, 75.8%	**p=0.044**
Which methods do you use for transition?**			
Consultation form	n=13, 27.7%	n=19, 45.2%	
Special form	n=3, 6.4%	n=6, 14.3%	
Face to face	n=15, 31.9%	n=8, 19%	$\chi2$=7,331 p=0.197
Electronic mail	n=1, 2.1%	n=2, 4.8%	
Both physicians meet	n=3, 6.4%	n=1, 2.4%	
Suggest find a neurologist	n=12, 25.5%	n=6, 14.3%	
Are you satisfied with the transition procedure?			
Yes, a lot	n=5, 16.4%	n=6, 18.1%	
Yes, a little	n=9, 30.3%	n=11, 34.6%	
Undecided	n=5, 16.1%	n=5, 15.7%	$\chi2$=2,629 p=0.622
No, could be better	n=12, 38.4%	n=10, 30.3%	
Never	n=0	n=1, 3.2%	

* "Pearson-$\chi2$" crosstabs were used to examine the relationships between two qualitative variables.
**More than one answer was given to the question.

Table 3. Conditions affecting the transition

Pediatric neurologists (n=31)	Neurologists (n=33)
Which factors increase the necessity of transitioning POMS patients to the adult clinics?	
- Do not want to legal responsibility due to >18 years (71%)	- Administer more effective immunotherapy to reduce possible future disability in adult clinic (64%)
- Insurance payment of some drugs > 18 years (65%)	- Desire to follow up on pediatric-onset MS patients (48%)
- Pregnancy plan (61%)	- Pediatric neurologists do not have enough experience about MS (39%)
Which factors reduce the possibility of transitioning POMS patients to the adult clinics?	
- Bonded, reluctant to leave pediatric neurologist (81%)	- Reluctance/uninformedness of pediatric neurologists for newer disease-modifying treatment agents (48%)
- Neurologists spend less time for patients (68%),	- Excess of patients in adult clinics (42%)
- Inability to communicate with a neurologist (42%)	- Difficulties communicating with parents (36%)
- Do not want to be in the same clinic with adult patients (32%)	
Do you think support is needed to realize the adaptation of patients to adult clinics?	
- Yes, a lot (n=17, 55%)	- Yes, a lot (n=12, 36%)
- Yes, maybe (n=12, 39%)	- Yes, maybe (n=13, 39%)
- Undecided (n=2, 6%)	- Undecided (n=7, 21%)
- No, needless	- No, needless (n=1, 3%)
Which group of health care providers facilitates the transfer process?	
- Physiotherapist (n=16, 52%)	-Physiotherapist (n= 15, 45%)
- Daily treatment units, specially trained nurses (n= 26, 84%)	-Daily treatment units, specially trained nurses (n= 26, 79%)
- Sufficient neurologists in the patient's place of residence (n=18, 58%)	-Sufficient neurologists in the patient's place of residence (n= 20, 61%)
Which ones do you think necessary for the better transition of patients?	
- Establishing a national system for the transition of MS patients (n= 18, 58%)	- Establishing a national system for the transition of MS patients (n=13, 39%)
- Creation of a specialized transition unit (n=18, 58%)	- Creation of a specialized transition unit (n=13, 39%)
- Providing transfer with joint meetings of neurologists and pediatric neurologists (n=25, 81%)	- Providing transfer with joint meetings of neurologists and pediatric neurologists (n=27, 82%)
- Writing detailed and official transfer notes (n=22, 71%)	- Writing detailed and official transfer notes (n=21, 63%)
Abbreviations: MS: multiple sclerosis, POMS: Pediatric onset multiple sclerosis	

Discussion

According to this multicentric survey, satisfaction with the transition procedure was suboptimal among pediatric neurologists and neurologists. Although consultation forms and face-to-face methods were usually applied in the transition procedure, both physician groups supported implementation of joint meetings, detailed transition notes and specialized transition units for more efficiency. The transfer procedure was applied more frequently by pediatric neurologists while fewer neurologists were transferring patients from pediatric neurologists. This discrepancy is likely due to the larger number of neurologists in practice compared to pediatric neurologists: this reduces the number of POMS patient per participating neurologist. Another statistical significance was in the method, face-to-face interaction used more by pediatric neurologists than neurologists. The majority of physicians agreed on the need for support in the adaptation of patients to adult clinics, for daily treatment units, specially trained nurses, and communication between neurologists and pediatric neurologists.

The aim of the transition is to prepare children, youth, families, and physicians for disease in adulthood. Transition and transfer to adult medical care can often be problematic [14]. There are very few objective data for transition/transfer care. Therefore more clinical studies are needed for particular disorders [15-17]. In the light of current studies, establishment of transition programs is important for physicians, non-physician health personnel, family, patients and caregivers. A detailed transfer note is important in the transition period, as is a joint transition clinic attended by pediatric and adult neurology specialists. This was also found in our study where both physician groups were somewhat satisfied but recommended improvement, preferably with a transition clinic. While pediatric neurologists had more face-to-face contact with neurologists, it was statistically significant that this method was used less by neurologists.

As they are in a period of separation from parents' care and assistance during clinical visits, it may be difficult for 18 year-olds to access specialized health care. Therefore, they may perceive follow-up in adult age as problematic [18]. Additionally, cognitive and communicative skills can be affected especially in neurological conditions, increasing difficulties experienced in the adult health

care system. For such reasons, many pediatric neurologists are concerned for the patient. Moreover, pediatric patients may not succeed in finding a neurologist for themselves, moving effectively to adult clinics, and may even discontinue their follow-up and treatment [19]. Patient transfers without a transition protocol may further reduce compliance with adult clinical care and limit the coordination of care [20-22]. Communication between pediatric and adult neurology clinics can improve patient care and although might initially appear as excess time spent for a single patient, ultimately reduces the cost of health care [18].

The age of transition should be based on the patients' abilities to resume responsibilities and take decisions which is usually possible after graduation from high school. As in the literature [23, 24], the majority of physicians in our study considered 18 years of age for patient transition. However adolescence is being prolonged in the current era according to changes in economical and cultural factors, employment and education status, and independence [25, 26]. Nevertheless, pediatric neurologists are bound to stop the follow-up of chronic patients after 18 years of age because of the health care system, legal responsibilities, insurance coverage of some drugs after age 18 years, and pregnancy issues, as observed in our study.

Another finding was the closer nature of patient-physician relationships in childhood possibly preventing patients and physicians from separating from each other. Likewise, difficulties in communicating with neurologists, time allowed in neurology visits, and reluctance of 18 year-olds to be in the same clinic with elderly or disabled patients complicate the transition period. Similar problems with the process of transition have been detected among general practitioners, adolescent health care providers, or pediatricians. The higher frequency of diseases such as epilepsy, neurometabolic diseases, cerebral palsy, and muscular disorders in childhood than in adulthood, and the greater experience of pediatric neurologists in these diseases affects the transfer of these patients to adult clinics. In our study, neurologists' higher experience with MS had a positive effect on transition while social reasons of POMS patients was in the opposite direction.

Co-working in the same hospital was common in our series. In general pediatric neurologists are more likely to work in a large hospital. This probably increases their use of the face-to-face transition method more than adult neurologists. The presence of neuroradiology, inpatient facilities, laboratory facilities, and enough treatment units reinforce the ability to diagnose, treat and follow up MS patients for both physician groups. Insufficient intensive care access in adult clinics may represent a drawback for adult MS patients.

The limitations of the study is the small number of participants. Although this number could have been increased in neurologists, it could not be increased in pediatric neurologists due to few pediatric neurologists were followed up demyelinating disorders. An almost equal number of pediatric neurologists and neurologists answered the questionnaire despite pediatric neurologists' lesser experience about demyelinating disorders. The lack of homogeneity in the physicians' experience may be another limitation of the study. Other factors to be examined and data to be collected include the opinion of patients, and the answers of physicians in general neurological care rather than specialized clinics. On the other hand, this is the first study on the transition procedures of POMS patients in Turkey and the recommendations can inspire studies on other chronic disorders in childhood, guide national and international transition clinics, and serve as a basis for the development of health policies.

Conclusion

In conclusion, both groups of physicians support the adaptation of POMS patients to adult clinics. Related requirements were listed as physiotherapists, daily treatment units, specially trained nurses. In addition the number of local neurologists was an important factor. Establishing a national system for transition, creation of a specialized units, providing facilities, allowing time for joint meetings of neurologists and pediatric neurologists, assistance in writing and sending detailed official transfer notes were the most important suggestions for transition according to both physician groups. Establishment of these procedures for POMS patients might contribute to prevention of disability in adulthood.

Acknowledgments
The author is grateful to Banu Anlar, Aslı Tuncer, and Pınar Acar Özen for contributing to this article.

Conflict of interests
The authors declare that there is no conflict of interest in the study.

Financial Disclosure
The authors declare that they have received no financial support for the study.

Ethical approval
Ethical compatibility of the study was approved by Hacettepe University Ethics Committee (Project number GO 21/416, Desicion number 2021 /07-58)

References

1. Bailey S. Bridging the gaps: Health care for adolescents. Psychiatric Bulletin. 2003;27:397.
2. Kaufman M, Pinzon J, pédiatrie Scd, l'adolescent Cdlsd. La transition des jeunes ayant des besoins particuliers vers les soins pour adultes. Paediatrics & Child Health. 2007;12:789-93.
3. Cooley WC, Sagerman PJ. Supporting the health care transition from adolescence to adulthood in the medical home. Pediatrics. 2011;128:82-200.
4. Nabbout R, Teng T, Chemaly N, Breuillard D, Kuchenbuch M. Transition of patients with childhood onset epilepsy: Perspectives from pediatric and adult neurologists. Epilepsy Behav. 2020;104:106889.
5. Allen D, Gregory J. The transition from children's to adult diabetes services: understanding the 'problem'. Diabet Med. 2009;26:162-6.
6. Pound N, Sturrock ND, Jeffcoate WJ. Age related changes in glycated haemoglobin in patients with insulin-dependent diabetes mellitus. Diabet Med. 1996;13:510-3.
7. Visentin K, Koch T, Kralik D. Adolescents with Type 1 Diabetes: transition between diabetes services. J Clin Nurs. 2006;15:761-9.
8. Holmes-Walker DJ, Llewellyn AC, Farrell K. A transition care programme which improves diabetes control and reduces hospital admission rates in young adults with Type 1 diabetes aged 15-25 years. Diabet Med. 2007;24:764-9.
9. Westwood A, Henley L, Willcox P. Transition from paediatric to adult care for persons with cystic fibrosis: patient and parent perspectives. J Paediatr Child Health. 1999;35:442-5.
10. Anderson DL, Flume PA, Hardy KK, Gray S. Transition programs in cystic fibrosis centers: perceptions of patients. Pediatr Pulmonol. 2002;33:327-31.
11. Malbrunot-Wagner AC, Bonnemains C, Troussier F, Darviot E, Chiffoleau M, Person C, et al. [Transition from pediatric to adult care: experience of a cystic fibrosis care center]. Arch Pediatr. 2009;16:235-42.
12. Camfield P, Camfield C. Transition to adult care for children with chronic neurological disorders. Ann Neurol. 2011;69:437-44.

13. Blum RW, Garell D, Hodgman CH, Jorissen TW, Okinow NA, Orr DP, et al. Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. J Adolesc Health. 1993;14:570-6.

14. Betz CL. Approaches to transition in other chronic illnesses and conditions. Pediatr Clin North Am. 2010;57:983-96.

15. Christie D, Viner R. Chronic illness and transition: time for action. Adolesc Med State Art Rev. 2009;20:981-7.

16. Rapley P, Davidson PM. Enough of the problem: a review of time for health care transition solutions for young adults with a chronic illness. J Clin Nurs. 2010;19:313-23.

17. Tuffrey C, Pearce A. Transition from paediatric to adult medical services for young people with chronic neurological problems. J Neurol Neurosurg Psychiatry. 2003;74:1011-3.

18. Young NL, Gilbert TK, McCormick A, Ayling-Campos A, Boydell K, Law M, et al. Youth and young adults with cerebral palsy: their use of physician and hospital services. Arch Phys Med Rehabil. 2007;88:696-702.

19. Oskoui M, Wolfson C. Current practice and views of neurologists on the transition from pediatric to adult care. J Child Neurol. 2012;27:1553-8.

20. Peter NG, Forke CM, Ginsburg KR, Schwarz DF. Transition from pediatric to adult care: internists' perspectives. Pediatrics. 2009;123:417-23.

21. Shaw KL, Southwood TR, McDonagh JE. Transitional care for adolescents with juvenile idiopathic arthritis: a Delphi study. Rheumatology (Oxford). 2004;43:1000-6.

22. Suris JC, Akré C, Rutishauser C. How adult specialists deal with the principles of a successful transition. J Adolesc Health. 2009;45:551-5.

23. Burke R, Spoerri M, Price A, Cardosi AM, Flanagan P. Survey of primary care pediatricians on the transition and transfer of adolescents to adult health care. Clin Pediatr (Phila). 2008;47:347-54.

24. Dobson JV, Bryce L, Glaeser PW, Losek JD. Age limits and transition of health care in pediatric emergency medicine. Pediatr Emerg Care. 2007;23:294-7.

25. Sawyer SM, Azzopardi PS, Wickremarathne D, Patton GC. The age of adolescence. Lancet Child Adolesc Health. 2018;2:223-8.

26. Curtis AC. Defining adolescence. J Adolescent Family Health. 2015;7:Article 2.