ORIGINAL ARTICLE

Treatment Comfort of Adult Neurologists in Childhood Onset Conditions

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ABSTRACT: ***Background:*** The majority of children with chronic neurodevelopmental disabilities are surviving to adulthood. Our goal was to assess how prepared and comfortable adult neurologists are in treating young adults with childhood onset chronic neurological conditions and evaluate the difficulty pediatric neurologists experience when transferring these patients to adult care. ***Methods:*** We conducted a cross-sectional study using two postal surveys of all pediatric and adult neurologists in the province of Quebec, Canada. ***Results:*** The response rate was 51.5%, with 119 neurologists completing the survey. Half of neurologists agreed that adult neurologists may not have adequate training in childhood onset disorders to prepare them to manage the disorders in adulthood, and 60% of pediatric neurologists reported having difficulty finding an adult provider for their patients. Adult neurologists were least comfortable treating patients with autism, chromosomal or metabolic disorders, and cognitive or behavioral disorders. ***Conclusion:*** Almost half of those surveyed believed that adult neurologists are not adequately trained to care for this growing patient population. Improving treatment comfort and knowledge among adult neurologists in childhood onset chronic neurological conditions may smooth the transition of these young adults from pediatric to adult care.

RÉSUMÉ: Les neurologues qui traitent des adultes sont-ils à l'aise de traiter des malade atteints de pathologies qui débutent dans l'enfance? ***Contexte :*** La majorité des enfants qui ont des troubles neurodéveloppementaux chroniques atteignent maintenant l'âge adulte. Le but de notre étude était d'évaluer le niveau de préparation et de confort des neurologues qui traitent des adultes vis-à-vis la prise en charge de jeunes adultes atteints de maladies neurologiques chroniques, qui ont débuté dans l'enfance, et d'évaluer les difficultés rencontrées par les neuropédiatres quand ils orientent ces patients vers les soins aux adultes. ***Méthode :*** Nous avons effectué une étude transversale au moyen de deux enquêtes postales auprès de tous les neuropédiatres et de tous les neurologues qui traitent des adultes de la province de Québec, au Canada. ***Résultats :*** Cent dix-neuf neurologues ont complété le questionnaire, soit un taux de réponse de 51,5%. La moitié des neurologues étaient d'avis que les neurologues qui traitent des adultes n'ont pas une formation adéquate sur les maladies qui commencent dans l'enfance pour les préparer à prendre en charge ces patients à l'âge adulte et 60% des neuropédiatres ont rapporté qu'ils avaient de la difficulté à trouver un neurologue qui traite des adultes pour prendre en charge leurs patients. Les maladies face auxquelles les neurologues qui traitent des adultes éprouvaient le plus d'inconfort étaient l'autisme, les maladies chromosomiques ou métaboliques, les troubles cognitifs ou comportementaux. ***Conclusion :*** Près de la moitié des répondants croient que les neurologues qui traitent des adultes n'ont pas une formation adéquate pour assurer les soins auprès de cette population sans cesse croissante. L'amélioration des connaissance chez les neurologues qui traitent des adultes pour des maladies neurologiques chroniques débutant dans l'enfance pourrait les rendre plus à l'aise de prendre en charge le traitement de ces patients et pourrait faciliter la transition de ces jeunes adultes des soins pédiatriques aux soins adultes.

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The transition to adult centered healthcare has become a priority mandate in pediatrics over the past decade with improved survival of children with complex medical conditions and disabilities[1,2]. This has been attributed in part to advances in medical care and also to a shift in attitudes towards their care[3]. Over 85% of children with cerebral palsy (CP), half of children with spina bifida, and 85% of children with Duchene muscular dystrophy (DMD) are now passing the threshold into adulthood[4-6]. With increased survival, these young adults with childhood onset chronic neurological disorders are increasingly graduating to an adult healthcare milieu[7]. A recent study of health care utilization in young adults with cerebral palsy showed that limited access to specialist physicians contributed to a gap in health care for these patients[8]. It is not known how well prepared and comfortable adult neurologists are in caring for these patients, or how difficult it may be for pediatric neurologists to transfer them to adult care.

Our goal was to assess how prepared and comfortable adult neurologists are in treating young adults with childhood onset chronic neurological conditions and compare this with the difficulty pediatric neurologist experience when transferring these patients to adult care in the province of Quebec, Canada.

Methods

Research Design

This was part of a larger cross-sectional study (STAND: Study on the transition of adolescents with neurological disorders) using two self-administered postal questionnaires, one for pediatric neurologists and one for adult neurologists.

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Eligible survey participants were neurologists licensed and actively practicing in the province of Quebec, with a separate questionnaire designed for pediatric and adult neurologists. Demographic information on all surveyed neurologists was gathered from the Collège des Médecins du Québec, including sex, language of correspondence, year of neurology certification and city of current practice. The questionnaires were developed based on available questionnaires in the literature in other specialties with input from an expert panel on the domains and the range of included items used to establish face validity of the questionnaires and to finalize content and clarity. Ethics approval was obtained from the McGill University Institutional Review Board (IRB) before initiating study.

Statistical Analysis

PASW statistics software version 18.0 (PASW, Chicago, IL 2009) was used for data entry and statistical analysis. Responses were described as percentages and absolute numbers for categorical data. The number of years in practice was calculated as of 2010 using the year of neurology certification. The Wilcoxon rank sum test was used to assess differences between groups for ordinal variables. All hypothesis tests were two-sided with α=0.05.

Results

A total of 231 eligible neurologists were identified to be included in the survey: 209 adult neurologists and 22 pediatric neurologists practicing in Quebec as of July 1 2009. 119 neurologists (16 pediatric neurologists and 103 adult neurologists) responded and agreed to complete the questionnaire (51.5%). Variation in the sample sizes listed in tables compared with the overall response rate is attributed to missing responses for those particular questions. Women, anglophones and pediatric neurologists were more likely to participate, as were neurologists with fewer years in practice. The median number of years since residency was 21 years.

Adult neurology training

Adult neurologists (N=103) were asked two questions seeking their opinion on the adequacy of their neurology residency programs in training them to care for young adults with childhood onset neurological disorders. For the first statement "my residency in adult neurology provided me with adequate training to care for these young adult with childhood onset neurological conditions", none of the participating adult neurologists strongly agreed, 45 (55.6%) somewhat agreed while 36 (44.4%) somewhat or completely disagreed, and 22 did not respond. For the second statement "Adult neurologists may not have the training in childhood onset chronic neurological disorders to prepare them to manage them in adulthood", 43 (41.7%) somewhat or completely agreed, only 19 (18.4%) somewhat or completely disagreed and 39 (37.9%) had a neutral opinion, with only two who did not respond.

Pediatric neurologists were also asked this second question. Of the 16 participating pediatric neurologists, 12 (75.0%) agreed with a rating of 4 or 5, only two (12.5%) disagreed with a rating of 2 and two (12.5%) gave a rating of 3, with none giving a rating of 1 or not responding (Table 1). Pediatric neurologists were more likely to think adult neurologists do not have adequate training (Wilcoxon Rank Sum statistic 5.476, p =0.019).

Treatment comfort level of adult neurologists

Adult neurologists were asked to rate their level of comfort in treating patients with each of ten selected neurological disorders on a 4 point scale from "completely comfortable" to "impossible" (Table 2). The participating adult neurologists reported being most comfortable (completely or somewhat comfortable) treating patients with cerebrovascular disorders (95.9%), headache (95.9%), epilepsy (92.9%), followed by multiple sclerosis (MS 79.8%), CP (72.7%), Tourette syndrome (61.2%) and Neuromuscular disorders (58.2%). The three disorders adult neurologists were the least comfortable treating (i.e. "not comfortable" or finding it "impossible") were autism (88.8% of adult neurologists), chromosomal/metabolic disorders (73.5%), and cognitive/behavioral disorders (50.0%). General adult neurologists reported themselves as significantly more comfortable treating patients with Tourette syndrome, multiple sclerosis, headache and epilepsy when compared to neurologists with a subspecialty. There was no significant difference in reported treatment comfort between neurologists based on the number of years in practice.

Table 1: Pediatric versus adult neurologists' opinion on adult neurology training

	5 point Likert scale*						
	1	2	3	4	5	Missing	Total
Adult neurologists	5	14	39	31	12	2	103
Pediatric neurologists	0	2	2	7	5	0	16
All neurologists	5	16	41	38	17	2	119

"Adult neurologists may not have the training in childhood onset chronic neurological disorders to prepare them to manage them in adulthood." * 1 represents "completely disagree", 5 represents "completely agree".

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Table 2: Reported comfort level in treating patients with selected neurological disorders: Adult neurologists

Neurological disorder	n	Completely comfortable n (%)	Somewhat comfortable n (%)	Not comfortable n (%)	Impossible n (%)
Autism	98	1 (1%)	10 (10%)	57 (58%)	30 (31%)
Chromosomal or metabolic disorders	98	1 (1 %)	25 (26%)	61 (62%)	11 (11%)
Cognitive or Behavioral disorders	98	16 (16%)	33 (34%)	46 (47%)	3 (3%)
Neuromuscular disorders	98	14 (14%)	43 (44%)	39 (40%)	2 (2%)
Tourette Syndrome	98	21 (21%)	39 (40%)	34 (35%)	4 (4%)
Cerebral palsy	99	19 (19%)	53 (54%)	23 (23%)	4 (4%)
Multiple Sclerosis	94	56 (60%)	19 (20%)	18 (19%)	1 (1%)
Epilepsy	98	54 (55%)	37 (38%)	7 (7%)	0 (0%)
Headaches	97	67 (69%)	26 (27%)	4 (4%)	0 (0%)
Cerebrovascular disease	97	68 (70%)	25 (26%)	3 (3%)	1 (1%)

Difficulty transferring patients

Sixty percent of pediatric neurologists reported having difficulty finding an adult provider for transferring young adults, most rating the level of difficulty as "very difficult". They were also asked to rate their level of difficulty in transferring patients with 10 selected neurological disorders on a 4 point scale from "completely comfortable" to "impossible" (Table 3). Overall, epilepsy, MS and cerebrovascular disorders were reported to be the least difficult to transfer, i.e. not at all difficult for the majority of participants. These correspond with disorders adult neurologists rated as being comfortable treating. The majority of pediatric neurologists reported that transfer was somewhat difficult, very difficult or impossible for patients with cognitive/behavioral disorders, followed by patients with CP, autism, chromosomal/metabolic disorders, Tourette syndrome, headache and neuromuscular disorders.

Discussion

Many of the surveyed neurologists believed adult neurologists may not have adequate training in childhood onset chronic neurological disorders to prepare them to manage them in adulthood. It is interesting that a direct question about the adequacy of their own adult neurology training resulted in a greater number of missing responses than when asked indirectly, possibly reflecting a self-report bias. A propensity to give socially desirable responses is well established in self-report

Table 3: Difficulty transferring patients with different neurological disorders: Pediatric neurologists

Neurological disorder	n	Not at all difficult n (%)	Somewhat difficult n (%)	Very difficult n (%)	Impossible n (%)
Cognitive or Behavioral disorders	13	0 (0%)	4 (31%)	6 (46%)	3 (23%)
Autism	10	1 (10%)	4 (40%)	2 (20%)	3 (30%)
Cerebral palsy	14	1 (7%)	9 (64%)	3 (21%)	1 (7%)
Chromosomal or metabolic disorders	13	2 (15%)	9 (69%)	2 (5%)	0 (0%)
Tourette Syndrome	12	2 (17%)	6 (50%)	3 (25%)	1 (8%)
Headaches	12	3 (25%)	8 (67%)	1 (8%)	0 (0%)
Neuromuscular disorders	14	6 (43%)	7 (50%)	0 (0%)	1 (7%)
Cerebrovascular disease	14	9 (64%)	5 (36%)	0 (0%)	0 (0%)
Epilepsy	14	11 (79%)	3 (21%)	0 (0%)	1 (7%)
Multiple Sclerosis	13	11 (85%)	2 (15%)	0 (0%)	0 (0%)

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questionnaires, and a less personally directed question may have an improved sensitivity[9]. Despite this, none of the participating adult neurologists strongly agreed that their residency provided them with adequate training, with almost half disagreeing. Patients with autism and chromosomal or metabolic disorders, cognitive or behavioral disorders were rated as the most difficult to transfer to adult care by pediatric neurologists and were also the patient groups that adult neurologists felt the least comfortable treating. However, although a large number of adult neurologists were somewhat or completely comfortable treating patients with cerebral palsy, the majority of pediatric neurologists stated having difficulty transferring these patients to adult care. Unmeasured factors other than physician treatment comfort also likely play a role in determining difficulties transferring patients to an adult care provider.

This is the first survey of which we are aware that has assessed neurologists' preparedness and treatment comfort as well as difficulties transferring young adults with childhood onset chronic neurological disorders. Our study has some limitations. A selection bias may be present if participants and non participants are systematically more or less comfortable treating patients with these disorders. It is also important to outline that treatment comfort does not determine quality of care or willingness to accept patient transfers. Further studies are needed to explore the barriers specific to the transfer and transition of neurology patients to adult care, and qualitative or mixed methods studies would be ideally suited to address this.

Adult neurology residency curriculums can benefit from additional training in transition and management of young adults with childhood onset chronic neurological conditions. Pediatric neurology residents would also benefit from learning about transition as a process and the individualized steps needed for patients to achieve a successful transition as adults. Improving treatment comfort and knowledge among adult neurologists in childhood onset chronic neurological conditions may smooth the transition of these young adults from pediatric to adult care.

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