Study on the Transition of Adolescents with Neurological Disorders (STAND)

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Abstract

<u>Background</u>: Children with chronic neurological disorders are increasingly surviving to adulthood and transitioning to adult healthcare. Our objectives were to describe, from the neurologists' perspective, current practice and views on health care transition in Quebec, including barriers and facilitators to the process, if patients experience a gap in care, and if adult neurologists are adequately trained to care for these patients.

<u>Methods:</u> We conducted a cross sectional study using two postal surveys of all Quebec pediatric and adult neurologists.

<u>Results:</u> The overall response rate to the mailing was 65.4%, with 51.5% participation rate. Most do not have a transition program in place but some plan to develop one in the next two years. Nearly half of neurologists believed patients experience a gap in care during the transition process. Half of neurologists agreed that adult neurologists may not have adequate training in childhood onset chronic neurological disorders to prepare them to manage these disorders in adulthood, and 60% of pediatric neurologists reported having difficulty finding an adult provider for their patients. The majority of neurologists agreed that patient's knowledge of their medical condition and medication, compliance with medication, capacity for active participation during office visits, co-existence of a communication or behavioral disorder, and need for multidisciplinary care were all important factors affecting the success of transition.

<u>Conclusion</u>: Half of surveyed neurologists believed patients experience a gap in care during the transition period. Neurologists reported multiple barriers to the transition process including both patient and physician specific factors. Almost half of surveyed physicians believed adult neurologists are not adequately trained to care for this growing patient population.

Sommaire

La problématique: Les enfants souffrant de troubles neurologiques chroniques vivent de plus en plus jusqu'à l'âge adulte. Nos objectifs étaient de décrire, du point de vue du neurologue au Québec, la pratique courante et les opinions à l'égard de la transition de ces adolescents des soins pédiatriques aux soins adultes, incluant les barrières au processus, si les patients éprouvent un carence en soins durant cette période, et si les neurologues pour adultes ont la formation requise pour prendre soin de ces patients.

<u>Les méthodes:</u> Nous avons fait une étude transversale par envoyant deux questionnaires par la poste à tous les neuropédiatres et neurologues pour adultes du Québec.

<u>Résultats</u>: Notre taux de réponses à l'envoi des questionnaires était de 65.4%, avec un taux de participation de 51.5%. La plupart n'avaient pas de programme de transition sur place, mais plusieurs planifiaient développer un programme dans les deux prochaines années. Presque la moitié des neurologues croyaient que les patients éprouvent une carence en soins durant la période de transition aux soins adultes. La moitié des neurologues croyaient que les neurologues pour adultes n'ont peut être pas la formation requise pour prendre la relève des soins des jeunes adultes ayant un trouble neurologique chronique débutant en enfance. 60% des neuropédiatres éprouvaient des difficultés à trouver un médecin pour adultes pour prendre la relève des soins de leurs patients. La majorité des neurologues croyaient que la connaissance du patient de sa maladie et de ses médicaments, la conformité aux médicaments, la capacité de participer pleinement durant les visites chez me médecin, la présence d'un trouble de communication ou de comportement, et le besoin de soins multidisciplinaires étaient des facteurs jouant des rôles importantes durant la période de transition des soins.

<u>Conclusion:</u> La moitié des neurologues croyaient que les patients éprouvent une carence en soins durant la période de transition. Les neurologues ont fait rapport de plusieurs obstacles à la transition des soins, soit des facteurs reliés aux patients et Page **5** of **86**

d'autres reliés aux médecins et services de soins. Presque la moitié des neurologues croyaient que les neurologues pour adultes n'ont pas la formation requise pour prendre soin de ce groupe croissant de patients.

List of Abbreviations

AAP: American Academy of Pediatrics CF: Cystic fibrosis CHD: Congenital heart disease CMQ: Collège des Médecins du Québec CI: Confidence Interval CP: Cerebral palsy CPS: Canadian Pediatric Society DMD: Duchenne muscular dystrophy HCPs: Health care professionals IRB: Institutional Review Board MM: Mixed methods MMAT: Mixed methods appraisal tool MS: Multiple sclerosis MUHC: McGill University Health Centre QUAN: Quantitative QUAL: Qualitative SHCN: Special health care need

Preface

This thesis consists of five chapters. The first chapter provides an overview of healthcare transition and outlines the research objectives. The second chapter is a literature review on perspectives of healthcare professionals on the process and factors involved in health care transition. The third chapter describes the methods of the study, and the results and analysis are presented in the fourth chapter. In the fifth and final chapter we discuss the study findings and make recommendations for future research.

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Chapter 1. Overview and Objectives

What is transition?

Transition of care is not simply the physical transfer of a patient and their medical record to an adult center but is rather planned and managed as a process. The position statement by the Society for Adolescent Medicine defines health care transition as "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care system". (1)

The consensus statement by the American Academy of Pediatrics (AAP) on health care transitions for young adults with special health care needs defines transition in health care as "a dynamic, lifelong process that seeks to meet their individual needs as they move from childhood to adulthood. The goal is to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood." (2)

The benefits of developing an organized transition program with improved continuity of care include better patient care, reduced long term health care costs, and improved sharing of information among health care professionals.(2) Transition programs aim to improve the young adult's skills in negotiating the adult heath care system independently, minimize secondary illnesses, plan for their long term needs, and promote autonomy. A recent study comparing health care service use between adolescents and young adults with cerebral palsy in Ontario showed a decline in the proportion of visits to specialists and an increase in emergency department visits as these individuals become young adults. (3) The authors postulate that the increase in emergency department visits result from limited access to specialist care.

Position Statements

Over the past decade multiple consensus and position statements have been published on healthcare transition. The AAP published their consensus statement on health care transitions for young adults with special health care needs in 2002. (2) They outlined six critical steps for successful transition. The first is identifying a health care professional (HCP) who assumes responsibility for care coordination and planning in partnership with other HCPs, the youth and their family. The second step is to "identify the core knowledge and skills required to provide developmentally appropriate health care transition services to young people with special health care needs and make them part of training and certification requirements for primary care residents and physicians in practice." The third is preparing and maintaining an up-to-date medical summary that will be accessible to collaborating HCPs. The fourth is to create a transition plan together with the youth and their family by age 14 years and update this annually. The fifth step is to follow primary and preventive guidelines recognizing that youth with special health care needs may require additional resources to optimize their health. The last proposed step is to ensure affordable continuous health insurance coverage during this transition period, a step less applicable in Canada where a public health care system is in place.

The Society of Adolescent Medicine published a position paper in 2003 on the transition to adult health care for adolescents and young adults with chronic conditions following a national consensus conference in 2001 where the AAP consensus statement also originated.(4) Their principles of successful transition include providing services that are both developmentally and chronologically appropriate, preparing youth for common health promoting and damaging behaviours, enhancing their autonomy and personal sense of responsibility. Transition planning also needs to be flexible and individualized, and is most successful transition as designated professional taking responsibility for the process together with the youth and their family. They identified the six critical first steps for successful transition as outlined in the AAP consensus statement. In addition, they recommend ongoing education of patients, families and providers to highlight the importance of a developmentally appropriate and coordinated **Page 10** of **86**

transition. They also recommend that adults receive care in an adult healthcare setting and to engage adult health care providers in the transition process to make adult oriented health services more available to youth with chronic health conditions. Collaborative development of best practice guidelines will help manage young adults with childhood onset chronic conditions that adult health care providers currently may not be as comfortable treating. They also recommend eliminating policies that impede a timely transition.

The Canadian Pediatric Society (CPS) issued a position statement in 2006 on the care of adolescents with chronic illness, with some specific recommendations for transition.(5) The CPS states that pediatricians should be flexible and take into consideration the developmental age of youth when deciding on the time to transfer them to adult care. The transition to adult care should be continuous, comprehensive and coordinated, with discussions regarding transition beginning between the ages of 10 and 12 years. The CPS also issued a position statement on the transition to adult care for youth with special health care needs. (6) This position statement describes different cultures of care between pediatric and adult care in the type and level of support, decision-making, consent processes and family involvement. The health care goals for transition planning are adolescent involvement in the management of their condition; adolescent and family understanding of their condition; understanding of personal potential for activity, education, recreation and vocation; completion of adolescent developmental tasks; and the attainment of self-esteem and self-confidence. The core principles of transition planning are to start early in childhood, giving the child increasing responsibility and information with age, collaborate with adult health care providers and community health clinics, and involve youth with cognitive disabilities in a way that is meaningful to them. Furthermore, transition planning should be youth-focused and youth-paced within the family context, with support provided for the family.

The United Kingdom Department of Health published a best practice guideline in 2006 on improving the transition of young people with long term conditions.(7) They present four models of transition: a dedicated follow-up service within an adult setting, a Page 11 of 86

seamless clinic with both child and adult professionals, a generic transition team within the pediatric hospital such as the On Trac model in British Columbia, or having generic transition coordinators for larger geographical areas. Specific to young people with neurological conditions and disabilities, the UK policy states that they are the least well served as there is often no service available to care for them as adults. Youth with neurodevelopmental disabilities often need multidisciplinary care yet their disability makes it more difficult for them to access these services which are also less available to them as adults. The UK policy recommends establishing neurodevelopmental teams made up of a consultant in rehabilitation medicine jointly pediatric and adult, a specialist transition nurse, an occupational therapist, and a general practitioner with interest in disability. The concept of a key worker and lead professional are emphasized.

Every 10 years in the United States, Healthy People (<u>http://www.healthypeople.gov</u>) sets science-based national health objectives reflecting changing public health priorities. Healthy People 2010 established the goal that all young people with special health care needs will receive the services needed to make necessary transitions to all aspects of adult life, including health care, work, and independent living. A new objective proposed for Health People 2020 is to "increase the proportion of parents or other caregivers of youth with disabilities aged 12 to 17 years who report engaging in transition planning from pediatric to adult health care." (DSC HP2020-15) Feedback to date on this objective is to include wording that youth with disabilities are partners and participants in planning for transition from pediatric to adult health care.

Several subspecialty or disease specific guidelines and models of transition have also been developed, such as for inflammatory bowel disease, congenital heart disease, type 1 diabetes or cystic fibrosis, but none specific for neurological disorders. (8-11)

Transition in Neurology

The transition to adult centered health care has become a priority mandate in pediatrics over the past decade with improved survival of children with complex medical conditions and disabilities. This has been attributed in part to advances in medical care Page 12 of 86

and also to a shift in attitudes towards their care. (12) Today, the majority of children with chronic neurodevelopmental disabilities are surviving to adulthood. 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. (13-15)

The overall disability prevalence in Canada is estimated to be 13.5% standardized to the 2001 population, which is comparable to the estimated prevalence in the United States of 12.8%.(16, 17) The reported prevalence of disability in children obtained from Statistics Canada is 4.6% in children aged 5-14 years and 4.7% in young adults aged 15-24 years.(17) Many of the conditions listed by Statistics Canada under their definition of disability are either neurodevelopmental or commonly seen in a pediatric neurology practice, namely difficulties with hearing, vision, speech, mobility, agility, learning, as well as developmental delay, developmental disorder (includes genetic syndromes, autism, or mental retardation with CP), psychological (behavioural disorders), and chronic conditions (including epilepsy, CP, spina bifida, and muscular dystrophy).

The increased prevalence and survival of these children with neurodevelopmental disabilities pose new challenges to both pediatric and adult neurologists involved in their care. In most Canadian pediatric insitutions, neurology patients over 18 years of age are transferred to an adult neurologist or physician. The age at transfer of care to an adult neurologist can be delayed until 21 years in cases where a specialized adult center or provider cannot easily be identified. Graduating to an adult healthcare milieu however is important in providing these young adults with age-appropriate services not as readily available in pediatrics. The adolescents transferring from pediatric neurology often have complex medical conditions with physical disabilities as well as limitations in cognitive and communication skills which increase their difficulties in transitioning to and navigating through the adult care system. A recent review on the transition of adolescents with cerebral palsy and spina bifida identified only 11 original studies, none of which explored specifically the concerns of neurologists. (18)

Perspectives of both the pediatric and adult neurologists on the barriers and facilitators to this transition are essential in making key recommendations in planning transition programs in neurology. Our literature review will focus on the concerns of HCPs on the transition process from pediatric to adult centered care. The goal of our study is to determine current practices and views of neurologists on healthcare transition specific to the field of neurology in Quebec.

Specific Objectives

- 1. Identify current practices in transitioning young adult patients with childhoodonset neurological conditions.
- 2. Identify barriers and facilitators of transfer and transition perceived by neurologists.
- 3. Determine if neurologists perceive that patients experience a gap in care during the transition period.
- 4. Determine if neurologists believe that adult neurologists have adequate training to care for young adults with childhood onset chronic neurological conditions.

Concerns of health care professionals on barriers and facilitators to transition: a thematic analysis of the literature

Introduction

Children with chronic neurological disorders are increasingly surviving to adulthood, posing a new challenge to neurologists involved in their care when faced with graduating these children to an adult centered practice.(13-15) Transition programs aim to improve the young adult's skills in negotiating the adult heath care system independently, minimize secondary illnesses, plan for their long term needs, and promote autonomy.(2) The position statement by the Society for Adolescent Medicine defines health care transition as "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care system".(1) Many adolescents in pediatric neurology practise have special health care needs and are optimal candidates to benefit from a transition program. They often have complex medical conditions with physical disabilities as well as limitations in cognitive and communication skills increasing their difficulties in transitioning to, and navigating through, the adult health care system.

Perspectives of both the pediatric and adult neurologists involved in their care are essential in making key recommendations in planning such transition programs in neurology. A recent review on the transition of adolescents with CP and spina bifida identified only 11 original studies, none of which explored specifically the concerns of neurologists on the barriers and facilitators to transition.(18) The purpose of this review is to identify and synthesize concerns of all health care professionals (HCPs) on the transition process from pediatric to adult centered care.

Methods

Overview of the method: A comprehensive search of the literature was undertaken to identify, select, appraise and synthesize relevant quantitative, qualitative and mixed methods studies exploring the perspectives of HCPs on the transition process in young adults with childhood onset chronic conditions within all disciplines. We conducted a qualitative synthesis of research-based knowledge using thematic analysis to highlight important themes in the literature.

Specific Objectives: To outline the concerns of HCPs regarding barriers and facilitators to the health care transition of young adult patients with childhood onset conditions.

Identification of potentially relevant references based on titles and abstracts: The first step of our strategy was to be comprehensive and include all potential citations related to health care transition of young adults. Bibliographic databases were searched on June 21st 2010, including: Medline via Ovid (1950 to June week 2 2010), PsychInfo via Ovid (1967 to June week 3 2010) and CINAHL. The search terms used in Medline are listed are Table 2.1, and this strategy was adapted for both PsychInfo and CINAHL. The search strategy was developed and adapted with the help of a health sciences librarian from McGill University.

- 1. Young Adult/
- 2. Adolescent Health services/
- 3. Pediatrics/
- 4. "Continuity of Care"/
- 5. Patient Transfer/
- 6. Transfer Agreement
- 7. (transition adj9 care).ti.
- 8. Adolescen*.ti.
- 9. (adult adj2 care).ti.
- 10. Adolescent/
- 11. 1 or 2 or 3 or 8 or 10
- 12. 4 or 5 or 6
- 13. 7 or 9
- 14. 11 and 12 and 13

The MESH term "health transition" could not be used in Medline as it refers to a different phenomenon as follows: "Demographic and epidemiologic changes that have occurred in the last five decades in many developing countries and that are characterized by major growth in the number and proportion of middle-aged and elderly persons and in the frequency of the diseases that occur in these age groups." Similarly, the phrase "health transition" could not be used in CINAHL as it is defined in a similar way as above, as: "The change in health care needs and status due to epidemiologic and demographic influences."

Figure 2.1 outlines the identification and selection process. A total of 451 references from Medline, PsychInfo and CINAHL were imported into Endnote X2 reference manager and 52 duplicates were deleted. The titles and abstracts of these 399 references were reviewed by MO and 219 citations were retained as pertaining specifically to the topic of health care transition in young adults.





The second step was to narrow down the set of references to identify empirical studies exploring perspectives of HCPs on transition. Titles and abstracts of the 219 identified articles were reviewed, and 21 were selected. Of the 198 references that were rejected, 12 were case reports or case studies, 7 were clinical practice guidelines or consensus statements, 136 were review articles or editorials, and 43 were empirical studies not pertaining to HCPs.

A further 157 references were identified using citation tracking by screening references that cite the 21 selected relevant papers using ISI Web of Science. From the 157 references identified from the first loop, 5 duplicates were removed. The titles and abstracts of the 152 references remaining were reviewed and 95 identified on health care transition. Of the latter, 15 empirical studies were identified on perspectives of HCPs. Of these, 9 were duplicate studies identified in our search of bibliographic databases and two studies were published in German and could not be retained.

References of the 4 selected studies were searched again for a second loop of citation tracking in ISI Web of Science. 84 references were identified, of which 15 were not on transition and 58 were not empirical studies exploring perspectives of HCPs. The 11 remaining studies were duplicates already identified either in our search of bibliographic databases or from our first loop of citation tracking, reaching saturation. Thus a total of potential 24 studies (21 from the original search + 3 from citation tracking) were identified as pertaining to perspectives of HCPs on health care transition. The full text articles of these 24 studies were retrieved.

Selection of relevant studies based on full-text papers: The full text articles of the 24 studies were reviewed using the inclusion and exclusion criteria listed in Table 2.2.

Table 2.2: Inclusion and exclusion criteria used in the selection process

Inclusion criteria:

1. Study should address the topic of health care transition

2. Study should explore the perspective of health professionals (physicians, nurses, social workers, physical therapist, and occupational therapist)

3. Primary empirical study

Exclusion criteria:

1. Study addressed the topic of health transition as defined by Medline MESH term (see above)

2. Study explores the perspective of patients or family members

3. Review articles, editorials, conference proceedings.

Of the 24 studies for which full-text articles were retrieved, 20 were included and four were rejected. An overview of the methods of these 20 studies is presented in table 2.3: 14 were observational QUAN studies, 3 MM studies, and 3 QUAL studies.

Reference	Year	Method	Participants
1(19)	2007	QUAN: Cross-sectional study	58 pediatric dialysis centers in North
		Mailed Survey	America and Europe
2(20)	2008	QUAN: Cross-sectional study	103 primary care pediatricians in Rhode
, ,		Mailed Survey	Island, USA
3(21)	2009	QUAN: Cross-sectional study	45 HCPs in a pediatric cardiology
		Mailed Survey	clinic, in Toronto, Canada
4(22)	2007	QUAN: Cross-sectional study	73 pediatric emergency department
		Mailed Survey	medical directors, in USA
5(23)	2004	QUAN: Cross-sectional study	291 team members, CF, in USA
		Mailed Survey	
6(24)	2001	QUAN: Cross-sectional study	104 CF program directors in USA
		Mailed Survey	
7(25)	2009	QUAN: Cross-sectional study	363 gastroenterologists in USA
		Mailed Survey	
8(26)	1999	QUAL: Focus groups	8 pediatric and adult clinicians from
		Content analysis	sickle cell disease clinics in USA
9(27)	2009	QUAN: Cross-sectional study	69 Pediatric cardiology programs in
		Mailed Survey	USA and Europe
10(28)	2009	QUAN: Cross-sectional study	448 team members of CF programs, in
		Mailed Survey	USA
11(29)	2003	QUAL: Focus groups	Two MDs of young adults with
		Thematic analysis	disabilities in USA
12(30)	2010	QUAN: Cross-sectional study	1289 internists and pediatricians, in
		Mailed Survey	USA
13(31)	2009	QUAN: Cross-sectional study	67 internists in USA
		Mailed Survey	
14(32)	2004	MM: Cross-sectional study	40 HCPs in USA
		Mailed survey, content analysis	
15(33)	2005	QUAL: Focus groups	50 HCPs of youth with disabilities, in
		Content and narrative analyses	USA
16(34)	2002	QUAN: Cross-sectional study	10 primary care physicians, in USA
		Mailed Survey	
17(35)	2003	MM Cross-sectional study	478 HCPs involved in the care of teens
		Mailed survey, content analysis	with juvenile idiopathic arthritis, UK
18(36)	2009	QUAN: Cross-sectional study	209 adult specialists in Switzerland
		Mailed Survey	
19(37)	2004	MM: Cross-sectional study	227 HCPs for SCD in USA
		Mailed survey, content analysis	
20(38)	2003	QUAN: Cross-sectional study	37 centers for chronic endocrine disease
	1	Mailed Survey	in Italy.

Table 2.3: Overview of the 20 included articles

MM: Mixed methods

QUAN: Quantitative

QUAL: Qualitative

Appraisal of selected studies: The Mixed Methods Appraisal Tool (MMAT) (Version 2009.11.16) was used for quality assessment of the selected studies. (39) There is no consensus on the criteria to be used for the quality appraisal of MM studies. The MMAT, developed at McGill University, takes on average 15 minutes per study to apply and has an intra-class correlation of 0.8 based on pilot testing in 2009. The MMAT appraisal describes the methodological quality of the three components of mixed methods research: MM, QUAL and QUAN (observational, non-randomized controlled or randomized controlled experimental). The quality appraisal of the selected studies is presented in table 2.4. No studies would be excluded based on quality assessment; therefore a total percentage score was not used.

Table 2.4: Quality appraisal of selected studies

Table 2.4.1. Qualitative studies:

Methodological quality criteria	Selected studies			
	(26)	(29)	(33)	
1.1. Do the researchers state a qualitative objective or question?	Yes	Yes	Yes	
1.2. Is there a description of an appropriate qualitative approach or design or method?	Yes	Yes	Yes	
1.3. Is there a description of the context of the study and how findings relate to the context?	Yes	Yes	Yes	
1.4. Is there a description of the participants and a justification for the sampling?	Yes	No	Yes	
1.5. Are the qualitative data collection and analysis processes described?	No	Yes	Yes	
1.6. Do the researchers describe their reflexivity?	No	No	No	

Table 2.4.2. Mixed methods studies:

Methodological quality criteria	Select	Selected studies			
	(32)	(35)	(37)		
2.1. Is there a combination of qualitative and quantitative data collection	Yes	Yes	Yes		
techniques and/or data analysis procedures?					
2.2. Do the researchers describe and justify the mixed methods design?	No	Yes	No		
2.3. Is there an integration of qualitative data (or findings) and quantitative	Yes	Yes	Yes		
data (or results)?					

Methodological quality criteria	Selected studies													
	(19)	(20)	(21)	(22)	(23)	(24)	(25)	(27)	(28)	(30)	(31)	(34)	(36)	(38)
3.1. Is the sampling and sample justified?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
3.2. Do the researchers describe and justify measurements (origin and/or validity and/or standard)?	No	Yes	No	No	Yes	Yes	No	Yes	Yes	Yes	Yes	No	Yes	No
3.3. Is there (i) a control for confounding variables when applicable, and (ii) an acceptable response rate (60% or above)?	No	Yes	No	Yes	No	Yes	No	No	Yes	No	No	No	Yes	No

Table 2.4.3. Observational quantitative studies:

Synthesis of retained studies: We used an inductive thematic analysis for synthesis. In qualitative research, thematic analysis is a process of synthesizing qualitative data into themes and sub-themes.(40) In the field of literature reviews, thematic analysis is used to conduct qualitative synthesis of original qualitative, quantitative and/or mixed methods research studies.(41) It consists of building themes from the text of documents reporting retained studies.(42) Inductive thematic analysis is data-driven, without trying to "fit it into a pre-existing coding frame or the researcher's analytic preconceptions".(43) This inductive approach is ideal for our literature review as it allows us to explore the richness of the available literature prior to any interpretation. The results sections of all 20 selected studies were manually coded by MO to generate initial categories that organize the data into meaningful themes related to perspectives of HCP on the transition process and factors involved. These categories were then reviewed to consolidate key themes that recurred across the data. Once the key themes were identified, the studies were reviewed to ensure that no reference to a theme was missed.

Findings

We identified 10 themes in our analysis from the 20 included studies. An overview of these themes is presented in table 2.5.

	THEMES											
REFERENCE	1	2	3	4	5	6	7	8	9	10		
(19)	Х		Х			Х			Х			
(20)	Х	Х	Х	Х	Х							
(22)	Х		Х									
(24)	Х	Х				Х				Х		
(23)	Х	Х				Х				Х		
(28)	Х	Х	Х	Х		Х	Х					
(27)	Х		Х		Х	Х			Х			
(38)	Х	Х	Х	Х	Х							
(26)	Х		Х		Х					Х		
(32)	Х		Х	Х	Х							
(33)	Х		Х		Х	Х		Х	Х			
(31)	Х		Х	Х				Х		Х		
(21)		Х					Х			Х		
(35)			Х	Х	Х	Х	Х	Х	Х	Х		
(36)			Х		Х							
(25)				Х			Х	Х				
(29)					Х	Х		Х				
(30)					Х			Х	Х			
(34)					Х				Х	Х		
(37)			Х		Х		Х					

Table 2.5: Overview of themes from selected articles

Theme 1: A predetermined age alone may not determine readiness to transfer.

- Theme 2: The suggested time to start the transition process is highly variable but often later than recommended.
- Theme 3: Although most pediatric centers do not have a transition program or policy in place, the majority agree that there is a need for one.
- Theme 4: Providing a transfer summary may be an important facilitator of transition however it is not a universal practice.
- Theme 5: Poor communication between the pediatric and adult provider is a barrier to the transition process.
- Theme 6: Developmental delay, cognitive disability and complexity of medical condition are barriers to successful transition.
- Theme 7: Patient's understanding of their medical condition and their medications is a facilitator to transition.
- Theme 8: The adult health care provider's lack of knowledge or training in childhood onset conditions is a barrier to successful transition.
- Theme 9: The lack of availability of adult providers and specialty resources is a barrier to successful transition.
- Theme 10: Parents may be reluctant to transfer to adult care.

Theme 1: A predetermined age alone may not determine readiness to transfer. An age limit policy and practice for transfer of care to an adult center is commonly reported among pediatric subspecialists, varying between 15 to 22 years of age (19, 20, 22-24, 26-28, 31-33, 38) The most commonly cited ages are 18 and 21 years. However in practice young adults older than this set age limit continue to be cared for in pediatric centers. (22-24, 28, 38) Overage exceptions are usually made for patients with special health care needs such as patients with cystic fibrosis (CF), congenital heart disease (CHD), sickle cell disease, or patients in oncology, nephrology, or who are technology-dependent such as patients with baclofen pumps for spasticity. Among surveyed primary care pediatricians, "many more adolescents with special health care needs remained in pediatric practice, or hung out (28.4%), compared with their peers without special needs (6.6%)". (19) Maturity is taken into consideration along with age when assessing patient readiness to transfer, as young patients are not always ready to assume decision-making responsibility.(26, 27, 31-33) Concerning the time of transitioning, one pediatrician stated: "It needs to be instituted by the medical care providers when they recognize a certain level of maturity, a certain age, or certain point in an individual's life".(26)

Theme 2: The suggested time to start the transition process is highly variable but often later than recommended. The AAP published a consensus statement 8 years ago on health care transitions for young adults with special health care needs (SHCN). Among their recommendations was to prepare a health care transition plan by age 14 years together with the patient and their family.(2) However many of the surveyed HCPs believed the transition process should begin later than this, often stating 1 or 2 years prior to transfer.(20, 21, 23, 24, 28) The majority of health care providers of children with CHD in Toronto suggested that the transition process should start as early as 13-16 years of age.(21) In a survey of CF programs, although the transfer of care occurs at a median age of 19 years, the transition process starts at a median age of 17 years, "leaving a limited amount of time for patients, families and care teams to delineate and foster self-care skills". (28) A timely transition process would allow to anticipate and prepare the patient for transition at the peri-pubertal age.(38)

Theme 3: Although most pediatric centers do not have a transition program or policy in place, the majority agree that there is a need for one. On average, a third of surveyed HCPs reported having a transition program or clinic in place, although most believed there was a need for one. (19, 27, 28, 32, 35, 37) A written transition policy was reported by an even lower proportion of HCPs, the lack of which was reported as a barrier to transition. (20-22, 26, 33, 35, 36, 38) The lack of protocol was reported as "leaving patients unprepared for an abrupt transfer"(26), contributing to the loss of follow-up in the adult center (35), and limiting the coordination of care.(31, 36)

Theme 4: Providing a transfer summary may be an important facilitator of transition however it is not a universal practice. Maintaining an up-to-date medical summary that is accessible and portable is recommended by the AAP in their consensus statement on Transition.(2) However, fewer than half of surveyed HCPs reported providing or receiving a medical summary before transfer of care.(20, 24, 38) HCPs in adult centers reported difficulty obtaining past medical records as a barrier to transition. (25, 31, 32, 35)

Theme 5: Poor communication between the pediatric and adult provider is a barrier to the transition process. Lack of communication between pediatric and adult providers was raised as a barrier to transitioning patients among HCPs.(26, 27, 29, 32-35) Communication is not only helpful prior to transfer, but also to provide feedback from the adult specialist after the transfer takes place.(33, 38) Despite this, communication between providers is not routine practice.(20, 30) A transition program can promote better communication among providers.(37)

Theme 6: Developmental delay, cognitive disability and complexity of medical condition are barriers to successful transition. Children with SHCN are the focus of transition programs as they move on to adult centered care. These children are at increased risk of having difficulties in transitioning and their transfer can be delayed. Patient characteristics reported by HCPs as barriers to successful and timely transition include developmental delay, cognitive disability and complexity of medical condition. (23, 24, 27, 28, 33, 35) A survey of general practitioners reported that many "felt ill

equipped to deal with specific complex disabilities, lacked experience and knowledge about the management of intellectual disability and lacked confidence in managing these patients".(29)

Theme 7: Patients' understanding of their medical condition and their medications is a facilitator to transition. Having a limited understanding of their medical condition, their medication or side effects has been reported as a barrier to successful transition by HCPs. (21, 25, 35) The patient's ability to list their medications and their function (why they are taken) has also been used in assessing a patients' readiness for transfer.(28, 37)

Theme 8: The adult health care provider's lack of knowledge or training in childhood onset conditions is a barrier to successful transition. One of the key objectives of the AAP consensus statement on the transition of young adults with SHCN was to "identify the core knowledge and skills required to provide developmentally appropriate health care transition services to young people with SHCN and make them part of training and certification requirements for primary care residents and physicians in practice". (2) However, the lack of training of adult HCPs in childhood onset chronic disease was reported as a barrier to care for these young adults by both pediatric and adult healthcare providers.(29-31, 33, 35) As stated by one physician "they will continue to go to that peds pulmonologist because when they go to an adult pulmonologist, they don't know what to do with them".(33) Adult providers can also lack training in adolescent health and developmental and mental health issues of adolescents. (25, 35)

Theme 9: The lack of availability of adult providers and specialty resources is a barrier to successful transition. Young adults with special health care needs may require more resources and services to optimize their health. (2) However, HCPs may be unaware of available support services in adult sites or these may be less available than in the pediatric milieu. (19, 34) Furthermore, the lack of availability of adult specialists and primary care providers with knowledge of childhood onset chronic disorders is a barrier to transfer of care.(27, 30, 33) Inadequate resources, including

developmentally appropriate resources for patients and parents and significant losses of multidisciplinary support in the adult sites were also reported.(35)

Theme 10: Parents are reluctant to transfer to adult care. Family resistance to transfer the patient to an adult provider was reported as a common barrier to transition.(21, 23, 24, 26, 30, 31, 34, 35) This resistance has been attributed to an overdependence of families on the pediatric provider (26) or that parents are often "reluctant to relinquish responsibility for health care/decision making to young adult patients".(31)

Discussion

Although most Canadian pediatric institutions have an age limit of 18 years, many adolescents beyond this age remain cared for in the pediatric setting. HCPs make overage exceptions for adolescents with SHCN, with either developmental disabilities or complex medical conditions of childhood onset. This vulnerable group of adolescents benefits most from a transition program which helps provide continuity in developmentally appropriate health care services. Within this framework, HCPs agreed that age alone should not determine readiness to transfer to adult care and that maturity was an important factor among others in facilitating transition. The consensus statement on health care transitions for young adults with SHCN recommends that the transition process begin early at 14 years of age to ensure successful transition by 18 years.(2) Most HCPs surveyed suggested starting the transition process much later than this recommendation, leaving less time for preparation and planning. Most pediatric centers however do not have a transition program or policy in place, which may contribute to the variability and lateness in the suggested age to start the transition process. Most HCPs agreed that they would benefit from a formal transition program, which would not only better prepare the patient and family but contribute to improved communication between providers. Providing a comprehensive transfer summary is an important part of the transfer and transition process, as highlighted by HCPs as well as consensus statements and clinical guidelines. It was a surprising finding that many HCPs surveyed did not send these reports or receive them. Even fewer HCPs

communicate directly when transferring patients, with fewer still communicating after the transfer has taken place. This feedback would ensure continuity of care, where the pediatrician receives confirmation that the adult physician has taken over the care of their patient.

Adolescents with SHCN are at increased risk of having difficulties transitioning to an adult health care center, either experiencing a gap in care or being transferred at a later age than recommended. Developmental delays, cognitive disabilities and complex medical conditions are perceived as barriers to transition by HCPs, as is the adolescent's limited understanding of their medical condition and medications, which may be more prevalent in patients with SHCN. Often when these factors are present the transfer is postponed or deferred, either because of poor transition coordination or limited resources to transfer these patients to. Pediatric and adult HCPs both perceive a limitation in the adult provider's knowledge and training in childhood onset conditions. This can translate into reduced confidence in the adult health care worker's ability to care for the patient and reluctance to transfer patients, either from the pediatric provider, the patient or family. This can also contribute to difficulties finding an appropriate adult provider, which delays the transition process. A lack of specialty resources is an important barrier to the transition process.

Adolescents with SHCN benefit from multidisciplinary and specialized care in the pediatric setting, and often these resources are scarce in adult care. This applies especially to certain subspecialty clinics that historically were exclusively pediatric in nature such as CHD or CF clinics. Many specialties have taken steps to remedy this barrier, such as the development of adult clinics for CHD and additional training of adult cardiologists in congenital disorders. The perceived reluctance of parents to transfer to adult care and their dependence on the pediatric provider may be due to their lack of confidence in the adult care system and poor preparation of the family for the transition process.

Our literature review and qualitative synthesis of research-based knowledge has many strengths. We engaged the help of an experienced health sciences librarian to develop

our search strategy and adapt it to different databases. We searched three large databases and used citation tracking reaching saturation to identify all potential studies. Although this method was thorough, it was not comprehensive. These studies were selected using predetermined inclusion and exclusion criteria and a systematic quality appraisal of the selected studies was performed.

Our review also has some limitations. In our search of bibliographic databases, every effort was made to have a broad and inclusive definition of transition. However in this relatively new field of study there is no corresponding MeSH term, making the search strategy challenging and potentially leading to missed studies. The MeSH term "health transition" referred to a different epidemiologic phenomenon and establishing a consistent MeSH term in this field would be advantageous in the future.

The three studies identified as having mixed methods (i.e. using both qualitative and quantitative methods in their study) might be argued to be only quantitative studies as they all used self administered questionnaires to collect their data. The authors of these three studies described their method as combining both qualitative and quantitative analysis, therefore we chose to respect this categorization. Although an inductive thematic analysis approach was used in our synthesis, which aims to be data-driven, the themes do not emerge in a vacuum from the data. (43) The reviewer's (MO) epistemological assumptions will shape the themes retrieved from the data. In this sense the thematic analysis may not necessarily be reproduced if performed by another researcher. A specialized software was not used to assign text to themes, which was coded manually by MO. The thematic analysis was also not validated by a second reviewer. The writing of our review also did not provide an in-depth discussion of each retained study's methods. We were not able to identify any studies exploring perspectives of neurologists on health care transition. Many pediatric neurology patients, such as adolescents with CP, developmental disabilities and DMD, have SHCN. HCPs views in other specialties may not necessarily reflect those of neurologists.

Conclusion

The findings of our review contribute to the conceptual knowledge of healthcare transition from a HCP's perspective. We sought to synthesize common practices, barriers and facilitators to the transition process as perceived by HCPs. No studies were identified as exploring perspectives of neurologists on healthcare transition. Although this review highlights key issues of HCPs' views on transition in other diagnoses, these may not be applicable to neurology patients who have different SHCN. This warrants further research specific to the field of neurology. Our study explores current practices and views of neurologists on health care transition in Quebec.

Chapter 3. Methods

Research Design

We conducted a cross sectional study using two self-administered postal questionnaires, one for pediatric neurologists and one for adult neurologists. The questionnaires were developed by the two investigators (MO & CW) with expertise in neurology, epidemiology and statistics to obtain information from neurologists about the current practice and views on healthcare transfer and transition of young adults with childhood onset neurological disorders.

Target Population

Eligible survey participants were neurologists licensed and actively practicing in the province of Quebec as of July 1 2009. A complete list of all pediatric and adult neurologists practicing in the province of Quebec was obtained from the Association des Neurologues du Québec. All neurologists registered on the provincial health plan (Régie d'Assurance Maladie du Québec) are required to be members of this association, and their up to date contact information is maintained by the Association. This list was compared with the active list of Quebec neurologists maintained by the Royal College of Physicians and Surgeons of Canada and the Collège des Médecins du Québec for completeness and questionnaires were mailed out to all neurologists by regular mail.

Instruments

Two questionnaires were developed: one for pediatric neurologists and one for adult neurologists. Responses to the questionnaires were anonymous, but unique numerical identifiers allowed targeted second mailings to non-responders only. To ensure confidentiality, mailing list management and data entry were performed separately.

The physicians who chose not to participate had the opportunity to express their wishes. Physicians were given the option in the cover letter to state their decision by

ticking off a box on the last page of the questionnaire indicating that they do not wish to participate in the study. They were then asked to return the last page by fax or mail. There was space available on the last page of the questionnaire to indicate the reason for not agreeing to participate. Consent was implied for individuals who agreed to complete the questionnaire.

Definitions

Since there are no universally accepted definitions of transfer or transition in health care, both questionnaires included the following introductory statement:

"For the purpose of this study...

Transition is the purposeful, planned, preparation of patients, families and caregivers for transfer of a patient from a pediatric to an adult care setting.

Transfer is the actual responsibility of care of the patient being moved from a pediatric setting to an adult care setting."

Content

The pediatric neurologist questionnaire (see Appendix 5 and 6 for English and French versions respectively) consisted of 20 items and the adult neurologist questionnaire (see Appendix 7 and 8 for English and French versions respectively) consisted of 14 items. Both questionnaires include questions on current transfer and transition practices, a section on physician and practice characteristics, and opinion statements on barriers and facilitators to the transition process. The pediatric neurology questionnaire included additional questions on transition programs and policies in place.

Two separate questions addressed our third objective to determine if neurologists believe that patients experience a gap in care during the transition period. The first opinion statement was rated as yes/no/don't know: "In your opinion, do young adults entering your practice experience a gap between pediatric and adult care?" The second question asked participants to rank their opinion on a 5 point Likert scale from Page 32 of 86 completely disagree to completely agree. "There is often a large time gap between the last visit with the pediatric caregiver and the first visit with the adult neurologist."

The fourth objective was addressed by two questions in the adult neurology questionnaire exploring their view on their training to care for young adults with childhood onset chronic neurological conditions.

- Do you agree/disagree with the following statement: "my residency in adult neurology provided me with adequate training to care for these young adult with childhood onset neurological conditions". This first question was rated as strongly agree, somewhat agree, somewhat disagree, and strongly disagree.
- "Adult neurologists may not have the training in childhood onset chronic neurological disorders to prepare them to manage them in adulthood." This second questions was rated on a 5 point Likert scale from "completely disagree" to "completely agree".

Pediatric neurologists were only asked the second question as the first one did not apply to them.

Demographic information on the neurologists was gathered from the Collège des Médecins du Québec and the Royal College of Physicians member sections, including sex, language of correspondence, year of medical graduation, year of neurology certification and city of current practice. Additional demographic information gathered from responding neurologists in the questionnaire included their main area of subspecialty and the estimated percentage of their patient population under the age of 30 years for adult neurologists and over the age of 12 years for pediatric neurologists.

The questionnaires were developed based on available questionnaires in the literature in other specialties.(27, 31, 44) Draft versions of the questionnaires were reviewed independently by an expert panel (pediatric neurologist and nurse practitioner not associated with the research team) at the McGill University Health Centre (MUHC) involved in the care of young adults with chronic neurological disorders. Their input on Page 33 of 86 the domains and the range of included items was used to establish face validity of the questionnaires and to finalize their content and clarity. The two study questionnaires, cover letter and follow-up letter were then translated into French using a rigorous translation process including peer-review.

Questionnaire administration

The implementation of the questionnaire follows Dillman's "Tailored Design Method", a recent Cochrane database systematic review on the topic, as well as other recommendations.(45-48) These methods are used to facilitate the mailings and to encourage a high response rate from physicians. The questionnaires were kept short, requiring approximately 10 minutes to complete and were administered over the course of a maximum of 2 contacts between September and November of 2009. Each questionnaire package included a cover informational letter (see Appendix 1 and 2), a questionnaire (see Appendix 5, 6, 7, and 8) and a pre-addressed, pre-stamped envelope. Non-responders received a follow-up letter (see Appendix 3 and 4) along with a second copy of the questionnaire and a pre-addressed, pre-stamped envelope two months after the first mailing. Both the cover and follow-up letters were individually hand signed by both investigators.

Statistical Analysis

PASW statistics software version 18.0 (PASW, Chicago, IL 2009) was used for data entry and statistical analysis. Transition processes were described as percentages and absolute numbers for categorical data, means and SD for continuous variables, and percentages for binary variables. 95% confidence intervals (CI) were calculated for selected outcomes directly related to one of our four objectives. The χ^2 test was used to assess differences between groups for categorical variables, the Wilcoxon rank sum test was used for ordinal variables, and two sample t-tests were used for continuous variables. The Bonferroni correction was used for multiple testing. Kappa statistics were used to estimate the agreement between two questions assessing the same concept with categorical variables. All hypothesis tests were two-sided with α =0.05. Responses to open-ended questions were entered as text and a text analysis was used to identify Page **34** of **86** common themes using a manual coding scheme. Participants and non-participants were compared with respect to geographic practice region, sex, language, pediatric or adult specialty, and years in practice calculated by subtracting the year neurology certification was obtained from the year questionnaires were completed (2009). Nonparticipants who indicated their reason for non-response were also compared to nonparticipants who did not return the last page of the questionnaire using these same variables.

Ethics

Response to the questionnaire constituted consent. The neurologists who received the questionnaire package and chose not to participate were given the opportunity to express their wishes by checking off a box on the last page of the questionnaire, with an option to specify the reason for non response. To ensure confidentiality of those neurologists who did respond, mailing list management and data entry were performed separately. The returned questionnaires are kept in secure locked filing cabinets in the Division of Clinical Epidemiology of the McGill University Health Centre (MUHC) and will be maintained for 5 years after study completion. Ethics approval was obtained from the McGill University Institutional Review Board (IRB) before initiating study (see Appendix 9 and 10).

Chapter 4. Results

Response rate and participant characteristics

A total of 231 eligible neurologists were identified: 209 adult neurologists and 22 pediatric neurologists practicing in Quebec as of July 1 2009. The first mailing resulted in 124 responses and the second mailing in an additional 27 responses. Overall, 151 neurologists responded to the mailing for an overall response rate of 65.4%. Of these, 32 responded indicating that they did not wish to complete the questionnaire and 119 responded and agreed to complete the questionnaire (51.5%), making up the participants group. Participants were 16 pediatric neurologists and 105 adult neurologists. Variation in the sample sizes listed in tables compared with the overall response rate is attributed to missing values for those particular questions.

The characteristics of the participants and non participants are presented in Table 4.1. Women, Anglophones and pediatric neurologists were more likely to participate, as were neurologists with a lower number of years in practice. Practicing in the greater Montreal area and practicing in a city that has a pediatric neurology centre (namely, Montreal, Quebec, and Sherbrooke) did not contribute to a difference in participation rate.

Characteristic	Participants n= 119	Non participants n=112	p value
Male	80 (67.2%)	91 (81.3%)	0.015
Pediatric neurologist	16 (13.4%)	6 (5.4%)	0.036
Francophone	87 (73.1%)	98 (87.5%)	0.006
Years in practice: mean (SD)	18.3 (11.2)	25.3 (12.0)	< 0.001
Greater Montreal area	79 (66.4%)	66 (58.9%)	0.241
City with pediatric center	91 (76.5%)	79 (70.5%)	0.306

Table 4.1: Comparison between participants and non-participants

Among all 231 eligible neurologists, women had statistically significant different number of years in practice (mean 15.1 years, SD 10.1 years) than men (24.0 years, SD 11.9 years) (p value <0.001). Among all 231 eligible neurologists, there were also more
women in pediatric neurology than in adult neurology, but the difference did not reaching statistical significance (45.5% versus 31.4%%, p value 0.16). Because of the high participation rate among the small group of pediatric neurologists, there were not sufficient numbers in each group (16 participants, 6 non participants) to make inferences on participation factors. Among adult neurologists, there was a significant difference between participants and non participants in the number of years in practice (mean 18.7years, SD 11.2 years and mean 25.5 years, SD 12.0 years respectively, p value <0.001) and language spoken (72.8% versus 90.3% Francophones respectively, p value 0.007). There was no significant difference in the number of years in practice between Francophones (mean 22.1 years, SD 11.9 years) and Anglophones (mean 22.0 years, SD 13.0 years) among adult neurologists (p-value 0.948). The characteristics of participating and non participating adult neurologists are outlined in Table 4.2.

Table 4.2:	Characteristics	of adult	neurologists:

Characteristic	Participants	Non-participants	
	n=103	n=106	p value
Male	73 (70.9%)	86 (83.5%)	0.082
Francophone	75 (72.8%)	93 (90.3%)	0.007
Years in practice: mean (SD)	18.7 (11.2)	25.5 (12.0)	< 0.001
Greater Montreal area	70 (68.0%)	61 (59.2%)	0.120
City with pediatric center	75 (72.8%)	73 (70.9%)	0.530

Among non participants (n=112), there was no statistically significant difference between those who returned the last page with a reason for not completing the questionnaire (n=32) and those who did not (n=80) in sex, pediatric or adult neurologist, language spoken, years in practice, practicing in the greater Montreal area, and practicing in a city with a pediatric center. The reason indicated for non response from the 30 neurologists who responded but did not complete the questionnaire were: 21 (70%) reported that they were not involved in the care of young adults, 3 (10%) had retired, 1 (3.3%) was too busy, 1 (3.3%) was not interested in the subject, 2 (6.7%) reported that they do not participate in studies, 1 (3.3%) had moved out of the province and 1 (3.3%) did not indicate a reason. Among participants (n=119), 81 (68.1%) worked in a University center and 41 (34.5%) were general neurologists. Among participating adult neurologists, 77 (64.7%) estimate that less than a quarter of their patients are under 30 years of age, while 22 (18.5%) estimate that 25 to 49% of their patients are under 30 years of age. 59% report working within a 20 minute drive from the nearest pediatric center. Among participating pediatric neurologists, 5 (31.3%) estimate that 25 to 49% of their patients are in adolescence while 6 (37.5%) estimate that 25 to 49% of their patients are in adolescence. All indicated working within a 20 minute drive from the nearest pediatric of an adult neurology center.

Transfer and transition practice and policy

Our first objective was to identify current practices in transitioning young adult patients with childhood-onset neurological conditions. In our survey, most pediatric neurologists did not have a written transition policy (75%) or a transition program in place (62.5%), but plan to develop one in the next two years (50.0%). The pediatric neurologist is usually the person responsible for the administration and coordination of the transfer/transition process (87.5%). The median age suggested for adolescents to be transferred to adult care by our participants is 18 years. Pediatric neurologists report a median of 3.0% of their patients is older than this age. 75% of pediatric neurologists believe the transition process should begin one year prior to transfer of care, and transfer on average 12.2 patients to adult care yearly (SD 6.2).

Although 43.8% (95% CI 19.5%, 68.1%) of pediatric neurologists reported communicating directly sometimes or almost always with the adult neurologist when transferring a young adult to their care, only 15.2% (95% CI 8.3%, 22.1%) of adult neurologists reported that they communicate directly with the pediatric neurologist sometimes or almost always during the transfer process (Table 4.3). All pediatric neurologists reported sending a transfer summary, and 71.4% (95% CI 62.8%, 80.0%) of adult neurologists reported receiving one.

Table 4.3: Current transfer practice

	Pediatric neurologists	Adult neurologists
	n=16	n=103
	Communicate directly	Communicate directly
Almost always	3 (18.8%)	2 (1.9%)
Sometimes	4 (25.0%)	14 (13.3%)
Rarely	5 (31.3%)	29 (27.6%)
Never	3 (18.8%)	52 (49.5%)
Missing value	1 (6.3%)	6 (5.8%)
	Send a transfer summary	Receive a transfer summary
Almost always	15 (93.8%)	42 (40.0%)
Sometimes	1 (6.2%)	33 (31.4%)
Rarely	0 (0%)	15 (14.3%)
Never	0 (0%)	8 (7.6%)
Missing Value	0 (0%)	5 (4.9%)

Pediatric neurologists were asked if they usually transfer patients to an adult neurologist or to a primary care physician for 10 selected neurological conditions. Table 4.4 shows the percentage of pediatric neurologists that transfer these patients preferably to an adult neurologist.

Table 4.4: Transfer preference of pediatric neurologists

Disorder	n	% that transfer to an adult neurologist
Cerebral palsy	15	46.7%
Neuromuscular	15	100.0%
Epilepsy	15	100.0%
Headache	15	33.3%
Movement disorders	14	100.0%
Spina bifida	12	50.0%
Chromosomal	14	78.6%
Autism	13	23.1%
Cerebrovascular disease	15	86.7%
Cognitive or behavioral	15	13.3%
disorders		

Patients with neuromuscular disorders, epilepsy, movement disorders, spina bifida, chromosomal/metabolic disorders and cerebrovascular disorders were more often transferred to an adult neurologist. Patients with headache, autism and cognitive/behavioral disorders were more often transferred to a primary care physician.

Adolescents with cerebral palsy were almost equally referred to adult neurologists and family physicians. 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".

Views on barriers and facilitators

Our second objective was to identify barriers and facilitators of transfer and transition perceived by neurologists. Participating neurologists were asked to provide their opinion on a list of opinion statements on possible barriers to transition, which are presented in Table 4.5. These opinion statements correspond to question 20 in the pediatric neurologist questionnaire and question 14 in the adult neurologist questionnaire. Each is rated on a 5 point Likert scale where 1 represents "completely disagree" and 5 represents "completely agree". For all except one of the listed statements at least half of the participants were in agreement. The one statement that stood out was "issues of sexuality are often not discussed with adolescent patients in the pediatric setting". For this statement, all adult neurologists responded "I don't know", with many adding question marks in the questionnaire margin. The results of this statement were therefore removed from our analysis.

Most neurologists agreed that the transition process is often poorly coordinated. Half agreed that their colleagues may be unwilling to care for young adults with chronic neurological disorders. Regarding patient specific factors, most neurologists were in agreement that young patients are not always ready to assume medical decision-making responsibilities, often don't know how to navigate the adult health care system, and often don't know their medical history. Furthermore most agreed that parents and caregivers can remain excessively protective and may not understand the privacy issues of the young adult patient, while adult neurology practices are described as less paternalistic than pediatric practices, e.g. patients may not get called when they miss an appointment. There was no statistically significant difference in opinions between pediatric and adult neurologists on the 7 opinion statements (excluding the statement on sexuality) using the Wilcoxon Rank Sum tests.

Table 4.5: Opinion statements on barriers to transition

	n	1	2	3	4	5			
		n (%)	n (%)	n (%)	n (%)	n (%)			
Young patients are not always ready to assume medical decision-making									
responsi	bilities	i.							
	117	1 (0.9%)	21 (17.9%)	34 (29.1%)	50 (21.6%)	11 (4.8%)			
The tran	isition	from pediat	ric to adult he	ealth care is o	ften poorly coo	ordinated.			
	116	3 (2.6%)	15 (12.9%)	33 (28.4%)	41 (35.3%)	24 (20.7%)			
Parents	and ca	regivers can	n remain exce	sively protect	tive and may n	ot understand			
1 al chts	anu ca				ive and may n	ot under stand			
the priva	acy issi	ues of the yo	oung adult pat	ient.					
_	116	1 (0.9%)	16 (13.8%)	31 (26.7%)	52 (44.8%)	16 (13.8%)			
Adult ne	eurolog	y practices	are less pater	nalistic than p	ediatric pract	ices (e.g.,			
patients	mav n	ot get called	when they m	iss an appoint	ment).				
1	117	1 (0.9%)	10 (8 5%)	30 (25.6%)	48 (41 0%)	28 (23.9%)			
N.C 11	11/	1 (0.270)	••••	so (25.070)	10 (11.070)	20 (23.570)			
My colle	eagues	may be unw	illing to care	for young adu	lits with chron	ic neurologic			
disorder	·s.								
	116	5 (4.3%)	20 (17.2%)	38 (32.8%)	38 (32.8%)	15 (12.9%)			
Patients often don't know how to navigate the adult healthcare system.									
			Ŭ		•				
	115	3 (2.6%)	11 (9.6%)	33 (28.7%)	43 (37.4%)	25 (21.7%)			
Young p	oatients	s often don't	know their m	nedical history	<i>.</i>				
	115	1 (0.9%)	20 (17.4%)	35 (30.4%)	50 (43.5%)	9 (7.8%)			

Neurologists were also asked to rank the importance of patient factors in relation to successful transition to an adult neurology practice. These opinion statements are presented in Table 4.6 and correspond to question 18 in the pediatric neurologist questionnaire and question 12 in the adult neurologist questionnaire. They are rated on a 5 point Likert scale where 1 represents "not important at all important", 5 represents "very important". The majority of neurologists agreed that patient's knowledge of their medical condition, patient's knowledge of their medication name/dose/side effects, and patient's compliance with medication were all important or very important factors. The young patient's ability for active participation during office visits and co-existence of communication impairment were also both ranked as important factors, however the patient's ability to attend office visits alone was not. The latter however was the only factor found to differ between adult and pediatric neurologists (Wilcoxon rank sum test statistic 8.624, p 0.003). Only 12.5% of pediatric neurologists believed that attending office visits alone was not an important factor, whereas 39.8% of adult neurologists

believed this was not an important factor. Co-existing behavioral difficulties was also ranked as an important factor, along with the need for multidisciplinary care.

	n	1	2	3	1	5				
	11	n (%)	2 n (%)	5 n (%)	+ n (%)	5 n (%)				
Patient's knowledge of their medical condition										
	114	4 (3.5%)	2 (1.8%)	20 (17.5%)	42 (36.8%)	46 (40.4%)				
Patient's knowledge of their medication name, dose and side effects										
	114	3 (2.6%)	5 (4.4%)	18 (15.8%)	40 (35.1%)	48 (42.1%)				
Patien	t's com	pliance with	medication							
	112	1 (0.9%)	1 (0.9%)	15 (13.4%)	38 (33.9%)	57 (50.9%)				
Knowl	edge of	f social sunno	rt grouns for t	their disease						
ILIIO	cuge of	i social suppo	it groups for	unen unseuse						
	113	2 (1.8%)	9 (8.0%)	46 (40.7%)	40 (35.4%)	16 (14.2%)				
Need f	or mul	tidisciplinary	care							
	112	2 (1.8%)	2 (1.8%)	32 (28.6%)	46 (41.1%)	30 (26.8%)				
Active	partici	ipation during	g office visits							
	114	2 (1.8%)	2 (1.8%)	27 (23.7%)	56 (49.1%)	27 (23.7%)				
Ability	to atte	end office visi	ts alone	, ,	,	,				
•										
	114	15 (13.2%)	26 (22.8%)	43 (37.7%)	23 (20.2%)	7 (6.1%)				
Co-exi	sting c	ommunicatio	n impairment							
	108	4 (3.7%)	8 (7.4%)	25 (23.1%)	46 (42.6%)	25 (23.1%)				
Co-exi	sting b	ehavioral diff	iculties							
	110	3 (2.7%)	8 (7.3%)	19 (17.3%)	51 (46.4%)	29 (17.3%)				

Table 4.6: Im	portance of	patient factors	in transition	process

Neurologists were asked what barriers to successful transfer they encountered in their practise other than the ones previously listed in our opinion statements. Some neurologists listed more than one barrier, and some repeated barriers already listed previously. These barriers included, in descending order of frequency, missing information on past medical chart/investigations (n=26), lack of multidisciplinary teams in the adult setting (n=26), patient or family reluctance to transfer (n=10), adult neurologist not being available (n=9) or not having adequate knowledge in childhood onset chronic conditions (n=9), lack of support in the adult health care milieu (n=5), non-adherence of patient to visits or medication (n=5) and not having a clear treatment plan (n=3).

Gap in care

Two questions addressed our third objective to determine if neurologists perceived that patients experience a gap in care during the transition period. For the first statement "In your opinion, do young adults entering/leaving your practice experience a gap between pediatric and adult care?", out of 115 responses, 51 thought young adults experience a gap (44.3%), 42 did not (36.5%), and 22 stated they don't know (19.1%). For the second statement "There is often a large time gap between the last visit with the pediatric caregiver and the first visit with the adult neurologist.", out of 116 responses, 49 (42%) agreed or completely agreed that young adults experience a gap with a rating of 4 or 5, 38 (33%) gave a rating of 3, and 29 (25%) disagreed or completely disagreed with a rating of 1 or 2. These opinions statements are presented in Table 4.7 and correspond to questions 5 and 14 in the adult neurologist questionnaire and to questions 16 and 20 in the pediatric neurologist questionnaire. For the 5 point Likert scale, 1 represents "completely disagree", 5 represents "completely agree".

There is often a large time gap between the last visit with the pediatric caregiver and the first visit with the adult neurologist.										
			5 point Likert scale							
Do young		1	2	3	4	5	Missing	Total		
experience	No gap	3	20	15	4	0	0	42		
a gap	Don't know	0	0	11	9	1	1	22		
pediatric	Gap	1	4	11	16	18	1	51		
and adult care?	Missing	0	1	1	0	1	1	4		
	Total	4	25	38	29	20	3	119		

|--|

There was no statistically significant difference in opinion between pediatric and adult neurologists by Wilcoxon Rank Sum test. To calculate the agreement between the two statements, the 5 point likert scale was collapsed into a 3 point scale by combining ratings of 1 and 2, keeping the rating of 3, and combining the ratings of 4 and 5. Responses to both questions showed a moderate agreement, with Kappa= 0.396, 95% CI (0.267, 0.525).

Adult neurology training

To address our fourth objective, adult neurologists 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", of the 81 adult neurologists who responded to the question, none strongly agreed, 45 (55.6%) somewhat agreed while 36 (44.4%) somewhat or completely disagreed, and 38 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", of the 117 adult neurologists who responded to the question, 55 (47.0%) agreed with a rating of 4 or 5, only 21 (17.9%) disagreed with a rating of 1 or 2 and 41 (35.0%) gave a rating of 3, with only 2 who did not respond. These opinion statements are presented in Table 4.8 and correspond to questions 8 and 14 in the adult neurologist questionnaire. For the 5 point Likert scale, 1 represents "completely disagree", 5 represents "completely agree". To calculate the agreement between the two statements, the 5 point likert scale was converted into a 4 point scale by excluding the rating of 3. The Kappa statistic was 0.396 with a 95% CI (0.196, 0.596) showing moderate agreement.

	Adult neurologists may not have the training in childhood onset chronic neurological disorders to prepare them to manage them in adulthood.									
			5 p	oin	t lik	ert	scale			
		1	2	3	4	5	Missing	Total		
"My residency in adult	Strongly agree	0	0	0	0	0	0	0		
neurology provided me with adequate training to care for these young adults with childhood onset neurological conditions".	Somewhat agree	1	6	24	11	2	1	45		
	Somewhat disagree	0	0	10	14	3	0	27		
	Strongly disagree	0	1	0	1	7	0	9		
	Missing	4	9	7	12	5		37		
	Total	5	16	41	38	17	1	118		

Table 4.8: Opinions of adult neurologists on adult neurology training

Pediatric neurologists were asked only the second question, which corresponds to question 14 in the adult neurologist questionnaire and to question 20 in the pediatric neurologist questionnaire. Although the sample size was small, pediatric neurologists were more likely to think adult neurologists do not have adequate training (Wilcoxon Rank Sum statistic 5.476, p 0.019). The raw data are shown in Table 4.9.

	5 point likert scale							
	1	2	3	4	5	Total		
Adult	5	14	39	31	12	101		
neurologists								
Pediatric	0	2	2	7	5	16		
neurologists								
Total	5	16	41	38	17	117		

Table 4.9: Pediatric versus adult neurologists' opinion on adult neurology training:

Adult neurologists were asked to rate their level of comfort in treating patients with 10 selected neurological disorders on a 4 point scale from "completely comfortable" to "impossible" (Table 4.10). The participating adult neurologists reported being most comfortable treating patients with cerebrovascular disorders, headache, multiple sclerosis (MS) and epilepsy. The two disorders adult neurologists were the least comfortable treating (i.e. "not comfortable" or finding it "impossible") were autism (87% of adult neurologists) and chromosomal/metabolic disorders (72%), followed by cognitive/behavioral disorders (50%), neuromuscular disorders (42%), Tourette syndrome (39%) and cerebral palsy (27%).

Table 4.10: Reported comfort level in treating patients with selected neurological

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

disorders: Adult neurologists

Pediatric neurologists were asked to rate their level of difficulty in transferring patients with these disorders (Table 4.11).

Table 4.11: Difficulty transferring patients with different neurological disorders:

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

Pediatric neurologists:

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 and autism, followed by patients with CP, chromosomal/metabolic disorders, Tourette syndrome and headache.

Discussion

The goal of this study was to describe, from the neurologist's perspective, the current practice and views on barriers and facilitators in transitioning youth with neurological disorders in Quebec. In keeping with this goal, we also gauged their opinion on how well they believed adult neurologists were trained to care for this patient population and furthermore if they believed these patients experienced a gap in care during the transition period.

Current practice: Most pediatric neurologists surveyed did not have a transition program or policy in place, but many planned to develop one in the next two years. This fits with a theme from our literature review, where most pediatric centers did not have a transition program or policy in place but the majority agreed that there is a need for one. Almost half of the participating neurologists believed that the transition process is poorly coordinated. The median age of 18 years suggested by our participants for transfer to an adult center is similar to previous surveys of HCPs and the standard age in Quebec for transfer of care to an adult setting. However 75% of pediatric neurologists in our study suggested starting the transition process at little as a year prior to transfer, which does not follow current recommendations set by the AAP.(2) A year may not be sufficient time to adequately prepare for a successful transition. Interestingly, our finding is consistent with the results of our literature review, where we found that the suggested time to start the transition process was often later than recommended, usually only 1-2 years prior to transfer.

All pediatric neurologists reported sending a transfer summary and three quarters of adult neurologists reported receiving these. Neurologists, however, do not frequently communicate directly with each other when transferring patients. The most common barrier listed by neurologists was missing information from the past medical chart or past investigations, suggesting that although providing a medical summary is common practice, the summary is often incomplete. Poor communication between providers has been outlined as a barrier to transition by other HCP's as well and the importance of maintaining an up to date medical summary that is made readily available has been outlined in consensus statements on the topic.(2, 6)

Barriers and facilitators to transition: A number of patient factors were reported as important barriers, such as knowledge of their medical condition and of their medication (name, dose, side effects), compliance with medication, active participation during visits, co-existence of a communication disorder or behavioral difficulties, and need for multidisciplinary care. It is important to note that a patient's ability to attend office visits alone was only perceived to be important by pediatric neurologists but not by adult neurologists. The patient factors agreed upon by most neurologists are similar to those reported in the literature by other HCPs. Since the statement addressing sexuality issues was not clear to many responders, we did not use it in our analysis. Future questionnaires could improve on the clarity of this statement perhaps by giving an example.

The other barriers commonly reported by our participants were lack of multidisciplinary teams in the adult setting, lack of support in the adult health care milieu, and adult neurologist issues (e.g. lack of availability, not having adequate knowledge in childhood onset chronic neurological disorders). Almost half of neurologists believed that their colleagues may be unwilling to care for this patient population. This may explain at least in part why 60% of pediatric neurologists reported difficulty finding an adult provider for their patients.

Adult neurology training: Almost half of surveyed neurologists believed adult neurologists may not have adequate training in childhood onset chronic neurological disorders to prepare them to manage them in adulthood. Surveyed adult neurologists were least comfortable treating patients with autism and chromosomal or metabolic disorders, followed by those with cognitive or behavioral disorders, neuromuscular disorders, Tourette syndrome and cerebral palsy. Patients with these same disorders were rated as the most difficult to transfer to adult care by pediatric neurologists, who usually transfer patients with neuromuscular disorders and chromosomal or metabolic disorders to an adult neurologist rather than a primary care physician, and patients with cerebral palsy are transferred equally between the two. Improving the adult neurologist's knowledge and comfort in treating patients with cerebral palsy, neuromuscular, chromosomal or metabolic disorders of childhood onset may help address this barrier. The adult health care provider's perceived lack of knowledge or training in childhood onset chronic conditions and lack of availability of adult providers to care for this patient population are both also barriers to transition outlined by other HCP's.

Gap in care during the transition period: Almost half of the participating neurologists believed that patients experience a gap in their care during the transition period. We found no difference in opinion between pediatric and adult neurologists. A benefit of a transition program is coordinated and continuous care during this period.

Strengths and limitations

This study has several important strengths. We were able to identify and survey the study population of all Quebec neurologists. To ensure complete coverage, the list maintained by the Association des Neurologues du Québec was compared with the list of both the Collège des Médecins du Québec and the Royal College of Physicians and Surgeons of Canada for completeness. Our questionnaire had a good response from physicians, with 65.4% responding to the mailing and 51.5% completing the questionnaires. Although the participation rate among pediatric neurologists was high (72.7%), the small absolute number of pediatric neurologists compared to adult neurologists may drive significance testing. Mean physician response rates of 54 to 61% have been reported in recent systematic reviews of mailed physician questionnaires.(49, 50) Among non participants, the majority of those who stated their reason on the last page of the questionnaire reported not being involved in the care of young adults. This group had similar characteristics to neurologists who did not state their reason for not participating, so it is plausible that most non responders were not involved in transition issues. The two most common reasons reported in the literature for physician non response are lack of time and perceived value of the study. In our sample only one physician reported lack of time as reason for non response. A greater portion of pediatric neurologists responded to our questionnaire than adult neurologists, as did women, Anglophones and neurologists with a lower number of years in practice. Pediatric neurologists are more involved in transition care and can have more interest in the study. There are also a greater percentage of women in pediatric neurology than in adult neurology, and women overall had a lower number of years in practice than men. Among adult neurologists, Anglophones and neurologists with a lower number of years in practice were more likely to participate. Response bias is invevitable as participants are more likely to be interested in the topic of transition.

The two study questionnaires were developed for the purpose of this study based on previous surveys of HCPs available in the literature. Feedback from an expert panel was used to establish face validity and to finalize the content and clarity of the questionnaires. However, as with all questionnaire-based research, our study has several limitations. We did not use specialized software for text analysis of the openended question on barriers to the transition process. These were manually coded by one investigator (MO) and the categories of responses created may lose some of the richness of the textual comments provided by the participants. The two concepts for which internal consistency was calculated using Kappa statistics were explored by two questions with a different number of categorical responses. The responses therefore required manipulation in order to calculate agreement, which may have altered the results. There was a large amount of missing data for one opinion statement in the adult neurologist questionnaire in response to: "my residency in adult neurology provided me with adequate training to care for these young adults with childhood onset neurological conditions". It is interesting that only 2 participants did not respond to the second opinion statement addressing the same concept from a less personal stance: "Adult neurologists may not have the training in childhood onset chronic neurological disorders to prepare them to manage them in adulthood." Furthermore, this survey of neurologists in a signle province may not be generalizable to other provinces or even other countries which do not have a publically funded universal healthcare system.

Conclusion and future directions

This is the first study to describe the current views and practices of neurologists in transition care. We found that most pediatric neurologists frequently transfer adolescents with traditionally pediatric onset chronic neurological disorders into the adult health care milieu, with many challenges. Patients and family alike are illprepared for this change and often unaware how to navigate the adult health care system. Patients may lack information regarding their condition or medications and the self management skills needed as adults. Pediatric neurologists similarly struggle to identify a suitable and willing adult neurologist or the appropriate multidisciplinary care setting for their patients. Transfer summaries, although usually provided, often lack detailed information according to adult neurologists, with frequent lack of communication both prior and after the transfer of care. Adult neurologists also may lack training or experience in managing this patient population. Many neurologists believe that patients experience a gap in care during this period. Furthermore, late adolescence is a time of uncertainty for the patient, who may experience adverse health and psycho-social consequences if developmentally appropriate and timely guidance is not provided. Perceived parental protectiveness and reluctance to transfer care to an adult setting may not be inappropriate in light of the limitations outlined by neurologists.

The benefits of implementing an organized neurology transition program are numerous. Providing continuity of care between pediatric and adult neurologists can improve patient care, information and data sharing as well as communication among health care professionals ultimately leading to reduced long term health care costs.(3) A transition program could also help educate patients on their disorder, medications and self management skills at an appropriate developmental and cognitive level. Although most neurologists provide a transfer summary, a complete transition plan and copies of previous investigations would be helpful in coordinating future care. Direct communication between HCP's during this transition process could also help minimize the gap in care patients may experience. Adult neurology residency curriculums can also benefit from additional training in transition and management of young adults with Page **52** of **86** childhood onset chronic neurological conditions. Having an established and formal transition program and infrastructure in place would be an asset for future adult neurology residents, with focused training on the process of transition and the management of traditionally pediatric disorders in the young adult. 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.

This study aimed to describe the neurologist's perspective on health care transition and provides a basis for understanding the challenges in moving from consensus guidelines to a practice of neurology transition that is feasible and beneficial to all. Whether patients truly experience a gap in care during the transition process can only be determined in a prospective study of a cohort of graduating pediatric neurology patients. It will be a challenge to identify good outcome measures of a "successful transition". This will need to be defined with additional input from families and especially the young adults who have graduated to adult care. Extrinsic modifiable factors are increasingly recognized as important determinants of quality of life of individuals living with chronic disabilities.(51) The contextual factors targeted in transition planning would ultimately improve the quality of life of young adults with chronic neurological disorders.

Appendix 1: Cover letter first mailing, English





Study on the Transition of Adolescents with Neurological Disorders (STAND)

September 4th 2009.

Dear Dr.____:

We are contacting you because we are conducting a study on transition of care in neurology in Quebec. An essential component of this study is to gather information from Quebec neurologists on their practices and beliefs about transitioning patients from pediatric to adult neurology care. A copy of the questionnaire for you to complete is included in this mailing.

As you know, children with chronic neurological disorders are increasingly surviving to adulthood, posing a new challenge to both pediatric and adult neurologists involved in their care. Describing current practices and challenges in neurology transition in Quebec is critical to ensure optimal planning of future resource allocation.

We kindly ask you to take a few minutes of your time to complete the attached brief questionnaire. Once completed, please return the questionnaire by fax or in the enclosed self-addressed, stamped envelope. Your responses will remain confidential.

If, for any reason, you choose not to participate, please check the appropriate box on the **last** page of the questionnaire. This will ensure that you do not receive any follow-up materials. It would be helpful to us, however, if you could let us know the reason(s) that you choose not to participate. If you do decide to participate, and we hope you will, your name and address will be deleted from our database at the end of the study.

If you have any questions, please do not hesitate to contact Dr. Maryam Oskoui at <u>maryam.oskoui@mcgill.ca</u>. This study has been approved by the Institutional Review Board of McGill University.

Thank you in advance for participating in our survey. Your cooperation is essential to the success of this project.

Sincerely,

Christina Wolfson, PhD Director, Division of Clinical Epidemiology McGill University Health Centre Professor, Department of Epidemiology & Biostatistics & Occupational Health, and Department of Medicine, McGill University Maryam Oskoui, MD, FRCPC CIHR fellow Department of Epidemiology & Biostatistics & Occupational Health, McGill University

Appendix 2: Cover letter first mailing, French





Étude sur la transition des adolescents atteints de troubles neurologiques

Le 4 septembre 2009.

Docteure, Docteur ;

Nous communiquons avec vous dans le cadre d'une étude sur la transition des soins neurologiques au Québec. Une composante essentielle de cette étude consiste à obtenir des renseignements de la part des neurologues du Québec au sujet de leurs pratiques et de leurs opinions concernant la transition entre les soins neurologiques pédiatriques et les soins neurologiques pour adultes. Vous trouverez ci-joint le questionnaire à remplir.

Comme vous le savez, de plus en plus d'enfants atteints de troubles neurologiques chroniques survivent jusqu'à l'âge adulte, ce qui entraîne de nouveaux défis pour les neurologues traitants. Il est essentiel de décrire les pratiques et les difficultés actuelles concernant la transition des soins en neurologie au Québec afin de veiller à ce que la planification de l'affectation des ressources soit à l'avenir optimale.

Nous vous demandons de bien vouloir nous accorder quelques minutes pour remplir le bref questionnaire ci-joint. Une fois rempli, veuillez le renvoyer par télécopieur ou par retour de courrier, dans l'enveloppe préadressée et préaffranchie. Vos réponses seront gardées confidentielles.

Si, pour une raison quelconque, vous choisissez de ne pas remplir le questionnaire, veuillez cocher la case appropriée se trouvant à la **dernière** page du questionnaire afin de ne pas recevoir de documentation de suivi. Par ailleurs, il nous serait utile de connaître les raisons pour lesquelles vous n'avez pas participé à l'étude. Si vous décidez d'y participer, ce que nous espérons, votre nom et votre adresse seront effacés de notre base de données à la fin de l'étude.

Pour toute question, n'hésitez pas à communiquer avec la D^{re} Maryam Oskoui, à l'adresse courriel <u>maryam.oskoui@mcgill.ca</u>. Cette étude a été approuvée par le Comité d'éthique de la recherche de l'Université McGill.

Nous vous remercions à l'avance de votre collaboration à cette étude. Elle est essentielle au succès de ce projet.

Nous vous prions d'accepter, Docteure, Docteur, l'expression de nos sentiments distingués,

Christina Wolfson, Ph.D. Directrice, Division d'épidémiologie clinique Centre universitaire de santé McGill Professeure, Département d'épidémiologie, de biostatistiques et de santé au travail, et Département de médecine de l'Université McGill Maryam Oskoui, M.D., FRCPC Boursière des IRSC Département d'épidémiologie, de biostatistiques et de santé au travail de l'Université McGill

Appendix 3: Cover letter second mailing, English





Study on the Transition of Adolescents with Neurological Disorders (STAND)

November 4th 2009.

«GreetingLine»

Two months ago we mailed to you a brief survey seeking your views on transition from pediatric to adult neurology care. To date, we have not received your survey. To ensure that this study represents the views of Quebec neurologists, it is important that each neurologist selected completes and returns the survey.

If you have already completed and returned the questionnaire, please accept our sincere thanks. If not, we kindly ask you to take a few minutes of your time to complete the questionnaire at your earliest convenience. We have included a second copy of the questionnaire for you in this package.

Once completed, please return the questionnaire by fax or in the enclosed self-addressed, stamped envelope. Your responses will remain confidential. It is extremely important that your views be included in the study.

If you do not wish to participate for any reason, then please check the appropriate box on the last page of the questionnaire. This will ensure that you do not receive any follow-up materials. If you decide to participate, your name and address will be deleted from our database at the end of the study.

If you have any questions, then please do not hesitate to contact Dr. Maryam Oskoui at maryam.oskoui@mcgill.ca.

Thank you in advance for participating in our survey. Your cooperation is essential to the success of this project.

Sincerely,

Christina Wolfson, PhD Director, Division of Clinical Epidemiology McGill University Health Centre Professor, Department of Epidemiology & Biostatistics & Occupational Health, and Department of Medicine, McGill University & Occupational Health, McGill University

Maryam Oskoui, MD, FRCPC CIHR Fellow McGill University Health Centre Department of Epidemiology & Biostatistics

Appendix 4: Cover letter second mailing, French





Étude sur la transition des adolescents atteints de troubles neurologiques

Date

Docteure, Docteur

Il y a six semaines, nous vous avons fait parvenir un bref questionnaire afin de connaître votre opinion au sujet de la transition des soins neurologiques pédiatriques vers les soins neurologiques pour adultes. À ce jour, nous n'avons pas encore reçu votre questionnaire rempli. Pour que cette étude soit représentative de l'opinion des neurologues du Québec, il est très important que chaque neurologue sélectionné remplisse et renvoie le questionnaire.

Si vous l'avez déjà fait, veuillez accepter nos sincères remerciements. Si vous ne l'avez pas encore rempli, veuillez y accorder quelques minutes dès que vous le pourrez. Vous trouverez ci-joint un deuxième exemplaire du questionnaire.

Une fois rempli, veuillez le renvoyer par télécopieur ou par retour de courrier, dans l'enveloppe préadressée et préaffranchie. Vos réponses seront gardées confidentielles. Il nous est important d'inclure votre opinion dans cette étude.

Si, pour une raison quelconque, vous choisissez de ne pas remplir le questionnaire, veuillez cocher la case appropriée se trouvant à la dernière page du questionnaire afin de ne pas recevoir de documentation de suivi. Si vous décidez d'y participer, votre nom et votre adresse seront effacés de notre base de données à la fin de l'étude.

Pour toute question, n'hésitez pas à communiquer avec la D^{re} Maryam Oskoui, à l'adresse couriel <u>maryam.oskoui@mcgill.ca</u>.

Nous vous remercions à l'avance de votre collaboration à cette étude. Elle est essentielle au succès de ce projet.

Nous vous prions d'accepter, Docteure, Docteur, l'expression de nos sentiments distingués,

Christina Wolfson, Ph.D. Directrice, Division d'épidémiologie clinique Centre universitaire de santé McGill Professeure, Département d'épidémiologie, de biostatistiques et de santé au travail, et Département de médecine de l'Université McGill Maryam Oskoui, M.D., FRCPC Boursière des IRSC Département d'épidémiologie, de biostatistiques et de santé au travail de l'Université McGill



Study on the Transition of Adolescents with Neurological Disorders

Please return the questionnaire in the enclosed, self-addressed stamped envelope. Or, fax the completed questionnaire at (514) 934-4458.

If you do not intend to complete this questionnaire, PLEASE RETURN THE LAST PAGE.





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This survey is designed to elicit information on your approach to transition and transfer of care from pediatric to adult neurology. All of the information provided by you will be kept completely confidential.

This questionnaire is being completed on:

____ / ___ / ___ __ month/ day / year

For the purposes of this study...

Transition is the purposeful, planned, preparation of patients, families and caregivers for transfer of a patient from a pediatric to an adult care setting.

Transfer is the actual responsibility of care of the patient being moved from a pediatric setting to an adult care setting.

1. In what year did you finish neurology residency training?

I finished my neurology residency training in ______.

2. Which of the following is your main area of expertise/subspecialty?

- Cerebrovascular disease
- Headache
- Epilepsy
- Neuromuscular disorders
- Movement disorders
- □ Rehabilitation/ Neurodevelopmental disabilities
- Multiple Sclerosis/ Neuroimmunology
- □ Cognitive/ Behavioral disorders
- Neonatal Neurology
- Other (specify):
- □ I am a general neurologist

3. What percentage of your patient population is in adolescence (>12 years old)?

- **0** % (None)
- 🖵 < 25 %
- 25 to 49 %
- □ 50 to 74 %
- **□** ≥75 %
- **1**100 % (All)
- I don't know

- 4. Is there a transition program in your practice?
 - Yes
 - 🛛 No
 - Don't know
- \rightarrow If no, are there plans to develop a transition program in the next 2 years?
 - YesNo
 - Don't know
 - 5. Does your practice have a written policy on the transition and transfer of adolescents to adult health care?
 - Yes
 - 🛛 No
 - Don't know
 - 6. In your practice, who is responsible for the administration and coordination of the transfer/transition process? Please check all that apply
 - Pediatric neurologist
 - Clinical nurse
 - □ Administrative staff
 - Other (specify): ______

7. At what age do you feel the transition process should begin?

- **Early** adolescence
- □ 1-year prior to transfer
- At time of transfer
- Other (specify): _____
- 8. In your opinion, at what age should adolescents be transferred to adult care?

Adolescents should be transferred to adult health care at _____ years of age.

9. What percentage of your patients is above the age you usually recommend transfer to adult care?

About ______% of my patients.

10. How many patients do you transfer to adult care each year on average?

On average, I transfer _____ patients yearly to adult care.

11. For each of the following neurological disorders, specify if you usually transfer patients to a primary care physician or to an adult neurologist:

Neurological disorder	Primary Care Physician	Adult Neurologist
Cerebral palsy		
Neuromuscular disorders		
Epilepsy		
Headache		
Movement disorders		
Spina bifida		
Chromosomal/metabolic disorders		
Autism		
Cerebrovascular disease		
Cognitive/behavioral disorders	\square	\square

12. How far from your practice is the nearest adult neurology center?

- □ At the same center
- U Within a 20 minute drive
- □ More than a 20 minute drive
- Don't know

13. Do you send a written summary to the adult neurologist or primary care physician when transferring a young adult?

- Almost always
- Sometimes
- **D** Rarely
- Never
- 14. Do you have difficulty finding an adult neurologist or primary care physician for transferring young adults?
 - Yes
 - 🛛 No
 - → If YES, how difficult?
 - □ Somewhat difficult
 - Ury difficult
 - □ Virtually impossible
- 15. Do you communicate directly with the adult neurologist or primary care physician to assure that transfer was successful?
 - Almost always
 - □ Sometimes
 - **D** Rarely
 - Never

- 16. In your opinion, do young adults leaving your practice experience a gap between pediatric and adult care?
 - YesNoDon't know
- 17. For each of the following neurological disorders, rate the level of difficulty you experience when transferring young adults to adult care.

Neurological disorder	Not at all difficult	Somewhat difficult	Very difficult	Impossible
Cerebral palsy				
Neuromuscular disorders				
Epilepsy				
Tourette's Syndrome				
Multiple Sclerosis				
Chromosomal/metabolic	\Box	\Box	\Box	
Autism				
Headaches			\Box	
Cerebrovascular disease				
Cognitive /Behavioral disorders				

18. In relation to successful transfer to an adult neurology practice, please rank the importance of the following patient factors by circling the appropriate rank:

1 represents "not important at all" and 5 re	epreser	nts "ve	ry imp	ortant	"
Statement			Scale	9	
Patient's knowledge of their medical condition	1	2	3	4	5
Patient's knowledge of their medication name, dose and side effects	1	2	3	4	5
Patient's compliance with medication	1	2	3	4	5
Knowledge of social support groups for their disease	1	2	3	4	5
Need for multidisciplinary care	1	2	3	4	5
Active participation during office visits	1	2	3	4	5
Ability to attend office visits alone	1	2	3	4	5
Co-existing communication impairment	1	2	3	4	5
Co-existing behavioral difficulties	1	2	3	4	5
Other:	1	2	3	4	5

19. What barriers do you face in the transfer of young adults with neurological conditions?

20. Please give us your personal opinion on the following statements:

Statement			Scale		
Adult neurologists may not have the training in childhood onset chronic neurological disorders to prepare them to manage them in adulthood.	1	2	3	4	5
Young patients are not always ready to assume medical decision- making responsibilities.	1	2	3	4	5
The transition from pediatric to adult health care is often poorly coordinated.	1	2	3	4	5
Parents and caregivers can remain excessively protective and may not understand the privacy issues of the young adult patient.	1	2	3	4	5
Adult neurology practices are less paternalistic than pediatric practices (e.g., patients may not get called when they miss an appointment).	1	2	3	4	5
There is often a large time gap between the last visit with the pediatric caregiver and the first visit with the adult neurologist.	1	2	3	4	5
My colleagues may be unwilling to care for young adults with chronic neurologic disorders.	1	2	3	4	5
Patients often don't know how to navigate the adult health care system.	1	2	3	4	5
Issues of sexuality are often not discussed with adolescent patients in the pediatric setting.	1	2	3	4	5
Young patients often don't know their medical history.	1	2	3	4	5

1 represents "completely disagree", 5 represents "completely agree"

STAND

Study on the Transition of Adolescents with Neurological Disorders

If you do not wish to respond to the questionnaire, please complete this section; then return the questionnaire in the enclosed, selfaddressed stamped envelope or return this page by fax at (514)934-4458. This will prevent follow-up material from being sent to you.

□ I do not wish to complete this questionnaire

Please check off your reasons for not completing the questionnaire:

- **D** Topic not of interest
- **D** Too busy
- □ I do not follow young patients in my practice
- □ I do not participate in surveys

Other:_____

THANK YOU





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Étude sur la transition des adolescents atteints de troubles neurologiques Study on the Transition of Adolescents with Neurological Disorders

Veuillez retourner le questionnaire dans l'enveloppe affranchie et préadressée ci-jointe ou télécopiez le questionnaire au (514) 934-4458.

Si vous n'avez pas l'intention de remplir ce questionnaire, VEUILLEZ SVP RETOURNER LA DERNIÈRE PAGE.





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Ce sondage est conçu pour recueillir des renseignements sur votre approche à l'égard de la transition et du transfert des soins pédiatriques aux soins neurologiques destinés aux adultes. Tous les renseignements fournis demeureront confidentiels.

Ce questionnaire a été rempli le :

Pour le but de ce sondage...

Transition désigne la préparation planifiée, volontaire des patients, des familles et des aidants proches relativement au transfert d'un patient de soins pédiatriques aux soins destinés aux adultes.

Transfert désigne la relève de la responsabilité des soins donnés aux patients d'un milieu pédiatrique à un milieu destinés aux adultes.

1. En quelle année avez-vous terminé votre programme de résidence en neurologie?

J'ai terminé mon programme de résidence en neurologie en ______.

2. Quel est parmi les domaines suivants votre principal domaine d'expertise?

- □ Maladies cérébrovasculaires
- Maux de tête
- Épilepsie
- Maladies neuromusculaires
- □ Troubles de mouvement
- □ Réhabilitation/ Retard de développement
- □ Sclérose en plaques/ Neuroimmunologie
- □ Troubles cognitifs/ du comportement
- Neurologie néonatale
- Autre (veuillez préciser) : ____
- □ Je suis un neurologue généraliste

3. Quel pourcentage de vos patients sont des adolescents (>12 ans)?

- 0 % (Aucun)
- □ < 25 %
- entre 25 et 49 %
- entre 50 et 74 %
- **□** ≥75 %
- □ 100 % (Tous)
- Je ne sais pas

- 4. Y a-t-il un programme de transition au sein de votre pratique?
 - 🛛 Oui
 - Non
 - Je ne sais pas
 - → Si non, prévoit-on mettre sur pied un tel programme au cours des deux (2) prochaines années?
 - 🛛 Oui
 - 🛛 Non
 - Je ne sais pas
- 5. Existe-t-il au sein de votre pratique une politique écrite concernant la transition et le transfert des adolescents aux soins destinés aux adultes?
 - 🛛 Oui
 - 🛛 Non
 - Je ne sais pas
- 6. Au sein de votre pratique, qui est responsable de l'administration et de la coordination du processus de transfert/transition? Veuillez cocher toutes les réponses qui s'appliquent.
 - Neuropédiatre
 - □ Infirmière clinicienne
 - Personnel administratif
 - Autre (veuillez préciser) : _____
- 7. À votre avis, à quel âge le processus de transition devrait-il être amorcé?
 - Au début de l'adolescence
 - Une année avant le transfert
 - Au moment du transfert
 - Autre (veuillez préciser): _____
- 8. À votre avis, à quel âge les adolescents devraient-ils être transférés aux soins destinés aux adultes?

Les adolescents devraient être transférés aux soins destinés aux adultes à _____ ans.

9. Quel pourcentage de vos patients ont dépassé l'âge auquel vous recommandez habituellement le transfert aux soins destinés aux adultes?

Environ ______% de mes patients.

- Combien de patients en moyenne transférez-vous annuellement aux soins destinés aux adultes?
 Je transfère en moyenne ______ patients annuellement aux soins destinés aux adultes.
- 11. Pour chacun des troubles neurologiques suivants, veuillez préciser si vous transférez habituellement des patients à un médecin de famille ou à un neurologue pour adultes:

Trouble neurologique	Médecin de famille	Neurologue pour adultes
Paralysie cérébrale		
Maladies neuromusculaires		
Épilepsie		
Maux de tête		
Troubles de mouvement		
Spina-bifida		
Maladies génétiques/		
métaboliques		_
Autisme		
Maladies cérébrovasculaires		
Troubles cognitifs/du		
comportement		

12. À quelle distance de votre pratique est situé le centre de neurologie pour adultes le plus près?

- Dans le même centre
- A moins de 20 minutes en voiture
- A plus de 20 minutes en voiture
- Je ne sais pas
- 13. Envoyez-vous un rapport sommaire écrit au neurologue pour adultes ou médecin de famille au moment du transfert d'un jeune adulte?
 - Presque toujours
 - Parfois
 - □ Rarement
 - Jamais

14. Avez-vous de la difficulté à trouver un neurologue pour adultes ou médecin de famille pour le transfert de jeunes adultes?

- 🛛 Oui
- 🛛 Non
- → Si OUI, quel est le degré de difficulté?
 - Parfois difficile
 - Très difficile
 - □ Presque impossible

- 15. Communiquez-vous directement avec le neurologue pour adultes ou médecin de famille afin de vous assurer que le transfert s'est bien déroulé?
 - Presque toujours
 - Parfois
 - □ Rarement
 - Jamais
- 16. À votre avis, les jeunes adultes qui quittent votre pratique éprouvent-ils un un délai entre les soins pédiatriques et les soins destinés aux adultes?
 - 🛛 Oui
 - 🛛 Non
 - Je ne sais pas
- 17. Pour chacun des troubles neurologiques suivants, évaluez le niveau de difficulté que vous éprouvez lorsque vous transférez les jeunes adultes aux soins destinés aux adultes.

Trouble neurologique	Pas difficile du tout	Parfois difficile	Très difficile	Impossible
Paralysie cérébrale				
Maladies neuromusculaires				
Épilepsie				
Syndrome de Gilles de La Tourette				
Sclérose en plaques				
Maladies génétiques/ métaboliques				
Autisme				
Maux de tête				
Maladies cérébrovasculaires				
Troubles cognitifs/du comportement				

18. En ce qui concerne le transfert réussi aux soins neurologiques pour adultes, veuillez évaluer l'importance des facteurs suivants propres aux patients en encerclant le rang approprié :

1 signifie « pas important du tout » et 5 signifie « très important »

Affirmation			Échelle	;	
Connaissance par le patient de son état de santé	1	2	3	4	5
Connaissance par le patient du nom de son médicament,	1	2	3	4	5
de la dose et de ses effets secondaires					
Observance des prescriptions	1	2	3	4	5
Connaissance des groupes de soutien liés à sa maladie	1	2	3	4	5
Besoin de soins multidisciplinaires	1	2	3	4	5
Participation active pendant les visites médicales	1	2	3	4	5
Capacité à se rendre seul aux visites médicales	1	2	3	4	5
Difficultés de communication co-existantes	1	2	3	4	5
Troubles du comportement co-existants	1	2	3	4	5
Autre :	1	2	3	4	5

19. Quels sont les obstacles auxquels vous devez faire face en ce qui concerne le transfert de jeunes adultes atteints de troubles neurologiques?

20. Veuillez exprimer votre opinion personnelle à l'égard des affirmations suivantes :

1 signifie « entièrement en désaccord » et 5 signifie « tout à fait d'accord »

Affirmation		I	Échelle	•	
Les neurologues pour adultes n'ont peut-être pas la formation nécessaire en matière de troubles neurologiques chroniques qui apparaissent chez les enfants afin de les préparer à gérer ces troubles à l'âge adulte.	1	2	3	4	5
Les jeunes patients ne sont pas toujours prêts à assumer leurs responsabilités en matière de prise de décisions médicales.	1	2	3	4	5
La transition entre les soins pédiatriques et les soins destinés aux adultes est souvant mal coordonné.	1	2	3	4	5
Les parents et aidants proches peuvent avoir une attitude protectrice excessive et peuvent ne pas comprendre les questions de protection de la confidentialité du patient jeune adulte.	1	2	3	4	5
Les pratiques en neurologie adulte sont moins paternalistes que les pratiques pédiatriques (e.g., les patients ne reçoivent pas d'appel lorsqu'ils omettent de se présenter à un rendez-vous).	1	2	3	4	5
ll γ a souvent un long délai entre la dernière visite chez le pédiatre et la première visite chez le neurologue pour adultes.	1	2	3	4	5
Mes collègues n'ont peut-être pas envie de s'occuper de jeunes adultes qui souffrent de troubles neurologiques chroniques.	1	2	3	4	5
Souvent les patients ne savent pas comment naviguer à travers le système de santé pour adultes.	1	2	3	4	5
Souvent les questions relatives à la sexualité ne sont pas abordées avec les adolescents dans un milieu pédiatrique.	1	2	3	4	5
Souvent les jeunes patients ne connaissent pas leurs antécédents médicaux.	1	2	3	4	5

STAND

Étude sur la transition des adolescents atteints de troubles neurologiques Study on the Transition of Adolescents with Neurological Disorders

Si vous ne désirez section; retournez ensuite ci-jointe ou envoy empêchera que d	pas répondre au questionnaire, veuillez remplir cette le questionnaire dans l'enveloppe affranchie et préadressée ez cette page par télécopieur au (514) 934-4458. Cela es messages de suivi vous soient envoyés.
L 🗆	e ne désire pas remplir ce questionnaire
Veuillez cocl	ner la raison pour laquelle vous ne désirez pas remplir le questionnaire :
	Le sujet ne m'intéresse pas Je suis trop occupé Je ne m'occupe pas de jeunes patients Je ne participe pas aux études Autre :
	MERCI
UNIVERSITÉ MCGILL UNIVERSITY	CIHR IRSC Canadian Institutes of Health Research Institutes de recherche en santé du Canada

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Study on the Transition of Adolescents with Neurological Disorders

Please return the questionnaire in the enclosed, self-addressed stamped envelope. Or, fax the completed questionnaire at (514) 934-4458.

If you do not intend to complete this questionnaire, PLEASE RETURN THE LAST PAGE.





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This survey is designed to elicit information on your approach to transition and transfer of care from pediatric to adult neurology. All of the information provided by you will be kept completely confidential.

This questionnaire is being completed on:

____ / ___ / ____ month/ day / year

For the purpose of this study...

Transition is the purposeful, planned, preparation of patients, families and caregivers for transfer of a patient from a pediatric to an adult care setting.

Transfer is the actual responsibility of care of the patient being moved from a pediatric setting to an adult care setting.

1. In what year did you finish your neurology residency training?

I finished my neurology residency training in ______.

2. Which of the following is your main area of expertise/subspecialty?

- Cerebrovascular disease
- Headache
- Epilepsy
- Neuromuscular disorders
- Movement disorders
- □ Rehabilitation / Developmental disabilities
- □ Multiple Sclerosis/ Neuroimmunology
- □ Cognitive /Behavioral disorders
- □ Other (specify): _
- □ I am a general neurologist

3. What percentage of your patient population is under the age of 30?

- 🛛 0 % (None)
- □ < 25 %
- □ 25 to 49 %
- **5**0 to 74 %
- **□** ≥75 %
- □ 100 % (All)
- I don't know

4. In your opinion, at what age should adolescents be transferred to adult care? Adolescents should be transferred to adult health care at _____ years of age.

5. In your opinion, do young adults entering your practice experience a gap between pediatric and adult care?

- Yes
- 🛛 No
- Don't know
- 6. Do you receive a written summary from the pediatric neurologist when a young adult is transferred to you?
 - Almost always
 - Sometimes
 - □ Rarely
 - Never
- 7. Does the pediatric neurologist communicate directly with you to assure that transfer was successful?
 - Almost always
 - □ Sometimes
 - □ Rarely
 - Never
- 8. Do you agree/disagree with the following statement: "my residency in adult neurology provided me with adequate training to care for these young adults with childhood onset neurological conditions".
 - □ Strongly agree
 - Somewhat agree
 - Somewhat disagree
 - □ Strongly disagree

9. On average, how many patients are transferred to you from pediatrics each year?

On average, _____ patients are transferred to me each year from pediatrics.

10. How far from your practice is the nearest pediatric neurology center?

- □ At the same center
- □ Within a 20 minute drive
- □ More than a 20 minute drive
- Don't know

11. For each of the following neurological disorders, rate your level of comfort in treating patients.

Neurological disorder	Completely comfortable	Somewhat comfortable	Not comfortable	Impossible
Cerebral palsy				
Neuromuscular disorders				
Epilepsy				
Tourette Syndrome				
Multiple Sclerosis				
Chromosomal/metabolic disorder				
Autism				
Headaches				
Cerebrovascular disease				
Cognitive /Behavioral disorders				

12. In relation to successful transfer to adult neurology care, please rank the importance of the following patient factors by circling the appropriate rank:

	•				
Statement			Scale		
Patient's knowledge of their medical condition	1	2	3	4	5
Patient's knowledge of their medication name, dose and side effects	1	2	3	4	5
Patient's compliance with medication	1	2	3	4	5
Knowledge of social support groups for their disease	1	2	3	4	5
Need for multidisciplinary care	1	2	3	4	5
Active participation during office visits	1	2	3	4	5
Ability to attend office visits alone	1	2	3	4	5
Co-existing communication impairment	1	2	3	4	5
Co-existing behavioral difficulties	1	2	3	4	5
Other:	1	2	3	4	5

1 represents "not important at all", 5 represents "very important"

13. What barriers do you face in caring for young adults that are transferred to your care?

14. Please give us your personal opinion on the following statements:

Statement		_	Scale		
Adult neurologists may not have the training in childhood onset chronic neurological disorders to prepare them to manage them in adulthood.	1	2	3	4	5
Young patients are not always ready to assume medical decision-making responsibilities.	1	2	3	4	5
The transition from pediatric to adult health care is often poorly coordinated.	1	2	3	4	5
Parents and caregivers can remain excessively protective and may not understand the privacy issues of the young adult patient.	1	2	3	4	5
Adult neurology practices are less paternalistic than pediatric practices (e.g., patients may not get called when they miss an appointment).	1	2	3	4	5
There is often a large time gap between the last visit with the pediatric caregiver and the first visit with the adult neurologist.	1	2	3	4	5
My colleagues may be unwilling to care for young adults with chronic neurologic disorders.	1	2	3	4	5
Patients often don't know how to navigate the adult health care system.	1	2	3	4	5
Issues of sexuality are often not discussed with adolescent patients in the pediatric setting.	1	2	3	4	5
Young patients often don't know their medical history.	1	2	3	4	5

1 represents "completely disagree", 5 represents "completely agree"

STAND

Study on the Transition of Adolescents with Neurological Disorders

If you do not wish to respond to the questionnaire, please complete this section; then return the questionnaire in the enclosed, selfaddressed stamped envelope or return this page by fax at (514) 934-4458. This will prevent follow-up material from being sent to you.

I do not wish to complete this questionnaire

Please check off your reason for not completing the questionnaire:

- Topic not of interest
- Too busy
- □ I do not follow young patients in my practice
- □ I do not participate in surveys
- Other:_____

THANK YOU





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Étude sur la transition des adolescents atteints de troubles neurologiques Study on the Transition of Adolescents with Neurological Disorders

Veuillez retourner le questionnaire dans l'enveloppe affranchie et préadressée ci-jointe ou télécopiez le questionnaire au (514) 934-4458.

Si vous n'avez pas l'intention de remplir ce questionnaire, VEUILLEZ SVP RETOURNER LA DERNIÈRE PAGE.





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Ce sondage est conçu pour recueillir des renseignements sur votre approche à l'égard de la transition et du transfert des soins pédiatriques aux soins neurologiques destinés aux adultes. Tous les renseignements fournis demeureront confidentiels.

Ce questionnaire a été rempli le :

Pour le but de ce sondage...

Transition désigne la préparation planifiée, volontaire des patients, des familles et des aidants proches relativement au transfert d'un patient de soins pédiatriques aux soins destinés aux adultes.

Transfert désigne la relève de la responsabilité des soins donnés aux patients d'un milieu pédiatrique à un milieu destinés aux adultes.

1. En quelle année avez-vous terminé votre programme de résidence en neurologie?

J'ai terminé mon programme de résidence en neurologie en _____.

2. Quel est parmi les domaines suivants votre principal domaine d'expertise?

- Maladies cérébrovasculaires
- Maux de tête
- Épilepsie
- □ Maladies neuromusculaires
- □ Troubles de mouvement
- □ Réhabilitation/ Retard de développement
- □ Sclérose en plaques/ neuroimmunologie
- Troubles cognitifs/ du comportement
- Autre (veuillez préciser) :
- □ Je suis un neurologue généraliste

3. Quel pourcentage de vos patients ont moins de 30 ans?

- 0 % (Aucun)
- □ < 25 %
- Entre 25 et 49 %
- Entre 50 et 74 %
- **□** ≥75 %
- □ 100 % (Tous)
- **I** Je ne sais pas

4. À votre avis, à quel âge les adolescents devraient-ils être transférés aux soins destinés aux adultes?

Les adolescents devraient être transférés aux soins destinés aux adultes à _____ans.

- 5. À votre avis, les jeunes adultes qui se joignent à votre pratique éprouvent-ils un un délai entre les soins pédiatriques et les soins destinés aux adultes?
 - 🛛 Oui
 - Non
 - Je ne sais pas
- 6. Recevez-vous un rapport sommaire du neuropédiatre lorsqu'un jeune adulte vous est transféré?
 - Presque toujours
 - Parfois
 - □ Rarement
 - Jamais
- 7. Le neurolopédiatre communique-t-il directement avec vous pour s'assurer que le transfert s'est déroulé avec succès?
 - Presque toujours
 - Parfois
 - Rarement
 - Jamais
- 8. Êtes-vous en accord/en désaccord avec l'affirmation suivante : « Mon programme de résidence en neurologie m'a permis d'acquérir la formation appropriée pour m'occuper de ces jeunes adultes qui souffrent de troubles neurologiques depuis leur enfance ».
 - Très en accord
 - **Quelque peu en accord**
 - **Quelque peu en désaccord**
 - Très en désaccord
- 9. Combien de patients en moyenne vous sont transférés annuellement des soins pédiatriques?

En moyenne, _____ patients me sont transférés des soins pédiatriques annuellement.

10. À quelle distance de votre pratique est situé le centre de neurolopédiatrie le plus près?

- Dans le même centre
- A moins de 20 minutes en voiture
- A plus de 20 minutes en voiture
- Je ne sais pas

11. Pour chacun des troubles neurologiques suivants, évaluez dans quelle mesure vous vous sentez à l'aise de traiter les patients.

Trouble neurologique	Tout à fait à l'aise	Assez à l'aise	Pas à l'aise	Impossible	
Paralysie cérébrale					
Maladies neuromusculaires					
Épilepsie					
Syndrome de Gilles de La Tourette					
Sclérose en plaques					
Maladies génétiques/ métaboliques					
Autisme					
Maux de tête					
Maladies cérébrovasculaires					
Troubles cognitifs/du comportement					

12. En ce qui concerne le transfert réussi aux soins neurologiques pour adultes, veuillez évaluer l'importance des facteurs suivants propres aux patients en encerclant le rang approprié :

I signifie « pas important du tout » et 5 signifie « très important »						
Affirmation		Échelle				
Connaissance par le patient de son état de santé	1	2	3	4	5	
Connaissance par le patient du nom de son médicament, de la dose et de ses effets secondaires	1	2	3	4	5	
Observance des prescriptions	1	2	3	4	5	
Connaissance des groupes de soutien liés à sa maladie	1	2	3	4	5	
Besoin de soins multidisciplinaires	1	2	3	4	5	
Participation active pendant les visites médicales	1	2	3	4	5	
Capacité à se rendre seul aux visites médicales	1	2	3	4	5	
Difficultés de communication co-existantes	1	2	3	4	5	
Troubles du comportement co-existants	1	2	3	4	5	
Autre :	1	2	3	4	5	

1 signifie « pas important du tout » et 5 signifie « très important »

13. Quels sont les obstacles auxquels vous devez faire face dans le soin des jeunes adultes qui vous sont transférés?

14. Veuillez exprimer votre opinion personnelle à l'égard des affirmations suivantes :

			•		
Affirmation	Échelle				
Les neurologues pour adultes n'ont peut-être pas la formation nécessaire en matière de troubles neurologiques chroniques qui apparaissent chez les enfants afin de les préparer à gérer ces troubles à l'âge adulte.	1	2	3	4	5
Les jeunes patients ne sont pas toujours prêts à assumer leurs responsabilités en matière de prise de décisions médicales.	1	2	3	4	5
La transition entre les soins pédiatriques et les soins destinés aux adultes est souvant mal coordonné.	1	2	3	4	5
Les parents et aidants proches peuvent avoir une attitude protectrice excessive et peuvent ne pas comprendre les questions de protection de la confidentialité du patient jeune adulte.	1	2	3	4	5
Les pratiques en neurologie adulte sont moins paternalistes que les pratiques pédiatriques (e.g. , les patients ne reçoivent pas d'appel lorsqu'ils omettent de se présenter à un rendez-vous).	1	2	3	4	5
Il y a souvent un long délai entre la dernière visite chez le pédiatre et la première visite chez le neurologue pour adultes.	1	2	3	4	5
Mes collègues n'ont peut-être pas envie de s'occuper de jeunes adultes qui souffrent de troubles neurologiques chroniques.	1	2	3	4	5
Souvent les patients ne savent pas comment naviguer à travers le système de santé pour adultes.	1	2	3	4	5
Souvent les questions relatives à la sexualité ne sont pas abordées avec les adolescents dans un milieu pédiatrique.	1	2	3	4	5
Souvent les jeunes patients ne connaissent pas leurs antécédents médicaux.	1	2	3	4	5

1 signifie « entièrement en désaccord » et 5 signifie « tout à fait d'accord »

STAND

Étude sur la transition des adolescents atteints de troubles neurologiques Study on the Transition of Adolescents with Neurological Disorders

Si vous ne désirez pas répondre au questionnaire, veuillez remplir cette	
section;	

retournez ensuite le questionnaire dans l'enveloppe affranchie et préadressée ci-jointe ou envoyez cette page par télécopieur au (514) 934-4458. Cela empêchera que des messages de suivi vous soient envoyés.

□ Je ne désire pas remplir ce questionnaire

Veuillez cocher la raison pour laquelle vous ne désirez pas remplir le questionnaire :

- Le sujet ne m'intéresse pas
- Je suis trop occupé
- □ Je ne m'occupe pas de jeunes patients
- □ Je ne participe pas aux études
- Autre : _____

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