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Brief Communication

Building the Bridge From Pediatric to Adult Neurological Care

Katherine M. Sawicka[1,2,3], Lindsey M. Vogt[4], Danielle M. Andrade[3,5], Hans D. Katzberg[3,6], Steven P. Miller[4,7], Mahendranath Moharir[4], David F. Tang-Wai[3,5] and Ana Marissa Lagman-Bartolome[4,8]

[1]Child Health Evaluative Sciences, SickKids Research Institute, Toronto, Canada, [2]Institute of Health Policy, Management, and Evaluation, Dalla Lana School of Public Health, University of Toronto, Toronto, Canada, [3]Department of Medicine, Division of Neurology, University of Toronto, Toronto, Canada, [4]Department of Pediatrics, Division of Neurology, The Hospital for Sick Children, University of Toronto, Toronto, Canada, [5]Division of Neurology, University Health Network, Toronto Western Hospital, Toronto, Canada, [6]Division of Neurology, University Health Network, Toronto General Hospital, Toronto, Canada, [7]BC Children's Hospital Research Institute, University of British Columbia, Vancouver, BC, Canada and [8]Division of Pediatric Neurology, Children's Hospital, London Health Sciences Center, Western University, London, Canada

ABSTRACT: In this brief communication, we discuss the current landscape and unmet needs of pediatric to adult transition care in neurology. Optimizing transition care is a priority for patients, families, and providers with growing discussion in neurology. We also introduce the activities of the *University of Toronto Pediatric-Adult Transition Working Group – a* collaborative interdivisional and inter-subspeciality group of faculty, advanced-practice providers, trainees, and patient-family advisors pursuing collaboration with patients, families, and universities from across Canada. We envision that these efforts will result in a national neurology transition strategy that will inform designation of health authority attention and funding.

RÉSUMÉ : Combler le fossé qui existe entre les soins neurologiques pédiatriques et ceux destinés à des patients adultes. Dans ce bref article, nous voulons discuter du paysage actuel en matière de soins de transition de l'enfant à l'adulte en neurologie ainsi que des besoins non satisfaits qui en découlent. L'optimisation de ces soins est une priorité pour les patients, les familles et les prestataires de soins et fait l'objet d'un débat grandissant dans le champ de la pratique neurologique. Nous voulons aussi présenter les activités du groupe de travail sur la transition entre les soins pédiatriques et le secteur adulte de l'Université de Toronto. Il s'agit d'un groupe collaboratif entre divers départements hospitaliers et spécialités médicales qui est composé de professeurs, de prestataires de soins en pratique avancée, de stagiaires et de conseillers qui collaborent avec les patients, les familles et les universités de tout le Canada. Nous espérons que ces efforts aboutiront à une stratégie nationale de transition en matière de soins neurologiques qui permettra d'attirer l'attention des autorités sanitaires et d'obtenir des fonds.

Keywords: Pediatric to adult transition care; neurology

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The journey of adolescents with chronic disease to adult health care is fraught with challenges. Some of the challenges include difficulty engaging with adult services, medication adherence, and missed medical appointments, resulting in poor disease-specific and social outcomes.[1] These challenges and poor outcomes have been associated with high health care costs.[2]

The key to improve the outcomes of youth with chronic neurological disease in adulthood is addressing the difference between *transfer* and *transition* of care. *Transfer* of care refers to the act of handing over the responsibility of medical care from one clinician to another clinician or clinical team. *Transition*, however, refers to the "purposeful and planned process that addresses the medical, psychosocial, and educational/vocational needs of adolescents/young adults with chronic conditions as they move from child-centered to adult-oriented health care systems".[1]

Effective *transition*, in contrast to transfer, has been proposed to result in improved outcomes.[3] Despite support for transition care being recognized as a global clinical and research priority by patients and families, there is a dearth of research and evidence-based procedures.[4] Recently, the Canadian Pediatric Society made a call to action with six recommendations to guide effective transition to adult care for youth with complex health needs. The six recommendations are: (1) ensuring transition care is continuous, comprehensive, coordinated, and developmentally appropriate, (2) employing a stepwise plan that increases autonomy and recognizes the changing parental/caregiver role during transition, (3) developing collaborative health care systems between pediatric and adult care across tertiary, community, and primary care settings, (4) redefining quality indicators according to youth perspectives, (5) implementing new educational initiatives

Corresponding author: A. M. Lagman-Bartolome; Email: anamarissa.lagman-bartolome@sickkids.ca

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Table 1: University of Toronto pediatric-adult neurology transition symposium agenda

Transition Symposium I	Transition Symposium II
Transition Care for Neurological Autoimmune Conditions *Speakers: Pediatric and adult autoimmune and neuroinflammatory disease specialists*	**Building the First Canadian Pediatric Neuromodulation Clinic and a New Model of Care for Transition** *Speakers: Pediatric and adult neuromodulation clinicians*
Transition Care for Complex Medical Conditions *Speaker: Complex medical care pediatrician and researcher*	**The Challenges of Transitioning Care of Patients with Mitochondrial Disease** *Speakers: Pediatric and adult neurologists/metabolics physicians*
Pediatric Transition Preparation in Neuromuscular Disease *Speaker: Pediatrician with expertise in neuromuscular disease and patient advocate*	**Trainees' Perspectives on Transition of Care** *Speakers: Pediatric and adult neurology residents*
Transition Care for Neurovascular Disease *Speaker: Pediatric and adult neurovascular disease specialists*	**SMA Therapy: Effect of Cost of Therapy on Transition of Care** *Speakers: Pediatric and adult neuromuscular specialists*
Transition Care for Epilepsy *Speaker: Pediatric and adult epilepsy specialists*	**Insights from Transition in Other Fields: Transitioning Kidney Transplant Care from Pediatrics to Adults** *Speakers: Pediatric transplant specialist*
Transition Care: Visiting Professor *Speaker: International leader in transition care*	**Lessons I've Learned from Treating Adolescents & Young Adults with Headache** *Speakers: International leader in headache transition care*

to increase capacity to care for youth during transition, and (6) adapting program funding and payment models for physicians that are flexible to age cutoffs and shared care among pediatric and adult providers.[5]

Among neurological disorders, there is a scarcity of published literature regarding transition care – although this topic has been addressed in recent times. Transition care is required in many neurological conditions including autoimmune encephalitis, epilepsy, functional disorders, headache, hydrocephalus, multiple sclerosis and demyelinating conditions, movement disorders, neuromuscular disorders, neuropathic pain, neurometabolic disorders, neuro-oncology, sleep, and stroke. A qualitative study in 2011 aimed to understand parental perceptions of the transfer process of their children with neurological diseases. This study highlighted a sense of loss, fear, and uncertainty as their child transferred to adult care.[6] The subspecialty of epilepsy, among the number of other neurological subspecialties, has clearly led the field of transition thus far. Published guidelines are now available and have addressed the transition of care for pediatric epilepsy patients to adult care not only in general but also for specific groups of complex epilepsies.[7] The American Academy of Neurology (AAN) has also released a consensus statement outlining important considerations and proposed quality measures to assess outcomes of transition.[8]

Although investigation into the outcomes and experience of youth with neurological diseases during transfer and transition are evolving, few specific and systematic initiatives exist to inform the process. A recent systematic review outlined initiatives in neurology including educational workshops for youth, multidisciplinary clinics, mobile and web-based applications, and early start transition process. The focus of many of these interventions was developing self-management skills and orienting to adult services.[9] These initiatives have focused mostly on meeting the needs of patients and families, with few initiatives addressing the needs of health care providers to improve transition. The lack of organized regional, provincial, and national processes are barriers to effective implementation of transition initiatives.[10]

With the backdrop of the Canadian Pediatric Society call to action and AAN consensus statement, the pediatric and adult neurology divisions at the University of Toronto have committed to addressing the unmet needs of transition in neurology with formation of a working group. In this brief communication, we introduce the *University of Toronto Pediatric-Adult Transition Working Group*.

Our Pediatric-Adult Transition Working Group, established in 2021, is a collaborative interdivisional and inter-subspeciality group of faculty, advanced-practice providers, trainees, and patient-family advisors. The transition working group not only includes members from both adult and pediatric neurology care centers but also includes subspecialty representation from epilepsy, headache medicine, movement disorders, neuroinflammatory, neuromuscular, neurometabolics, neuromodulation, neuro-oncology, and stroke. In accordance with the recommendations of the Canadian Pediatric Society and AAN on transition care, the objectives of the working group are to: (1) deliver opportunities for education around transition planning into residency training and continuing medical education curriculums, (2) identify and address common barriers and facilitators for providing continuous, comprehensive, and coordinated transition care across neurological subspecialties, and (3) establish shared resources that can be used by patients, families, and healthcare providers across the field of neurology.

Taking these objectives into perspective, the group has undertaken initiatives to assess and educate on the topic of transition in neurology. Firstly, a survey (unpublished) was distributed in 2021 to assess faculty and resident perspectives. Less than 60% of faculty felt comfortable with the process of receiving and transferring patients from pediatric to adult care. Some reasons for discomfort included: (1) not knowing to whom or how to refer for adult care, (2) reviewing an overwhelming volume of clinical documentation during transfer of care, and (3) not knowing how to empower young adults to self-manage their disease. The results of this preliminary survey highlighted that a coordinated communication between pediatric and adult providers is required in the current landscape of transition care at our centers.

Another initiative of the transition working group was hosting two symposia on transition in 2021 and 2022 (Table 1 details the topics in the two symposia). The symposia were a platform for co-learning among academic and community neurologists, trainees, local transition experts from non-neurological subspecialties, international keynote speakers, and people with lived experience.

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The transition symposia were advertised broadly, and members of the Canadian Neurological Society, the Canadian Association of Child Neurology, and the Canadian Society of Clinical Neurophysiology were invited to participate. The symposia were integrated as part of residency academic half day for pediatric and adult neurology residents and regarded as required learning in anticipation of their future careers. Continuing medical education credits were available for practicing healthcare providers. Common discussions across sessions at the symposia included: "When is my patient ready to go to adult care?," "Who should provide their care next?," "When am I [patient] ready to move to adult care?," "What documentation should I send the adult provider,?" "How often should I see my patient in the adult clinic?," "Who do I [patient] talk to if I have a problem before my first appointment in the adult clinic?," and "How do we manage drug coverage while in adult care?." Although needs of patients are individualistic, these discussions at the symposia highlighted a role for shared resources across subspecialties to support transition such as transition readiness assessments, drug coverage navigation information, and referral templates.

In response to the initial ideas gathered from the informal survey and the symposia, the transition working group has outlined several deliverables over the next three years. First, the transition working group is collaborating with Program Directors of the pediatric and adult neurology residency training programs to integrate education and increase awareness about transition into the educational curriculum. This will be done by implementing and embedding teaching objectives on subspecialty rotations about how to carry out transition of a patient to adult care and future hands-on learning opportunities for residents in dedicated transition clinics. We aim to align these objectives with the entrustable professional activities (EPAs) as part of competency-based medical education.

Second, the working group will develop and distribute a database of all physicians in Toronto and the Greater Toronto Area who have expertise, interest, and interdisciplinary resources to care for transitioning patients.

Third, the transition working group will compile a guide for best practices for program funding and compensation models in shared pediatric and adult transition clinics.

Lastly, the working group is collaborating with patient and family advisors to create a centralized, accessible, and relevant online resource for patients, families, and providers to support transition to adult neurological care.

The University of Toronto Divisions of Pediatric and Adult Neurology have recognized transition as a critical area for research and program development. As this is a national issue, our Pediatric-Adult Transition Working Group invites providers, patients, families, and other university neurology programs and specialties from across Canada to collaborate and share ideas for ongoing projects and future work. The working group envisions that our combined efforts will result in a national neurology transition strategy that will leverage resources and health policy changes. We are excited for the future of transition care for chronic neurological diseases and hope that feelings of fear and uncertainty will be replaced by feelings of reassurance, safety, and empowerment in patients, families, and providers as they embark on crossing the bridge from pediatric to adult neurological care.

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