

The Transition from Pediatric-centred to Adult-oriented Care in Rheumatology

By Evelyn Rozenblyum, MD, FRCPC; and Lynn Spiegel, MD, FRCPC

Transition has been defined as “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented healthcare systems,” whereas transfer refers to “a single act of moving from one facility to another, typically with no preparation or planning ahead of time.”¹⁻³ As rheumatologic diseases affect both the patients’ physical and emotional development, it is important that we think about thoughtful ways to prepare them for transition to the adult healthcare system, rather than simply transferring them when they reach 18 years of age. This article focuses on the importance of transition, current efforts underway in Canada and future research initiatives in the field of transition in rheumatology.

Why Transition is Important

In Canadian centres, transfer to adult care typically occurs at age 18. However, the adolescent brain and personal identity develops well into the mid-twenties; therefore, youth may not be developmentally prepared to transition to adult care.⁴ Furthermore, during this critical time, young adults are often dealing with many areas of personal transition (i.e., relationships, school and career), making their medical needs a lower priority. These needs may not be properly addressed in routine clinic visits due to time constraints or lack of practitioner experience. Also, patients are often unprepared to take charge of their own medical management since their caregivers have typically assumed responsibility for coordinating appointments and tracking medications. These issues can lead to significant dropout from the medical system, with consequent compromise of disease control.⁵

Transition planning should begin in the pediatric centre from an early age. Encouraging patient autonomy and education around their disease and medications are paramount to the early transition process in pediatrics.

Transition Efforts Across the Country

Rheumatology centres across Canada have tried to address transition of adolescent patients’ needs in different ways. There are well-established Young Adult with Rheumatic Diseases (YARD) clinics, in Halifax, Montreal, Calgary, and Vancouver, which have been shown to be most successful in health outcomes and decreased rates of clinic dropouts.⁶ In Vancouver, care is shared between the adult and pediatric providers, bimonthly in a separate clinic space, for patients between 18-24 years old who were followed in the Pediatric Rheumatology Program.

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Multidisciplinary support is available for visits (i.e., nursing, social work, occupational therapy [OT] or physiotherapy [PT]).

Other centres, such as Halifax and Calgary, use a different approach. Halifax has quarterly clinics whereby the patient meets their new adult rheumatology provider in their familiar pediatric clinic, usually for one appointment prior to transition. In Calgary, the pediatric rheumatologist goes to the adult centre to help acquaint the patient to their new surroundings. Smaller centres across the country identify adult rheumatologists who have an interest in looking after young adults and refer to them almost exclusively.

Specialized clinics, such as the Lupus Program in Toronto, collaborate with adolescent medicine to help engage youth (as young as 13 years old) before they leave SickKids. In the general rheumatology clinics, there is a multidisciplinary approach with nurses, PT/OT practi-

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Pediatric Rheumatology Research in Canada

The Canadian Alliance of Pediatric Rheumatology Investigators: CAPRI is Growing Up

Lori B. Tucker, MD, FRCPC, Chair, CAPRI

Canadian pediatric rheumatology research has earned attention and respect nationally and internationally, largely due to pediatric rheumatology clinicians and investigators from all across Canada coming together to form a national research network: the Canadian Alliance of Pediatric Rheumatology Investigators (CAPRI).

As a group, we had worked together for many years on issues related to training, education and advocacy. A need for a group to represent and facilitate collaborative research across all Canadian pediatric rheumatology centres was identified in 2006 at a seminal meeting held in Vancouver, BC. We recognized that research in childhood rheumatic disease could only be effectively conducted in a multicentre manner, and decided to start a network. The group decided to focus on childhood arthritis, and out of that meeting, a New Emerging Team grant was submitted to CIHR and was successful. This was the birth of the Research on Arthritis in Canadian Children Emphasizing Outcomes (ReACCh-Out) study and the CAPRI group.

The mission of CAPRI is “pursuit of new knowledge for the benefit of children and adolescents with rheumatic diseases,” with objectives to: 1) facilitate research on childhood rheumatic diseases through collaborative multicentre studies involving pediatric rheumatology centres in Canada; 2) build an infrastructure for multicentre pediatric rheumatology research; 3) facilitate and foster pediatric rheumatology research in which single or a few centres participate; 4) facilitate research training for those interested in a career in pediatric rheumatology research and to foster research careers of new investigators; and 5) liaise with other research groups both nationally and internationally.



CAPRI members in Saskatoon.

Since the inception of the ReACCh-Out study, CAPRI has grown in research scope and membership. Our network includes as members all pediatric rheumatologists from every pediatric rheumatology centre in Canada, and has expanded to include research members who are not pediatric rheumatologists but engaged in pediatric rheumatology research, and trainees. Our initial project, ReACCh-

Out, has been a terrific success with 1,500 children with newly diagnosed juvenile idiopathic arthritis (JIA) enrolled from all across Canada. We have creatively utilized the enormous resources from the ReACCh Out cohort to study predictors of disease course, risk of flares, uveitis, pain, health-related quality of life, and novel genomic/biologic disease clustering. Our research in JIA has continued on from ReACCh Out, to include studies on biologic basis of disease (Biologically Based Outcome

Predictors in JIA [BBOP]; Principal Investigator [PI] Alan Rosenberg), and physical activity in children with JIA (Linking Exercise Activity and Pathophysiology in Canadian Children with JIA [LEAP]; PIs Lori Tucker and Ciaran Duffy). Several CAPRI members are international experts in childhood vasculitis research, and lead major research initiatives which involve CAPRI. These include A Registry of Childhood Vasculitis: E-entry (ArCHIVE) and the Pediatric Vasculitis Initiative (PedVas) (PI for both, David Cabral), and Brainworks (PI Susanne Benseler). Our next large project in development is launching a Canadian National JIA Registry, which will allow longitudinal data collection on children and youth with JIA across Canada,



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tioners and rheumatologists providing transition teaching with support from adolescent medicine and social work.

Importance of Adult Rheumatology Involvement

Collaborating with our adult rheumatology colleagues is extremely important to understand and address the needs of our young adult patients. Effective communication (verbal and written), education around psychosocial issues and identifying how to best coordinate our efforts are paramount to achieving this goal.

Challenges we can anticipate include the funding difficulties for additional multidisciplinary staff, longer appointments, and clinic space availability. However, we hope adult rheumatologists will be eager to work together to develop processes and programs.

Research Initiatives Through the Canadian Alliance of Pediatric Rheumatology Investigators (CAPRI)

CAPRI has created a working group to focus and unite our transition research efforts nationally with our adult colleagues. Currently, there are many collaborative national projects, such as evaluating a transition readiness questionnaire (the Readiness for Adult Care in Rheumatology [RACER]) and creating a transition toolkit through focus groups with patients, families and adult/pediatric rheumatology practitioners. Our goal is to develop a core set of outcome measures to evaluate the acceptability and effectiveness of transition programs that will be linked with the national registries.

Clinically, we aim to create several models of care that different-sized centres can adopt, with the eventual goal of having a transition program in every major centre in Canada. It is our hope that these initiatives will enhance collaboration between pediatric and adult rheumatologists in order to serve our patients and families better and to achieve excellent medical and psychosocial outcomes.

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and will be able to be linked to new projects as they come along. The JIA Registry has received start-up funding from The Arthritis Society, and is in a pilot testing phase with full implementation planned for late fall 2016.

The enthusiasm and growth of CAPRI could be best seen at our most recent scientific meeting, which took place in Toronto on April 12-13, 2016. Forty-five members from across the country attended the meeting, and there were sessions reviewing current research, workgroup sessions for established projects as well as emerging programs such as transition research, outside speakers and work sessions on employing knowledge-translation strategies using our research results, and discussion of future directions and goals. Evaluations of the meeting from attendees were very positive, and the excitement and engagement of participants was fantastic.

As a small pediatric research network, CAPRI is doing well with steady growth, while remaining open to new opportunities and driven by our members' interests. CAPRI is a member of the Mother, Infant, Child, and Youth Research Network (MICYRN), a coordination body of Canadian pediatric research networks, and this connection is providing opportunities for infrastructure development. We have good collaboration with U.S. and international pediatric rheumatology researchers and research groups, and we have now become an important voice of Canadian pediatric rheumatology research in a variety of settings. Most importantly, we are a collaborative bunch who recognize the value of working together, and enjoy it. We are fortunate to have within our CAPRI membership tremendous experience, wisdom, creativity and enthusiasm for research. Our most precious asset is our collegiality and ability to work together for common goals, and with that, the future of CAPRI is very bright.

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