The Ins and Outs of Canada's Top Transition Clinics

Dr. Paivi Miettunen is a pediatric rheumatologist from Calgary. She was born in the Arctic Circle in Finland and moved to Canada in her transitioning years as a youth. She completed her undergraduate medical training at McMaster University, her pediatric residency training at Dalhousie University, and her pediatric rheumatology fellowship at the University of British Columbia. She was appointed to the Faculty of Medicine at the University of Calgary in 2002, where she is currently the Division Chief for Pediatric Rheumatology.

Transition for children with chronic diseases has become of topical interest as more children with disabling or chronic conditions are surviving into adulthood and require follow-up for unforeseen periods of time in the adult world. My enthusiasm for this topic harkens back to my fellowship in Vancouver. Although I was filled with trepidation during my first clinic—patients seemed very complex to the novice fellow. Over the two year fellowship, faithfully attending the clinic each Monday, I came to appreciate the rewards and complexities involved in taking care of this group of patients. In this volume of the *CRAJ*, you will be able enjoy practical pearls from three transition clinics from across Canada: Montreal in the East, and Vancouver in the West, framing our home clinic in Calgary. You will also hear firsthand from a transitioned youth, Ms. Alla Guelber, who has written an article highlighting her special experience.

As each of the articles in this issue emphasizes, the success of transitioning clinics is about much more than simply hanging up a shingle, with a sign "Youth with Chronic Rheumatic Diseases Here." As some rheumatologists in the country may attest, running a clinic on one's own, in a fee-for-service practice, is not for the faint hearted. Similarly, if no policy is in place for who gets to accompany the patient to the clinic visits, one may be surprised to find increasingly older patients accompanied by well-meaning parents. Fortunately, by following simple guidelines set out in these articles, setting up a transition clinic should fulfill all of your expectations of an energetic enterprise!

The Basic-Basics

What types of pediatric rheumatology patients require care into adulthood?

This is a good question, as pediatric rheumatologists are used to assessing a variety of conditions, ranging from "unusual gait" to more significant illnesses, such as linear scleroderma, different childhood onset arthritidies, and various vasculitic disorders. The "patient inclusion criteria" was the first item that we developed when we applied for funding for a regional transition clinic in Calgary. Because of defined resources, we wanted to limit the clinic to patients who might have an adverse outcome if they did not receive ongoing care. We all recognize these patients—they show up in the emergency wards of adult hospitals in a medical crisis, with no physician who "knows the patient." From our cross-country survey, we found that all three clinics have focused on a similar group of patients: patients with inflammatory pediatric rheumatic diseases. In general, this group comprises two types of diagnoses. First, there are those patients with "adult type rheumatic diseases" such as systemic lupus erythematosus and Wegener's granulomatosis, for which up to 20% are diagnosed during childhood. The second group consists of "pediatric specific" diagnoses, such as juvenile dermatomyositis, different types of childhood arthritis, and uveitis associated with juvenile idiopathic arthritis—conditions that can be unfamiliar in disease presentation and expected outcome for our adult colleagues.

What medical issues may differ between pediatric onset rheumatic diseases compared to adult onset diseases?

Our next goal was identification of medical issues that may be specific to the pediatric/adolescent population, which therefore would require special attention in the transition clinic. For example, although medications rarely differ between pediatric and adult patients, there are some disease and treatment related complications that occur only in a growing child: delayed puberty, generalized and localized growth failure, and failure to attain normal peak bone mass. An illustration of localized growth failure is demonstrated by pediatric patients whose juvenile arthritis affects temporomandibular joints. These patients are at risk for growth failure of the jaw, which may require orthodontic and/or plastic surgery intervention in the young adult years.

Potential Barriers to Transitioning

Why can't we simply transfer the care of these patients to our adult colleagues after the patient turns 18?

It is good to review the three main barriers that have been identified by different subspecialties regarding the simple

transfer of care process. The first barrier involves parents and patients. From their point of view, a common obstacle is the perceived loss of trusted pediatric caregivers who must now be traded for new and unknown caregivers in an adult service. The second barrier involves the pediatric caregivers themselves—and yes, I suspect we have all been guilty at least once of this—those who have difficulty with "letting go" of their patients. Third, from an adult rheumatologist's point of view, lack of experience in "pediatric" diseases, busy clinics full of adult patients, and the (often accurate) perception of "time consuming adolescent patients and their parents" can be obstacles to transitioning.

Specific Adolescent Issues

As made clear in the transition articles in this issue of the *CRAJ*, the most important reason for having transition clinics is not the medical differences between children and adults, or even the three perceived barriers mentioned above, but the inherent challenges in the period of transition from adolescent to adulthood. Transition clinics are designed to help our patients with childhood onset diseases become independent in managing their chronic diseases, while completing the adolescent developmental tasks. These "developmental tasks" appear simple enough:

1. Consolidation of adolescent/young adult identity;
2. Establishment of relationships outside the family;
3. Achievement of independence from parents; and
4. Finding a vocation.

These are tasks that we have all navigated through. However, for the adolescent with a chronic illness, these goals may be much more difficult to achieve as the natural progress towards independence conflicts with the need for continuing adult supervision and support.

So what exactly is the "transition process" that is epitomized by specialized transition clinics?

It has been defined by the Society of Adolescent Medicine as "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented healthcare systems." Hmm, sounds simple, but when one examines the necessary skill-set to make this a success, it appears that the ideal healthcare worker for adolescent patients appears to be akin to a juggler: while taking the developmental tasks of the adolescents into account, he/she simultaneously plans for optimizing therapy, minimizing medication toxicity, educating families and patients regarding prevention of disease flares and complications, promoting school performance, providing vocational counseling and addressing concerns regarding reproductive health.

Adding a Fourth Barrier to Transitioning

If this skill-set seems daunting, you would not be the first to feel that way. In Calgary, after our initial excitement about establishing a transition clinic, we became more introspective. It appeared to us that unless we addressed the need for a multidisciplinary team—which we dubbed the "fourth barrier" to transition—our clinic may not succeed.

The Calgary Experience

Because our clinic in Calgary is relatively new, I will review the steps that we took in order to make our clinic a reality. Our first advice would be to foster patience—like Rome, our transition clinic was not built in a day. In 2004 we applied for funding from the Internal Medicine's Innovation Project to establish a regional transition clinic. Dr. Anne-Marie Crawford, from adult rheumatology, spearheaded the project with collaboration from other rheumatologists: Dr. Nicole Fahlman from adult rheumatology, and Drs. Nicole Johnson and myself, Paivi Miettunen from pediatric rheumatology. We are very pleased that our group of physicians has increased to include Dr. Norma Jibb from adult rheumatology.

We were very fortunate that the three first barriers to transition were relatively easy to address. Not only did we have pediatric rheumatologists who were keen to transition their patients who were 18 years of age and older (and at times less than 18 years of age). We also had an equally enthusiastic group of adult rheumatologists who had a similar philosophy regarding the need for transitioning. Regarding a component of the "third barrier"—unfamiliarity with pediatric specific diagnoses—all rheumatologists in Calgary attend once weekly citywide rheumatology rounds. During these rounds, adult and pediatric diagnostic dilemmas are discussed so that awareness for more age-specific diagnoses remains current, regardless of one's primary interest. Finally, in looking at the "fourth barrier" to transitioning—we felt that secure funding was critical to help staff the clinic with allied healthcare workers, a group we felt was essential in ensuring the success of the clinic.

It was this fourth barrier that took us two years to secure, but finally, the doors to our transition clinic opened at an outpatient clinic at the Adult Rheumatology Unit of the University of Calgary in February 2006. Our initial aim was to organize a young adult program that would include pre-transition assessment for transition readiness, post-transition focus groups to identify potential gaps in our service, medical follow-up, and involvement of allied health specialists to allow for counseling regarding generalized fitness, insurance coverage, vocational counseling, fertility and other important issues.

The clinic structure consists of a vibrant multidisciplinary team, with physicians, nurses, physiotherapist and a social worker, and takes place most Wednesday afternoons. Typically, two adult rheumatologists are present at each clinic, and pediatric rheumatologists attend the clinic once monthly.

So far, 100 patients, ranging in age from 14 to 21 years, have been transitioned from the pediatric program at Alberta Children's Hospital to the Foothills Transition program. Similar to Dr. Hazel's transition clinic in Montreal, we also accept young adult patients with childhood onset rheumatic diseases who have moved to Calgary from other parts of the country. In addition, we have added a unique feature to our clinic. Rather than concentrating simply on patients with pre-existing pediatric diagnoses, we opened our clinic to new diagnoses of inflammatory diseases in the young adult age groups (18 to 21 years). We felt that these patients were also in the midst of achieving their adult developmental milestones, and would benefit from the multidisciplinary support in the early stages of their disease.

Practical Pearls

We feel that our clinic has been successful in our initial goals, and that it has exceeded our expectations in two areas: a low number of "no shows" and high percentage of patients either in full time work or attending educational institutions.

As one of our transitioned patients, Ms. Alla Guelber points out in her article, there are many reasons for our successes. I would like to share some of the practical tools that we have found helpful in our clinic:

Clinic hours

The old adage of "early to bed, early to rise, makes a man healthy, wealthy and wise" does not seem to apply to teenage years. As documented by an informal survey at our pediatric rheumatology clinic, our adolescent patients prefer afternoon appointments. Similar nocturnal habits seem to abound across the country, as only one brave center out of three has morning clinics. The Vancouver transition clinic starts bright and early at 9 am. We, in Calgary, have resigned to the afternoon clinic, which starts at 1 pm. However, we found out that even that was a bit early for the Calgarian transitioning youth. Many request a visit after 4 pm. It turns out that this request is not because our patients don't have to rise before 4:00 pm, but because the majority of our patients have either full-time jobs, attend post-secondary school, or do both, and find it difficult to miss either school or work for doctor's appointments. Like many other young adults, the patients in our clinics do not have salary jobs with benefits, and a work shift missed is income missed. We have found that if we give ample notice regarding clinic appointments,

From left to right: **Ms. Terri Lupton** (Clinical Nurse Specialist), **Ms. Carol Johns** (Physiotherapist), **Dr. Norma Jibb** (Adult rheumatologist), **Mr. Leon Mitchell** (Social worker), **Dr. Paivi Miettunen** (Pediatric rheumatologist), **Dr. Anne-Marie Crawford** (Adult rheumatologist), **Dr. Nicole Fahlman** (Adult rheumatologist) and **Dr. Nicole Johnson** (Pediatric rheumatologist). Missing: **Ms. Lorena Totton** (clinic nurse)

are flexible with changes in appointment times, and run the clinic on time, we have much better success at seeing the patients for their regular clinic appointments. However—and this is very important—several phone calls, e-mails, and text messages may be required to remind our patients of upcoming appointments. As Ms. Alla Guelber points out in her article, our clinic nurse extraordinaire, Ms. Terri Lupton, is a master at finding ways for contacting patients. Our low "no show" rate, at 6%, attests in equal measures to our patients' appreciation of flexible scheduling and to gentle "nagging" of our patients.

Born to be free

In pediatrics, we are used to having large examining rooms to accommodate the accompanying family members—it is not unusual to have two sets of parents, a grandparent, and perhaps a sibling (or three) join the patient. However, this type of setup is clearly not ideal for fostering independence in the young adult, nor for generating an easy atmosphere for inquiring about HEADS (home, education, alcohol, drugs and sex), which is an essential part of the young adult clinic interview. However, before we step into the room with the young adult, it is good to remember Dr. Hazel's observations from Montreal: brushing up on one's adolescent communication skills is essential to ensure good rapport with this age group.

The three transition clinics covered in this issue of the *CRAJ* all handle the delicate situation of how to encourage the patients' independence by gradually "weaning off the parents" from the clinic visits in slightly different ways. In Calgary, similar to Vancouver, we start independent patient visits at the Children's Hospital. At the transition clinic, we allow parents to join for the first visit, and after that, the youths are seen on their own. We have rarely had protests either from the patients or their parents.

Feel good, look good

Another key to a successful clinic attendance seems to be providing the patients with what is important to them. In addi-

tion to addressing strictly "medical concerns," our young adults are keen to receive input from our physiotherapist, Ms. Carol Johns, during their visits. She does a wonderful job in assessing not only sore joints, but general issues about posture, stretching and weight training—always very popular topics, with both female and male patients.

Vocation, vocation, vocation

It is well known that many young adults with chronic childhood onset illnesses can have difficulties in reaching their vocational goals. Our social worker, Mr. Leon Mitchell, has been instrumental in engaging our patients' interest in either trade training or post-secondary education, and he has been wonderful in fishing out information about appropriate scholarships etc. We are very proud of our patients, of whom nearly 100% attend full-time post-secondary education or are in full-time employment.

Continuity of care

Continuity of care is important to all patients, but especially for the transitioning youth. We have found that one of the most appreciated aspects to our patients is ensuring that they have a family physician. In the pediatric setting, we encourage the patients to see this caregiver for all minor ailments, and even for initial assessment of a potential disease flare, to make sure that this physician stays engaged in the process. This physician might be the only one whom the patient knows consistently, so he/she is therefore one of the most important links in providing continuity of care during the young adult years.

Passing on the torch

The ultimate goal of passing on the care of the patients to our adult care colleagues is fostered by close collaboration between the adult and pediatric healthcare providers. In Calgary, both adult and pediatric physicians attend the patients' first visit to the transition clinic, the same visit that patients' parents typically join in. Having the pediatric specialist present helps the patient/parents transfer their confidence to another physician and to minimize anxiety about the new physician not knowing any of the past history. Finally, when it is time to exit from the clinic, this process is made much easier by having three adult rheumatologists participate in the transition clinic. These physicians have established a good rapport with the patients over several years, and when patients are deemed "transfer ready," they are smoothly transferred to our adult colleagues' individual adult clinics. We recognize that having so many physicians participate in the clinic is possible only because of the alternative funding arrangements.

Future Goals

While we feel extremely fortunate with our existing program, we are not ready to rest on our laurels! From our focus groups—designed to identify potential gaps in our service from our patients' and their parents' point of view—we have identified two areas that we are now gearing up to improve:

1. More disease and medication specific information

At first glance, this request may appear surprising, considering the many years these patients have spent in the pediatric setting. However, the young person who develops a chronic rheumatic condition at an early age has often not had specific education about his/her underlying condition, because parents have always been their mouthpiece. Although we do address disease specific issues again with the adolescents in the children's program, our patients welcome the opportunity for more disease related information as they become more independent regarding their disease management. This very same topic is highlighted in Dr. Tucker's article from the Vancouver clinic.

2. Organizing official peer support groups

One of the main attractions for the adolescents moving from the familiar pediatric setting to our transition clinic is the camaraderie offered by other patients of similar age. Our center has been very fortunate in having an enthusiastic patient group who is now planning to establish a more official peer support group.

The Secret Ingredient

At the end of the day, the success of the transition clinic in all centers seems to come down to a dedicated group of healthcare workers who genuinely enjoy adolescents. From our cross-country survey, we asked each center to describe the best and worst of the clinics. Starting with the worst, well, I will leave each center to identify their concerns, if any. The best was unanimous—the excitement of seeing our young patients gain independence and realize their life's goals, despite at times severe chronic illnesses.

For those centers who are contemplating setting up a transition clinic, the three clinics featured in this volume of *CRAJ* seem to have very similar advice: the best thing to do is to get a group of individuals together with similar interests, listen to the triumphs and challenges of others, and then make your own success. As we continue to work in these clinics, let's not forget to look in the mirror from time to time, and remind ourselves that there is that transitioned youth in there, somewhere, grinning.

Happy transitioning!