# A province wide review of transition practices for young adult patients with type 1 diabetes

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#### Abstract

Background: Most studies on the transition from pediatric to adult care focus on practices at a single institution. We examine the transition for young adults with type 1 diabetes across an entire Canadian province with a small, mostly rural population: Newfoundland and Labrador (NL). Our aim is to determine a comprehensive picture of how transition is occurring in one jurisdiction and explore potential methods for improvement. Methods: A provincial diabetes database and hospital admission data were reviewed for a cohort of young adults who transitioned into adult care to determine the number of transfers occurring, patient characteristics, and the number of diabetes-related hospitalizations. Semi-structured interviews with pediatric and adult diabetes providers were conducted to determine the current process of transition and identify ways for improvement, including the potential role of family physicians. Results: Between 2008 and 2013, 93 patients with type 1 diabetes transitioned into adult care. Fifteen interviews were conducted across the province's four regional health authorities. Various models of transition care are being employed, reflecting staff and resource availability. While no structured transition program was identified, many providers were comfortable with their current transition processes. Suggested improvements included more structured processes, shared educational resources, and a dedicated transfer clinic. Conclusions: In a province with a relatively small number of patients who transition out of pediatric care annually, we found different approaches for transitioning them into adult care, but this variation may not negatively impact patient outcomes.

#### Introduction

The transition from pediatric to adult care can be difficult for young adults with a chronic condition who require ongoing medical care, with many families not receiving appropriate services during this period.<sup>1</sup> There are also clear impacts on patient outcomes related to their move into adult care. For young adults with type 1 diabetes, this transition period is associated with poorer glycemic control and less frequent clinic attendance.<sup>2,3,4,5</sup> These young adults are also at higher risk for complications and hospitalization in the period after they move into adult care.<sup>5,6,7</sup> Because of the greater recognition of these risks, there has been more focus, in both practice and research, on improving transition.

While there are exceptions, <sup>8,9</sup> most studies on transition for individuals with type 1 diabetes have focused on practices at a single institution or program. This limited perspective may overlook the experiences of patients who are followed at centres without a dedicated pediatric diabetes or transition program. Taking this approach also likely under reports the experiences of patients who are cared for in rural or remote areas. In this article, we examine the transition for young adults with type 1 diabetes across an entire Canadian

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province: Newfoundland and Labrador (NL). Our aim is to determine how transition is occurring across this entire jurisdiction and to identify ways in which care delivery can be improved.

NL has one of the highest incidence rates of type 1 diabetes reported globally (49.9/100,000; 95% CI 42.2, 57.6). <sup>10,11</sup>Still the issue of transition to adult care for patients with diabetes has not been previously explored in the NL population. The NL population is also interesting from a transition perspective in that the region has a small and most rural population. Over half of the province's population of 528,000 live in a rural area, with a population density of 1.4 persons per square kilometer. <sup>12</sup> Health care in NL, including diabetes care, is delivered by four separate regional health authorities. There is only one tertiary care children's hospital, located in the provincial capital. Much of the population faces challenges in terms of accessing speciality health care services locally, including diabetes care. <sup>13</sup> Even though the province has a small population, there was little understanding of how transition care is being delivered in different regions. This lack of understanding of current practices is a barrier to identifying and implementing quality improvements, especially on a province-wide basis. The situation in NL related to diabetes transition is probably similar to that in other regions with mostly rural, widely dispersed populations. Understanding how transition occurs in NL can then provide insights into how the transition to adult care is managed in other jurisdictions and the type of interventions that can used to improve care.

#### Methods

In order to get a comprehensive picture of transition in the province, we used a mixed methods approach. Data about a cohort of young adults who transitioned into adult care were reviewed to determine the number of transfers occurring in the province, patient characteristics, and rates of diabetes-related hospitalizations. Pediatric and adult diabetes providers were interviewed about current transition processes and suggestions for improving practices.

#### Patient Cohort

There is a provincial diabetes database that captures all patients in NL diagnosed with type 1 diabetes up to 2015, based on the reporting of all diabetes nurses and diabetes educators in the province. A description of how cases were ascertained is available elsewhere. Using this database, we identified patients who turned 19 and transitioned to adult care between 2008-2013, the last year we were able to get complete patient data. Patient records were linked via coded identifiers to the Provincial Discharge Abstract Database (discharges from acute care facilities). We examined the number of patients transitioning into adult care and the basic demographic information about them. To compare the impact of transition on hospitalization rates, we looked at patients' hospitalizations in the three-year period both before and after their 18<sup>th</sup> birthday, around the point at which they would have transitioned.

## Interview Participants and Structure

Participants were identified by members of the research team and through inquiries to the relevant health authorities. Requests for interviews were sent via email by our study coordinator to the potential participants. Semi-structured interviews were conducted with participants using an interview guide which was developed by the research team to meet the study objectives (Appendix A). Participants located in the capital city were interviewed in-person; those located outside the capital were interviewed by telephone. All interviews were recorded and transcribed verbatim. A general inductive approach for qualitative analysis was used. <sup>14</sup> Qualitative description and thematic analysis were used to determine the current transition processes and to identify themes for improving the transition experience and related clinical practices. <sup>15,16</sup>

#### Ethics

Ethics approval for the project was obtained from the Newfoundland and Labrador Health Research Ethics Authority.  $^{17}$ 

## Results

Patient Cohort Characteristics

We identified 93 young adults with type 1 diabetes living in NL who turned 19 years of age between November 2008 and March 2013 and were therefore eligible for transition. Forty-seven (50.5%) were male and the mean duration for having diabetes at their 19th birthday was  $9.9 \pm 3.8$  years. In terms of geographic distribution, fifty-nine (63.4%) lived outside on an urban area as defined by Statistics Canada. Eighty-five (91.4%) were treated in the Eastern Health region. To comply with provincial privacy legislations, cell sizes <6 could not be reported, so we could not analysis differences by health regions further. The rate of diabetes-related hospitalizations increased from 15.6/100 person-years in the three years before their 18<sup>th</sup> birthday to 16.7/100 person-years in the three years after their 18<sup>th</sup> birthday. Over 7 (7.6%) people in the cohort had a hospitalization for diabetes ketoacidosis in the three years before age 18. Thirteen (13.98%) had a hospitalization for diabetes ketoacidosis in the two years after age 18.

# Current Transition Process by Health Region

Fifteen interviews were conducted with pediatric and adult diabetes providers, representing providers from all four health regions.

## Eastern Health Region

Eastern Health is the largest health region in NL by population served and includes the provincial capital region. Its pediatric endocrinology program has approximately 300 patients with type 1 diabetes under its care. The pediatric diabetes clinic consists of a multidisciplinary team including three pediatric endocrinologists, two diabetes nurse educators, a dietician, a social worker, a school teacher, and a consultant clinical psychologist. Clinic appointments usually involve the patient seeing all members of their care team, making the clinic visit duration around an hour. Outside of scheduled appointments, patients have access to an on-call physician via a 24/7 emergency phone line.

Young adults are currently transferred into adult care between 18-19 years of age, however some patients have remained in pediatric care into their 20s. Participants described the current transition process as informal and unstructured (Table 2, Quote 1). The pediatrician usually send a referral letter and patient medical summary to the nearest adult diabetes clinic and direct their patients to follow-up with that program. This transfer involves a complete change of the patients' diabetes care team and clinic location. Often the pediatric team is unaware of when their patients' first adult appointment will be or if the patient attends their first appointment (Table 2, Quote 2). In preparation, pediatricians said that as part of their regular clinic visits they would discuss with patients issues like taking more responsibility for their self-care, discussing lifestyle issues, and seeing teenage patients without their parents for part of their appointments as the patient reached the teenage years. It was not clear if all patients received guidance on these topics.

### Central Health Region

The Central Health Region has an outpatient pediatric type 1 diabetes practice serving approximately 30-40 patients. The outpatient clinic consists of a dietician, a diabetes nurse educator, and both pediatric and adult physicians. Transition preparation starts as early as age 10, when patients are encouraged to participate more in their appointments and start to be independent in their diabetes management. At age 16, providers begin to discuss what to expect during transition to adult care. Education topics include how to check their blood glucose, drug and alcohol use, and safe driving. Transition occurs at age 18. A lot of the early preparedness for patients has been motivated by the experiences of the clinic's lead pediatrician, who previously had system-related difficulties maintaining the care of patients after age 18. If patients stay in the region, only their physician changes from a pediatrician to an adult internist. If the patient does not regularly use an insulin pump, a computerized device for managing insulin usage, their diabetes might be managed by their family physician rather than an internist after transition. The dietician and diabetes nurse educators at the clinic manage both children and adults, ensuring continuity of care (Table 2, Quote 3). If patients move out of the region, e.g., for educational opportunities or work, the team recommends that the young adult contacts their campus clinic and/or a family physician in their new region. The pediatrician will then provide the patient's new physician with a patient medical summary. While recognizing that care can always improve, the team felt that their approach was effective at supporting patients who regularly attended clinic as they

transition into adult care.

### Western Health Region

The Western Health region has a pediatric diabetes patient population of 50-70 patients. The diabetes outpatient clinic, located at the region's main hospital, consists of two dieticians, two diabetes nurse educators, two pediatricians, and adult internists. Patients are assigned to one of the two pediatricians at diagnosis. There is also a diabetes nurse educator located in another part of the region who sees patients in person and uses telemedicine to consult with a pediatrician when needed. Clinic appointments follow a set structure in terms of seeing the various members of the health care team and scheduled in advance at regular intervals.

Transition preparation starts between ages 15-16 when providers begin to discuss what to expect during transition and patients are encouraged to attend part of their appointments without their parent or guardian. Topics are covered through discussion with the staff and educational resources, such as handouts. If patients stay in the region after their 18<sup>th</sup> birthday, their physician changes from a pediatrician to adult internist and the patient must take over the responsibility of scheduling their own appointments. The rest of the clinic team, e.g., dieticians, nurses, remain the same. If patients move out of the region, the team recommends that the patient contact a family physician in their new location and to get a referral to the local adult diabetes clinic. The diabetes clinic offers to keep in touch with their former patients through email to assist with their diabetes management, as many young adults only move out of the region temporarily for work or education (Table 2, Quote 4). The clinic staff also allows former patients to book an appointment without a referral, which allows for quick reconnection if a patient needs assistance. Because of the ability for people to reconnect quickly to the diabetes program and the staff's familiarity with the patients, the clinic team felt that they are able to effectively support transition for their population.

## Labrador-Grenfell Health Region

The patient population in the Labrador-Grenfell region is small, with about 7 pediatric type 1 diabetes patients in their care and less than 1 patient transferring from pediatric to adult care per year. The pediatric type 1 diabetes team consists of a pediatrician, a nurse educator, and a dietician. Transition preparation starts at age 16 and patients are transferred at age 17. To prepare for transition, patients are encouraged to take more responsibility for their diabetes management and to attend appointments without their parents or guardian. They also provide patients with information about going to university, drug and alcohol use, sexual education, and other relevant topics. At the time of transition, if the patient is staying in the Labrador-Grenfell health region, the care team and clinic location remains the same with only the physician changing from a pediatrician to a family physician (Table 2, Quote 5). The clinic structure also remains the same with appointments being automatically booked for patients every 3 months, reducing loss to follow-up for those young adult patients who remain in the region. If they are moving to another region, the Labrador-Grenfell team assists the patient in finding a new physician. For all patients transitioning, the pediatrician sends a referral letter to their new adult physician. Table 1 provides a summary of the programs in the four regions.

Table 1: Summary of diabetes transition across health regions

	Eastern Health	Central Health	West
Number of pediatric patients with 1 type diabetes	~300	30-40	50-70
Transition preparedness starts	around 17	as early as 10	15-16
Age of transition	18-19, but some into their 20s	18	18
Physician transferred to in the region	Internist	Internist	Intern
Other health professionals transferred to in the region	New	Same Providers	Same

Table 2: Participant Quotes

Quote #	Participant	Quote
1	Pediatrician	"There's no formal preparation. It's just a few conversations."
2	Diabetes Educator	"It's not a transition, it's a transfer, and basically, that's it. We just send them off."
3	Dietician	"The fortunate thing in this area is that the diabetes nurse educator and dietician involve
4	Dietician	"I just simply tell them we [the pediatric diabetes care team] are here, so if you are comir
5	Diabetes Educator	"If they're staying in our area, they will be transferred to a family physician that we have
7	Diabetes Educator	"Do you go to work or go to school or do you come to a doctor's appointment to talk abo
6	Pediatrician	"What some young people have told me after transferring over is they sit in the [adult
8	Pediatrician	"Where it's easier for them [the patient] to get in to see maybe their [primary care physic
9	Pediatrician	"I think they [most primary care physicians] manage a lot more type 2 in their practices,
10	Diabetes Educator	"It would be nice if the patients had the opportunity to come here [the adult clinic] be
11	Diabetes Educator	"I think we need to start our young people early and let them know and let them get exc

### Barriers to Care and Suggestions for Improving Transition

There were several common challenges identified by participants. All programs reported that balancing school and work along with regular medical appointments and self-care is challenging for many young adults (Table 2, Quote 6). The fact that young adults often have unstable living arrangements, e.g., moving back and forth for college or work, also caused challenges for some patients. It was felt that there is a decreased access to care for young adults, with shorter appointment times and no longer having access to a 24-hour dedicated diabetes help line maintained by the children's hospital. Young adults develop a sense of familiarity and comfort with their care team and their facility which they did not have with the adult clinic (Table 2, Quote 7). Providers reported difficulty finding adult physicians accepting new patients or adult care providers being "reluctant" to accept young adult patients with diabetes, perhaps because of limited staffing, perceived complexity of the patients' condition, or resources. Patient transfers between regions add additional challenges because pediatric providers lack established connections with adult physicians in those areas, meaning the task of finding an adult physician often falls solely on the patient. Adult providers felt that many young adults were not adequately prepared for the transition to adult care.

In terms of suggested improvements, there was a clear divide between participants in the three mostly rural regions and Eastern Health. Participants from the other regions reported being mostly comfortable with their current transition practices. Their suggested improvements included more shared educational resources and possibly expanding the role played by primary care physicians (Table 2, Quote 8). Other participants felt that many primary care physicians faced barriers to increasing their involvement in type 1 diabetes management including short appointment times, appropriate levels of remuneration as well as a lack of experience with insulin pumps and other newer diabetes related technologies. Expanding the role of primary care physicians would require that patients have a primary care physician and that the scope of this role is appropriate (Table 2, Quote 9).

Participants from the Eastern Health region suggested that a more formal transition process needs to be implemented. This new program should include an assessment of young adults' knowledge about diabetes management; educational review sessions to ensure that all patients have the same diabetes management skills; and an opportunity to meet the new adult team and tour the adult facilities before their first appointment (Table 2, Quote 10). It was also emphasized that the transition program should start early, around ages 15-16 (Table 2, Quote 11). Many participants suggested that the structure of the formalized transition should include a transfer clinic, which would be a clinic appointment dedicated to preparing patients for their transfer into adult care. The adult clinics to which patients are transferred could providing young adults with a welcome letter with details about the care team, clinic procedures, parking and other information.

#### Discussion

We reviewed the transition experience of young adult patients with type 1 diabetes across the province of NL. We found that over a six-year period, only 93 patients with type 1 diabetes transferred into adult care.

For those who did, there was an increased in diabetes-related hospitalizations in the three-year period after they transition compared to the period before. No structured transition program was identified within any of the province's four health regions. Regardless, staff in rural regions felt mostly comfortable with their current transition practices due to the small population of patients transitioning each year, continuity in nursing and other non-physician providers, and staff familiarity with these patients. Staff in the largest health region identified the need for more structured transition processes. Participants also recommended starting early with preparing and educating patients, fostering independence and responsibility in the young adults, and expanding the involvement and education of family physicians in rural areas with insufficient access to specialist physicians.

Our study is one of the first to detail the processes by which rural health regions transition patients with diabetes into adult care. Rural areas are known to have less access to health care services, including diabetes specialists.<sup>19</sup> The lack of access to diabetes specialists may increase the difficulties rural patients have in transitioning to adult care and require different types of interventions to support transition than those appropriate for urban areas.<sup>20</sup> Reviewing the patient cohort, we identified the small number of patients (approximately 10 over the four health regions) who transition annually in rural areas, which can make it difficult to justify and maintain a structured diabetes program. While we did find issues for young adult patients in rural areas related to them having to move away for work, there also appeared from the providers' perspective to be advantages to living in rural communities, due to the level of personal connection patients can develop with their care teams. The continuity in non-physician providers can play a role insuring that patients are not lost to follow-up or are reconnected to care if they leave the region. We did not evaluate patient perspectives, which could have highlighted other issues related to accessing care for rural patients with type 1 diabetes.<sup>21</sup>

We found that there is variation to the type of physician to whom patients transition, e.g., internist, family physician. Similar variation in type of adult provider to whom patients transition is also seen in other disease areas.<sup>22</sup> In a recent review of diabetes centres in Ontario, Canada, we found that 42.9% changed to an adult endocrinologist, 25.8% changed to an internist or primary care physician, 27.4% stayed with a pediatric physician, and 3.9% had no adult diabetes care.<sup>23</sup> The presumption is that more specialist care may be preferable, but there is little evidence to support this; and guidelines focus on the ability of providers to connect patients to other services rather than their speciality.<sup>24</sup> Our finding highlight, however, some of the variation occurring related to access to specialists for young adults even within the same country. There was some disagreement amongst participants about the role primary care physician should play in supporting the transition of patients with type 1 diabetes. Transition care guidelines recommend integrating primary care providers into the transition process, but there is no guidance as to how this can be done most effectively<sup>21</sup> and more work is need to insure that primary care physicians accepting young adult patients with chronic conditions are appropriately supported.<sup>25,26</sup>

The approached we used combined reviews of administrative data with qualitative interviews to develop an understanding of how care is currently being delivered. We found this approach to be effective in focusing discussions on how to better structure and improve clinical care for this population. One of the reasons for focusing on NL was that it had high rates of type one diabetes. There was an assumption by some of the research teams that the high rates would result in a high number of patients transitioning out of care annually. While the NL rates of type 1 diabetes in Newfoundland are high, given its small population and the fact that diabetes type one diabetes is still a fairly rare condition, the absolute total patient numbers remained quite small, particularly in rural regions. Having a combined picture of the number of patients and the current processes for transition allowed us to focus interventions on addressing the needs identified by the specific problem program. In the rural areas, we identified the need for additional education resources and which we have identified and sent to these programs. For the Eastern Health region, which identified the need for a transfer clinic, we are currently working with their program to help develop and evaluate this clinic. Overall, having the data and understanding of current processes provided us a very good basis for focusing discussions on how to improve care and it could be approach used in other jurisdictions.

This study has a number of limitations. We hoped to include young adult patients who had recently transitioned, but after numerous attempts and invitations, no patients consented to participate in this study. Similarly, no family physicians involved in providing care to young adult diabetes patients participated despite numerous interview requests. The Eastern Health interviews coincided with the planning for a pilot transfer clinic and therefore many of the participants focused their suggestions for improvements around elements that were planned to be a part of this pilot project. Because of the small number of patients involved and restrictions related to ensuring privacy, we were unable to evaluate whether there are differences in patient outcomes between urban and rural areas. Given the potential differences in these patients' access to care, potential differences in patient outcomes, e.g., in terms of diabetes-related hospitalizations, could be an interesting question to pursue in future research.

## Conclusions

Transitioning from pediatric to adult care is a challenge for young adults with type 1 diabetes, with many falling out of care or facing adverse health outcomes. This study described the transition process for young adults with type 1 diabetes in NL through the lens of both pediatric and adult providers. In a province with a relatively small number of patients with diabetes who transition out of pediatric care annually, we found different approaches to managing the transition into adult care throughout the province. This variation reflected staff and resource availability at different centres, but providers felt that it may not necessarily have a negative impact on patient outcomes despite that we found an increase rate of diabetes related hospitalization in the period after they transition. The interviews also offered suggestions to improve the transition process including structured transition programs and increased support for primary care physicians. Educational resources could also be shared across centres. These recommendations should be considered by other diabetes centers outside of the province.

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# Appendix A

## Interview Questions

- 1. How many children with diabetes under the age of 18 do you see?
- 2. How many young adults are referred back to you from the pediatric center once they have reached 18-19?
- 3. What is the process by which you currently receive emerging young adults with Type 1 Diabetes into your practice?
- 4. What is the process by which you currently transition your patients into adult care?
- 5. Do any of your now adult patients stay here for any part of their diabetes care?
- 6. What is the specialty training of the adult physicians to whom the physicians send their patients to?
- 7. Do you have any way of knowing if patients are seen once they are transferred from your care?
- 8. How do you prepare your patients for the transition to adult care?
- 9. Do you feel your patients are usually prepared to make the transition when they do?
- 10. Are there any changes in the services provided when they transition into adult care?
- 11. What do you believe the goals of transition should be?
- 12. How well is our current method of transition meeting these goals?
- 13. What challenges do you see patients having navigating the adult system?
- 14. What are the challenges that you experience in the process of transitioning patients to adult care?
- 15. What forms of communications are used to let family doctors know about the transfer?
- 16. What should the role of the family doctor be for emerging adults with diabetes?
- 17. What needs to be in place to allow family physicians to play a greater role in supporting emerging adults with type 1 Diabetes?
- 18. Can you describe any initiatives at your center to improve the transition of diabetes patients into adult care?
- 19. What suggestions do you have for improving the transitioning of patients into adult care?
- 20. Is there anything you would like to add about the transition process to adult care?