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3 Acute diabetes complications across transition from pediatric to adult care in Ontario and
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5 Newfoundland and Labrador: a population-based cohort study
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Abstract

Background: Transition to adult diabetes care is a high risk period for acute complications, yet the optimal way to deliver transition care is unknown. We described and compared patterns of acute complications in youth with diabetes in two Canadian provinces with different models of transition care.

Methods: We used linked health administrative data to create two parallel population-based cohorts of youth with diabetes diagnosed before age 15 and who turned 17 years between 2006-2011 in Ontario and Newfoundland and Labrador (NL). Individuals were followed until 2015 or to a maximum age of 21. We compared unadjusted rates of diabetes-related hospitalizations across transition-age within provinces and the rates of events and proportion of individuals with at least one event in each age category between provinces.

Results: The rate of ketoacidosis in Ontario youth (n=2,525) was higher in those aged 19-21 years compared to 15-17 years (12.0 vs. 9.3/100 person-years, $p<0.0018$). There was no difference in the rate across transition-age in youth from NL (n=93). The rates of diabetes-related and ketoacidosis admissions were similar within each age-group between provinces except the rate of ketoacidosis was higher in 15-17 year olds in ON compared to NL. The proportion of individuals with at least one diabetes-related or ketoacidosis admission in each age category was similar between provinces.

Interpretation: In two Canadian provinces with different transition models and resources, we found consistency in poor outcomes. Adverse events for this vulnerable population are high in both provinces and efforts to optimize system-level transition care are needed.

Introduction

Young adults with type 1 diabetes face particular challenges related to having a chronic illness that requires intensive daily self-management and regular medical follow-up during a period when their social, developmental, educational, and living situations are often in flux (1). These issues can impact both their access to care and health outcomes. Over a third of youth in a US study had a care gap of >6 months when transferring from pediatric to adult care (2) and we found that in Ontario almost half (47.0%) had a >12-month gap in diabetes care across their transition to adult care (3). During this vulnerable period, youth are at increased risk for acute life-threatening complications, such as diabetic ketoacidosis (DKA), and for poor glycemic control, which both confer an increased risk of chronic complications (4-8). In a population-based Ontario cohort, the rate of diabetes-related hospitalizations increased significantly from 7.6 to 9.5 per 100 patient-years in the 2 years after transfer to adult care (6).

Gaps in care may be a result of deficiencies in transition processes causing some young people to be poorly prepared for adult care and dissatisfied with the transition process (4). Ineffective transition can lead to decreased frequency of diabetes visits and an increased risk of adverse events in early adulthood (1). Reported barriers to attending adult diabetes clinics include a low perceived value of the adult diabetes clinic visit, difficulty in communication to schedule appointments, and conflicting clinic and work schedules (9). The ideal method of transition care delivery for diabetes and other chronic illnesses has been tested but remains uncertain (10-12). Less is known about the impact of system-level delivery of transition care on health outcomes. In this study, we compared the occurrence of acute diabetes complications

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3 across the transition period in two Canadian provinces with different structures for transition and
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5 post-transition care.
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11 Children with diabetes in Ontario, the largest province in Canada, receive medical care at one of
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13 35 specialized paediatric diabetes centres (5 tertiary and 30 community) coordinated by the
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15 Ontario Paediatric Diabetes Network (PDN). Each centre has a multidisciplinary team consisting
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17 of physicians, nurses, dieticians and social workers (13). Centres staffed by paediatric physicians
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19 of physicians, nurses, dieticians and social workers (13). Centres staffed by paediatric physicians
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21 (either general paediatricians or paediatric endocrinologists) need to transfer care to other adult
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23 care providers by age 18 (3). In 2015, 28/35 (80%) of centres referred at least some individuals
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25 to an adult endocrinologist and there was a wide range of clinic-specific transition practices (14).
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32 Newfoundland and Labrador (NL) is a smaller province and has a single tertiary care paediatric
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34 diabetes centre that cares for over half of all children with diabetes in that province. The
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36 paediatric diabetes centre in St. Johns cares for over half of all children with diabetes in the
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38 province. The majority of adolescents with type 1 diabetes followed in St. Johns are referred to a
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40 young adult clinic in St. Johns which is run by a nurse practitioner and overseen by an internist.
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42 There are no protocols for transfer of care for patients living outside of St Johns.
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49 In both provinces, residents have universal government insurance that covers all medically
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51 necessary health care services. At the time of this study, there was no universal government
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53 insurance for prescription drugs for youth in either province. Drug costs are paid out-of-pocket
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3 by private extended health benefits or through the Ontario Drug Benefit Program (covers
4 families who receive social assistance). Public funding is available for insulin pumps for
5 individuals with type 1 diabetes who meet eligibility criteria related to diabetes management in
6 both provinces (15). However, in NL coverage is only available until age 25 (16). The objective
7 of this study is to compare the occurrence of acute diabetes complications across transition-age
8 in two Canadian provinces with different structures for transition care. We hypothesized that the
9 rates of adverse events across transition-age in Ontario might be lower compared to NL because
10 pediatric diabetes care is coordinated by a dedicated network of pediatric centres in Ontario that
11 has been associated with better health outcomes (17).
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28 **Methods**

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31 We conducted an observational population-based study of two parallel cohorts of youth with
32 diabetes during transition-age and into early adulthood using Ontario and NL health
33 administrative databases.
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40 *Data Sources*

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43 In Ontario, the following datasets were linked using unique encoded identifiers and analyzed at
44 ICES: the Pediatric Ontario Diabetes Database, a validated registry of all Ontario residents (aged
45 <19 years) with a diagnosis of diabetes (83% sensitivity, 99% specificity) (18); the Hospital
46 Discharge Abstract Database (information on discharges from acute care facilities); the Ontario
47 Health Insurance Plan Database (physician billing claims); the National Ambulatory Care
48 Reporting System (information on emergency department visits); the Registered Persons
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3 Database (demographics and vital statistics including outmigration of all legal residents in
4 Ontario); the Ontario Registrar General-Death (for cause of death); and the 2006 Canadian
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6 Census to assign neighbourhood material deprivation quintiles to Ontario residents. In NL, the
7
8 cohort was identified using a provincial diabetes database kept at the Janeway Pediatric Research
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10 Unit. This database captures all patients in the province diagnosed with type 1 diabetes between
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12 1989 and 2015, based on the reporting of diabetes nurses and diabetes educators. Patient records
13
14 were linked via coded identifiers to the following provincial administrative databases: the
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16 Provincial Discharge Abstract Database (discharges from acute care facilities); Medical Care
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18 Plan (MCP) Beneficiary Registry and Physician Claims Database (demographics and physician
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20 claims); Provincial Mortality System (mortality and cause of death); and the 2006 Canadian
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22 Census to assign neighbourhood material deprivation quintiles. To comply with privacy
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24 legislations, cell sizes <6 are reported as such.
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39 *Study population and setting*

40 For both provinces, we included individuals residing in their respective province, with a valid
41 provincial health insurance number, whose 17th birthday was between November 1, 2006 to
42 March 31, 2011, and who were diagnosed with diabetes before age 15. We followed patients
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44 until March 31, 2015 with variable length of follow-up to a maximum age of 21 years. Although
45
46 we are unable to distinguish between diabetes types in Ontario, the vast majority of youth have
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48 type 1 diabetes (13, 19). The NL cohort included only patients diagnosed with type 1 diabetes.
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50 We excluded individuals ineligible for provincial health insurance from age 15-19 and those who
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52 died before their 19th birthday. We also excluded individuals in Ontario with no diabetes
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3 physician visits from age 15-<17 because they may have moved out of the province or were
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5 receiving care from providers who do not bill the provincial health plan. We did not apply this
6
7 exclusion to the NL cohort because the physician claims database does not include visits to non-
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9 fee-for-service physicians, which account for approximately 35% of physicians in NL.
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17 *Outcomes*

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20 Outcomes including death, all-cause hospital admissions, diabetes-related admissions, and
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22 admissions for DKA were ascertained from age 15-21. Diagnostic codes for diabetes-related
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24 preventable hospitalizations, using the Agency for Healthcare Research and Quality
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26 specifications, were translated to International Classification of Diseases, 10th Revision,
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28 Canadian Enhancement (ICD-10-CA) codes to identify DKA-related and diabetes-related
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30 admissions (20, 21).
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35 *Baseline characteristics*

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38 We measured socioeconomic status using a validated census- and geography-based material
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40 deprivation index that measures marginalization at the level of the census dissemination area
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42 (representing a population of ~400–700 individuals) (22, 23). We categorized geographic
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44 residence as urban if their postal code is located in a census metropolitan area (CMA).
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49 *Analysis*

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52 Provincial privacy legislation does not allow sharing of individual patient data across provinces
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54 so we could not combine the Ontario and NL datasets. Therefore, we analyzed the cohorts
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3 separately. We described the baseline characteristics of individuals living with diabetes on their
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5 17th birthday in each province. For both provinces, we compared the crude rates and the
6
7 occurrence of at least one event of all admissions, diabetes-related (excluding DKA) and DKA
8
9 admissions across transition-age in three age categories (15-17, 17-19, and 19-21 years) using
10
11 the Friedman and Cochran's Q test respectively. To compare rates of diabetes-related admissions
12
13 and DKA admissions for each age category between provinces, we visually inspected for overlap
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15 between the 95% confidence intervals (CIs). Proportions of individuals with at least one
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17 diabetes-related admission or ketoacidosis admission were compared within each category
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19 between provinces using chi-square tests.
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25 Research ethics board approvals were obtained from the Hospital for Sick Children and NL
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27 Health Research Ethics Authority.
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34 **Results**

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37 Table 1 shows the baseline characteristics of the two cohorts (n=2,525, Ontario) and (n=93, NL).
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39 In NL 42.0% of individuals were in the most deprived quintile versus 18.1% in Ontario. 63.4%
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41 of individuals lived in a rural area in NL versus 15.0% in Ontario.
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46 *Diabetes-related hospitalizations*

47 48 49 Within province comparisons

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52 Table 2 shows the crude rates and percentage of individuals in each province with at least one
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54 all-cause, diabetes-related or DKA-related admission in each age category. There was an
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3 increase in the rate of DKA admissions per 100 person-years across transition-age in Ontario
4 (9.3 (95% CI 8.5- 10.2)) in those aged 15-17 years and (12.0 (95% CI 11.1-13.0)) in those aged
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7 19-21 years vs. $p < 0.0018$), but no difference across age categories in NL. There was also an
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10 increase in the percent of individuals in Ontario who had a DKA admission across transition-age
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12 (10.0% in those aged 15-17 years vs. 12.8% in those aged 19-21 years, $p = 0.0008$), but not in NL.
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14 There were no differences in the rate of all diabetes-related admissions across transition-age
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17 within Ontario or NL.
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Between province comparisons

31 The rates of ketoacidosis (figure 1) and diabetes-related admissions (figure 2) were similar
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33 within each age-group between provinces except the rate of ketoacidosis was higher in 15-17
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35 year olds in ON compared to NL. The proportion of individuals who had at least one diabetes-
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37 related or ketoacidosis admission in each age category was similar between provinces.
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Interpretation

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48 In this population-based cross-provincial study of youth experiencing different models of
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50 transition to adult diabetes care, we did not find consistent or large differences in the occurrence
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52 of acute diabetes complications across transition-age within provinces or among age categories
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54 between provinces despite important differences in access to specialized adult diabetes care
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3 between provinces. Although we hypothesized that outcomes in Ontario would be better than in
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5 NL because of the existence of the Ontario Pediatric Diabetes Network, we found little
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7 difference in rates of acute complications between provinces. It is possible that there are
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9 differences in other important outcomes between provinces that we did not measure such as rates
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11 of clinic attendance and patient satisfaction.
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19 We did find that there was an increase in DKA-related admissions across transition-age in
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21 Ontario. The rates of diabetes-related hospitalizations that we report are higher than those
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23 reported in a previous population-based study using Ontario administrative data from 1996-2002
24
25 (6). In the previous study, diabetes-related hospitalization rates increased from 7.6 to 9.5 per 100
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27 patient-years in the two years after transition to adult care. Our finding that the rate of DKA
28
29 increases across the age of transfer to adult care in Ontario is concerning and consistent with
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31 other published studies that have found the highest rates of adverse events during the ages at
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33 which individuals transfer to adult care. Among a subgroup of 2,561 participants who completed
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35 a questionnaire in the T1D exchange clinic registry in the United States, the percent who reported
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37 having a DKA event in the prior 3 months was highest in the 18-25 year old group (5%) (24).
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40 Among 49,859 pediatric patients with type 1 diabetes from registries in England/Wales, the
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42 United States, and Austria/Germany, the percent with at least 1 episode of DKA in the prior year
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44 was highest in the 13-18 year age group (6.8%)(25).
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3 We did not detect any statistically significant difference in DKA-related or other diabetes
4 admissions over time in NL. The number of adverse events was low and it is possible that the
5
6 small sample size in NL was insufficient to detect a significant difference. However, it is
7
8 reassuring that although a higher proportion of individuals are of lowest socioeconomic status in
9
10 NL, and there is a known association between lower socioeconomic status and an increased risk
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12 of adverse events (26-28), that the rates of adverse events were not higher in NL. This suggests
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14 that other factors, such as the delivery of health services or other social services, might be
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16 mitigating the occurrence of adverse events especially for those of low socioeconomic status in
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28 We did not find differences in the rates of diabetes-related and ketoacidosis admissions within
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30 each age-group between provinces except the rate of ketoacidosis was higher in 15-17 year olds
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32 in ON compared to NL. The proportion of individuals with at least one diabetes-related or
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34 ketoacidosis admission in each age category was similar between provinces. Because we did not
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36 find a difference in the proportion of individuals with at least one ketoacidosis admission in 15-
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38 17 year olds between provinces, the higher rate of events in the 15-17 year old group that we
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40 observed in ON must be due to individuals having multiple episodes. This suggests a need for
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42 increased support and preventative strategies targeted at those who have had a first episode of
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44 ketoacidosis and are known to be at risk for subsequent episodes (3).
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3 A higher rate of DKA, in general, not only across transition-age, has been associated with a
4 number of patient factors such as low socioeconomic status, worse glycemic control, and a prior
5 history of DKA, and a prior history of a mental health visit (24, 26, 28). We recently reported
6 that patterns of healthcare use during transition-age such as having >12 month gap in diabetes
7 care and having no primary care visits during transition is associated with an increased risk of
8 acute diabetes complications in early adulthood (3). These findings suggest that there may be
9 modifiable factors in the way transition care is delivered that might reduce the risk of acute
10 diabetes complications.
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26 To our knowledge, this is the first multi-jurisdictional study to examine differences in acute
27 diabetes complications between settings both with universal access to physician care but with
28 differences in the structure and access of specialized adult diabetes care across transition-age.
29 Yet our study has a number of limitations. We did not have information about glycemic control,
30 a factor to known to be associated with the risk of acute diabetes complications, but unavailable
31 in the administrative databases in either province. Despite comparable data sources and
32 consistent definitions to measure baseline characteristics and outcomes in both provinces, there
33 may be differences in coding practices between provinces. Also, we may have under-ascertained
34 outcomes if individuals moved out-of-province during the study. Our inability to combine
35 provincial datasets and the relatively small sample size from NL highlights the challenges of
36 conducting multi-jurisdictional studies. Efforts are underway in Canada to create an environment
37 that would enable greater cross-jurisdictional data sharing and analysis (29).
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3 Ongoing studies to characterize transition care in Ontario and NL will help to further elucidate
4 our findings. Efforts to optimize system-level transition care beginning in the context of pediatric
5 diabetes care and extending to adult care are needed to improve outcomes for this vulnerable
6 group. Adverse events for this population are high in both provinces and efforts to optimize
7 system-level transition care are needed.
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Table 1: Baseline characteristics of participants on their 17th birthday

Characteristic	Ontario n=2,525	Newfoundland and Labrador n= 93
Male sex, n (%)	1,309 (51.8)	47 (50.5)
Duration of diabetes (years)		
Mean \pm SD	7.4 \pm 3.8	7.9 \pm 3.8
Median (IQR)	6.7 (4.3-10.2)	7.6 (4.5-11.0)
Deprivation Quintile, n (%) (Canadian Marginalization Index 2006)		
1 (least deprived)	581 (23.0%)	13 (14.0%)
2	511 (20.2%)	13 (14.0%)
3	466 (18.5%)	15 (16.1%)
4	482 (19.1%)	13 (14.0%)
5 (most deprived)	456 (18.1%)	39 (42.0%)
Missing	29 (1.1)	*<6
Rurality, n (%)		
Non-CMA (rural)	380 (15.0)	59 (63.4)
CMA (urban)	2,130 (84.4)	34 (36.6)

*added to quintile 5 due to small cell size

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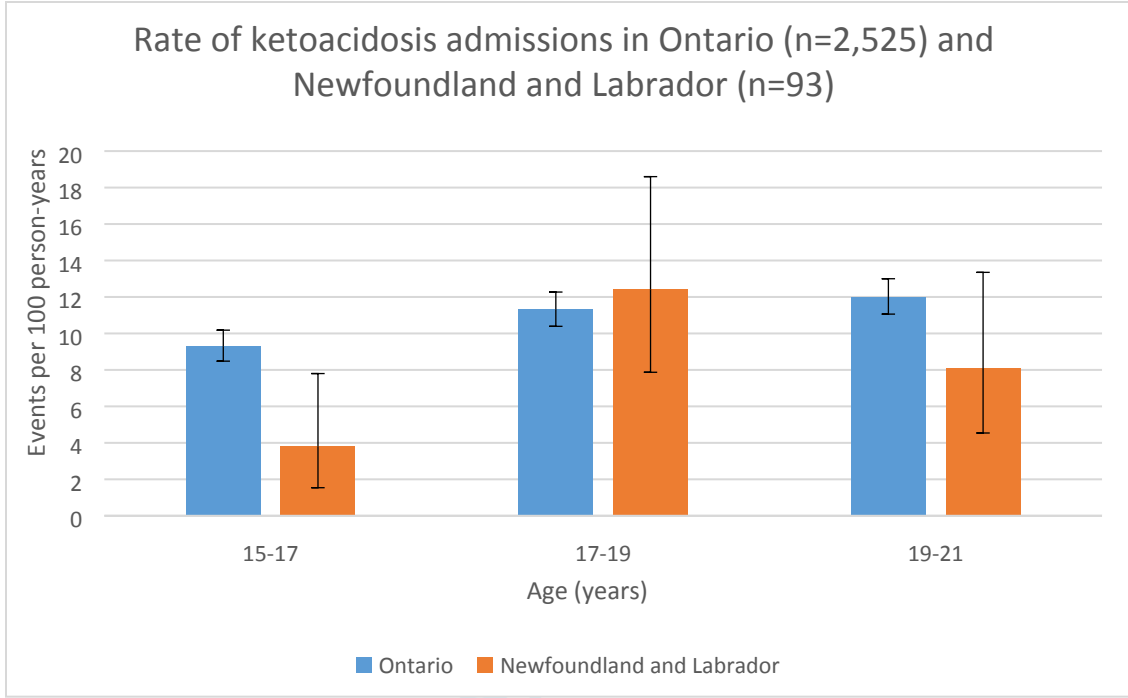
Table 2: Crude rates of death and hospital admission across transition-age in Ontario and Newfoundland and Labrador

Age (years)	Ontario				Newfoundland and Labrador			
	15-17	17-19	19-21		15-17	17-19	19-21	
Person-years	5,050	5,050	5,020		186	186	185.8	
Mortality (events/1000 person-years)			†<6	*p-value			†<6	*p-value
Admissions								
All								
Events/100 person-years, mean (95% CI)	21.5 (20.2, 22.8)	23.7 (22.4, 25.1)	26.5 (25.1, 28.0)	0.0301	15.1 (10.0, 21.8)	25.3 (18.6, 33.6)	24.2 (17.7, 32.5)	0.214
Proportion with the event, n (%)	593 (23.5)	669 (26.5)	650 (25.7)	0.0157	21 (22.6)	24 (25.8)	27 (29.0)	0.500
Diabetes-related								
Events/100 person-years, mean (95% CI)	12.0 (11.1, 13.0)	12.9 (11.9, 13.9)	13.9 (12.9, 15.0)	0.4258	8.6 (4.9, 14.0)	13.4 (8.7, 19.8)	10.2 (6.1, 15.9)	0.792
Proportion with the event, n (%)	330 (13.1)	348 (13.8)	349 (13.8)	0.5861	14 (15.1)	13 (14.0)	15 (16.1)	0.887
Non-‡DKA diabetes-related								
Events/100 person-years, mean (95% CI)	2.7 (2.3, 3.2)	1.7 (1.4, 2.1)	1.9 (1.5, 2.3)	<0.001	4.8 (2.2, 9.1)	†<6	†<6	
Proportion with the event, n (%)	115 (4.6)	70 (2.8)	56 (2.2)	<0.001	8 (8.6)	†<6	†<6	
‡DKA								
Events/100 person-years, mean (95% CI)	9.3 (8.5, 10.2)	11.3 (10.4, 12.3)	12.0 (11.1, 13.0)	0.0018	3.8 (1.5, 7.8)	12.4 (7.9, 18.6)	8.1 (4.5, 13.4)	0.112
Proportion with the event, n (%)	253 (10.0)	307 (12.2)	322 (12.8)	0.0008	7 (7.5)	13 (14.0)	13 (14.0)	0.180

*Determined using Friedman test for comparing admission rates and Cochran’s Q test for proportion with the event

†cell sizes <6 cannot be reported for privacy reasons

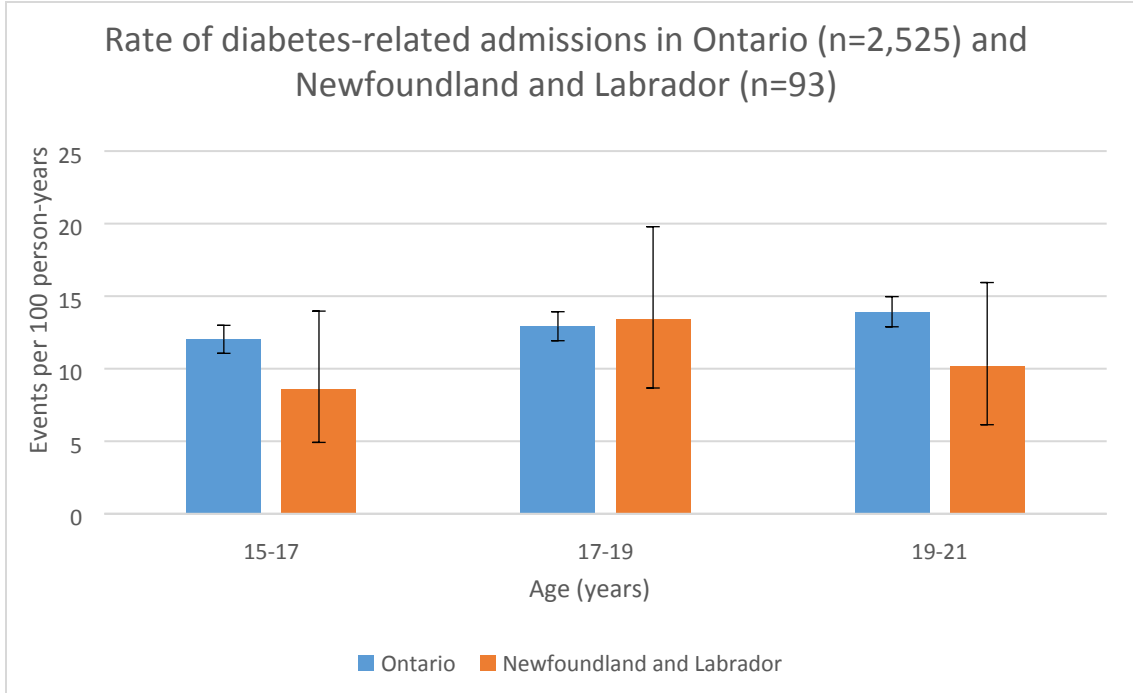
‡ diabetic ketoacidosis



*Error bars represent the 95% confidence interval of the mean rate of events

Confidential

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*Error bars represent the 95% confidence interval of the mean rate of events

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