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Original Research

Transition to Adult Diabetes Care: A Description of Practice in the Ontario Pediatric Diabetes Network

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Key Messages

- Patients with diabetes often experience gaps in care, adverse events and negative experiences as they transition from pediatric to adult care.
- Pediatric diabetes centres in Ontario have varied transition practices, and they identified several perceived system-level challenges to transition processes.
- Improved infrastructure for data collection and sharing may facilitate quality-improvement transition initiatives and evaluations.

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ABSTRACT

Objectives: Individuals living with diabetes often experience gaps in care, poor experiences and acute complications when they transfer from pediatric to adult care. We aimed to describe the structure of diabetes transition care in Ontario and to explore perceptions of barriers to optimal outcomes.
Methods: We conducted a cross-sectional descriptive study of 35 centres in the Pediatric Diabetes Network in Ontario between April and June 2017. We collected survey data about the number of individuals with all diabetes types transferring to adult care, transition practices and providers' perceptions of facilitators of and barriers to optimal transition.
Results: All centres completed the survey. In 2015, 631 of 7,485 (8.4%) individuals with all types of diabetes were transferred to adult care. Of those, 28 of 35 (80%) centres (representing 93% of individuals with all diabetes types) referred at least some individuals to adult endocrinologists. There is a range of centre-transition practices (e.g. structured preparation, workshops, combined visits, transition coordinators). Of the 35 centres, 25 (71%) reported conducting at least 1 initiative to improve transition care. Centres reported challenges related to transition preparation, communication with adult teams, adult programs' abilities to meet the needs of young adults and loss to follow up.
Conclusions: Variations in transition practices present a future opportunity to study the relationship between transition approaches and outcomes. The creation of a provincial data infrastructure that extends beyond transfer to adult care and that facilitates sharing among pediatric and adult centres could foster the development of a learning health system designed to improve transition care and outcomes.

Mots clés :
adolescent
diabète sucré
services de santé
transition vers les soins pour adultes
jeune adulte

RÉSUMÉ

Objectifs : Les individus qui vivent avec le diabète subissent souvent des lacunes en matière de soins, des mauvaises expériences et des complications à court terme lors de leur transfert des soins pédiatriques vers les soins pour adultes. Notre objectif était de décrire la structure des soins de transition des diabétiques en Ontario et d'examiner les perceptions sur les obstacles aux résultats optimaux.
Méthodes : Nous avons mené une étude descriptive transversale de 35 centres du Pediatric Diabetes Network en Ontario entre avril et juin 2017. Nous avons recueilli les données de l'enquête sur le nombre

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d'individus atteints de tout type de diabète qui étaient transférés vers les soins pour adultes, sur les pratiques de transition et sur les perceptions des prestataires des soins de santé sur les facilitateurs et les obstacles à une transition optimale.
Résultats : L'enquête a été remplie dans tous les centres. En 2015, 631 des 7485 (8,4 %) individus atteints de tout type de diabète ont eu leur transfert vers les soins pour adultes. Au moins quelques individus de 28 des 35 (80 %) centres (qui représentent 93 % des individus atteints de tout type de diabète) ont été orientés à des endocrinologues pour adultes. Dans les centres, on trouve des pratiques de transition variées (par ex. la préparation structurée, les ateliers, les visites combinées, les coordonnateurs de transition). Au moins 1 initiative pour améliorer les soins de transition a été menée dans 25 (71 %) des 35 centres. On rapporte aussi les enjeux liés à la préparation de la transition, à la communication avec les équipes de soins pour adultes, les capacités des programmes pour adultes à répondre aux besoins des jeunes adultes et à la perte de suivi.
Conclusions : Les variations dans les pratiques de transition offrent de nouvelles opportunités pour étudier la relation entre les approches de transition et les résultats cliniques. La création d'une infrastructure provinciale de données qui va au-delà du transfert vers les soins pour adultes et qui facilite le partage entre les centres pour enfants et les centres pour adultes pourrait promouvoir l'élaboration d'un système de santé apprenant conçu pour améliorer les soins de transition et les résultats cliniques.

Introduction

The transition from pediatric to adult diabetes care is a high-risk period for gaps in care and acute complications (1–4). There is little evidence to support the effectiveness of any model or approach to transition care for preventing adverse events (5,6). Since 2001, pediatric diabetes care in Ontario has been coordinated by the Ontario Pediatric Diabetes Network (PDN). The PDN is a program of the province's Ministry of Health and Long-Term Care overseen by the Provincial Council for Maternal and Child Health (7,8). The PDN includes 30 community and 5 tertiary specialized centres, each composed of physicians, nurses, dietitians and social workers with training in diabetes care. One of the objectives of the PDN is to build provincial consensus for setting standards of practice and enhancing the quality of pediatric diabetes care across Ontario. In 2016, the PDN's Transition to Adult Care Working Group published a report to address existing challenges associated with the transition from pediatric to adult diabetes care. The report includes recommendations for a more structured and consistent provincial approach to transition by leveraging currently available resources (9).

Studies of the transition experiences of both patients and providers (adult endocrinologists in the United States [10] and pediatric providers in Quebec, Canada [11]) have identified the need for improved transition preparation, care coordination and communication between pediatric and adult providers (12). In Canada, young adults typically transfer to adult care between 17 and 19 years of age (13). In Ontario, we have shown that 75% of youth 15 to 17 years of age with diabetes have pediatricians or pediatric endocrinologists as their pretransition diabetes physicians and, therefore, require transfer to adult diabetes physicians at the age of 18 years (4). Furthermore, almost half had more than a 12-month gap before seeing their eventual adult diabetes physician (4). The existence of a coordinated network of pediatric diabetes programs in Ontario provides a unique opportunity to study system-level transition care delivery not previously described. We aimed to describe the structure of diabetes transition care in Ontario (a large province with a coordinated network of 35 pediatric diabetes centres) and to explore perceptions of barriers to optimal transition outcomes.

Methods

We conducted a cross-sectional descriptive study of all 35 pediatric diabetes centres in the Ontario PDN. We collected data from the main contact at each centre (diabetes nurse or dietitian) using a survey designed to identify the number of individuals who transition to adult diabetes care, centre-specific transition practices, including the role of primary care providers, and perceptions of providers about transition facilitators and barriers (Supplementary Appendix). The survey was developed based on both a previous survey of PDN centres concerning the centres' characteristics and resources and the PDN Transition to Adult Care Working Group Recommendations Report (9,14). We also incorporated input from key informants (specialist physicians and experienced nurses) concerning both the content and the style of questions. After initial e-mails from the senior project manager of the PDN containing a recruitment letter, we sent e-mail invitations containing a link to the survey to the centre's main contact, who was either a diabetes nurse or a dietitian. These clinical team members were expected to have access to the information requested; if not, they were directed to consult an administrator. We collected survey data from April to June 2017 using a modified Dillman method (15). We used Research Electronic Data Capture (REDCap), a secure web application for building and managing the survey. Research ethics board approval was obtained from the Hospital for Sick Children.

Analysis

Each pediatric diabetes centre was categorized according to whether it was tertiary or community centre. The 5 tertiary centres are located in the pediatric academic health science centres in Ontario's major cities (Toronto, Ottawa, London, Hamilton and Kingston). The aspects of transition care at each centre were categorized as: 1) structured integration of transition goals and/or resources into regular follow-up care; 2) transition-readiness assessments; 3) transition workshops; 4) combined adult and pediatric visits; and 5) transition coordinators. Descriptive statistics were performed using Excel 2013. Narrative responses about the challenges in the process of transitioning patients to adult care were summarized and initially were grouped into descriptive categories by 1 clinician-researcher (RS). There were multiple iterations of the descriptive categories, and responses were reorganized and regrouped into the final agreed-upon categories with input from a second researcher (RC). Any disagreements were resolved by a third clinician-researcher (AG).

Results

Patient volume and referral patterns

All 35 centres responded to the survey. In 2015, the PDN centres collectively reported seeing a total of 7,485 individuals with all

types of diabetes in their pediatric programs (6,766 individuals with type 1 diabetes, 467 individuals with type 2 diabetes and 252 individuals with other types of diabetes). Of those, 631 of 7,485 (8.4%) with all types of diabetes transferred to adult care. Figure 1 shows the number of centres according to the volume of patients with type 1 diabetes in 2015. Figure 2 shows the number of centres according to the number of individuals with all types of diabetes who were transferred to adult care in 2015.

Of the pediatric centres surveyed, 19 of 35 (54%) are colocated with adult diabetes centres in the same clinic space; 9 of 35 (26%) are located in a different clinic space but within the same building; and 7 of 35 (20%) are not colocated with an adult diabetes centre. Of the 9 centres that are colocated with an adult diabetes centre in a different clinic space but in the same building, 3 of 9 (33%) share some resources (staff, administration, budget or educational materials).

Some pediatric centres (20 of 35 [57%]) reported that individuals have the option of receiving adult diabetes care from either a physician or a nonphysician provider at their centres. Among those 20 centres, a median of 78% (interquartile range, 65% to 91%) of individuals continued to receive adult diabetes care from either a physician or a nonphysician provider at their centre. Of those, there was continuity of the physician in 4 of 19 (21%) centres (1 remote centre does not have a physician). In 3 of those 4 centres, the physician was an adult endocrinologist. There was continuity of the diabetes nurses in 17 of 20 (85%), of the dietitians in 17 of 20 (85%) and of the social workers in 10 of 13 (77%) centres. Data about how long individuals continue to receive adult diabetes care at the same centres where they received pediatric care are unavailable.

For centres that transferred at least some individuals to adult care, most (29 of 35 [83%]) transferred individuals at age 18 years. Three centres reported that they continue to see some individuals until they are 19 years of age; 1 centre sees individuals 1 year into postsecondary education, and another sees young adults during their college/university years and will arrange follow-up visits at mutually convenient times to alleviate stress for the patients during this major life change. Of the centres, 28 of 35 (80%), representing 6,942 of 7,485 (93%) individuals with all types of diabetes, refer at least some individuals to adult endocrinologists, including the 3 centres in which there is continuity of care across transition with the same adult endocrinologists.

Transition models

Figure 3 shows the number of centres that used the most commonly reported transition initiatives. Of the centres, 25 of 35 (71%) reported that they had at least 1 transition initiative; in total, across all centres, there were 42 distinct initiatives. Overall, only 10 initiatives were formally evaluated. Of the 10 centres that did not report any initiatives, all were community centres, 7 transferred fewer than 30 patients to adult care in 2015 (3 did not report the number transferred) and 7 had at least some patients stay at the same centre for either physician or nonphysician adult diabetes care.

Other ongoing transition initiatives reported include applications for smartphones and putting stickers on charts to identify individuals near transition. Among the centres that continue to follow individuals into adulthood, 1 has a young-adult clinic with specialized appointment times for individuals aged 18 to 25 years, another schedules regular meetings for adult diabetes-education programs, and another accommodates individuals who are living out of town by arranging appointments when they return home for school breaks, communicating via e-mail and using video conferencing. One centre has a Complex Center for Diabetes Care for those who need additional support. Another centre uses the Ontario PDN transition recommendations as a guide.

Primary care providers' role in transition

Most centres that refer individuals to different providers for adult care reported that primary care physicians do not play active roles in the transition process and that only some are informed about the transition plan. The most common form of communication between the referring pediatric diabetes centres and the primary care providers about the plan for transition to adult diabetes care is a medical summary (28 of 35 [80%]). Some centres indicated that primary care physicians could be better informed about the transition plans and could help to support the transition because they have longstanding relationships with the family. Suggestions for an enhanced role for primary care physicians included ensuring that the patients are receiving follow-up diabetes care and making second referrals to adult diabetes care if they became aware that the individuals had fallen out of care. One

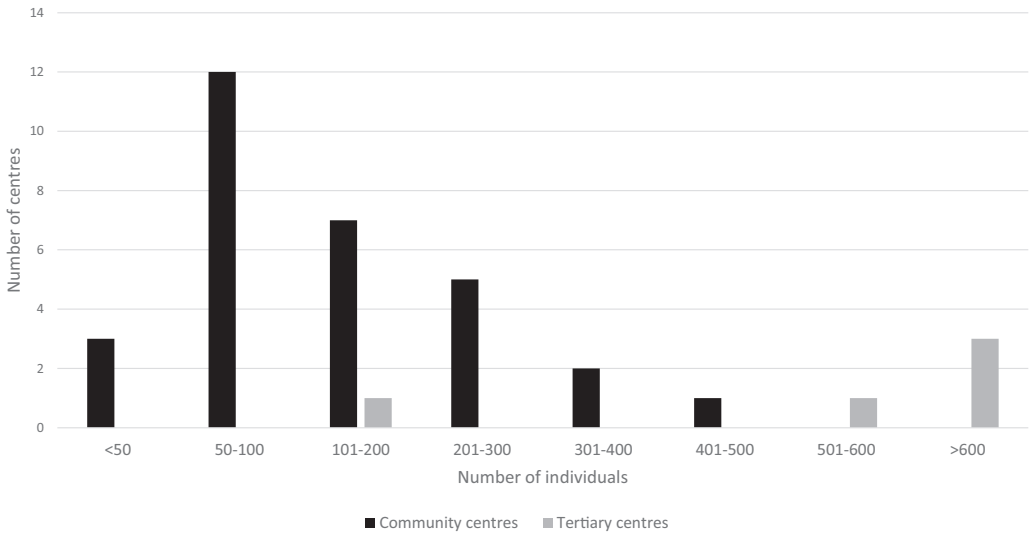

Figure 1. The number of centres according to the number of individuals with all types of diabetes who were seen at Ontario Pediatric Diabetes Network centres in 2015.

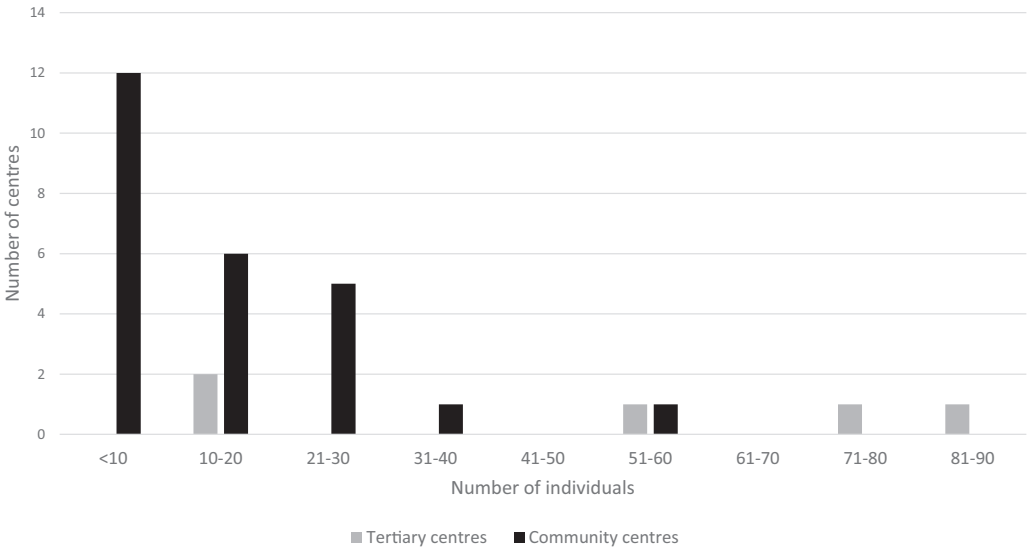

Figure 2. The number of centres according to the number of individuals with all types of diabetes who were transferred to adult care in the Ontario Pediatric Diabetes Network in 2015.

centre suggested that as patients transition to adult care, primary care providers could take over some aspects of diabetes care, such as navigating access to financial support, mental health support and thyroid management.

Challenges of transition

The reported transition-related challenges fit into 4 main themes: transition preparation, communication between pediatric and adult teams, adult diabetes programs not aligned with the needs of young adults and loss to follow up. We review each of these findings below. A summary of the challenges categorized by theme is presented in Table 1.

Respondents identified several ways in which preparing individuals for transition is challenging. First, respondents reported that individuals and their parents may not feel ready for transition, and there is a concern that individuals may not be mature enough to take ownership of their diabetes care. Addressing this problem is also challenging because respondents reported a lack of staff and resources to support transition-preparation education and difficulties with engaging teenagers in transition preparation due to competing life priorities. From a process perspective, there is no formal transition-care approach at many centres, and families may continue to contact the pediatric team for advice and care after transition. This challenge may also be related to a deficiency in communication between pediatric and adult providers. It was identified that not all diabetes team members have the opportunity to communicate information to adult providers and that discharge and transfer letters from the pediatric centres are not always sent or received.

Respondents identified that adult diabetes programs may not be meeting the needs of young adults in several ways. First, pediatric providers perceive that adult diabetes clinics have fewer staff and resources and may not have multidisciplinary holistic models of care, including access to social workers. Second, adult diabetes physician visits may be less frequent, and not all adult endocrinologists have approaches that are friendly to young adults. Finally, the respondents articulated that the process of booking and

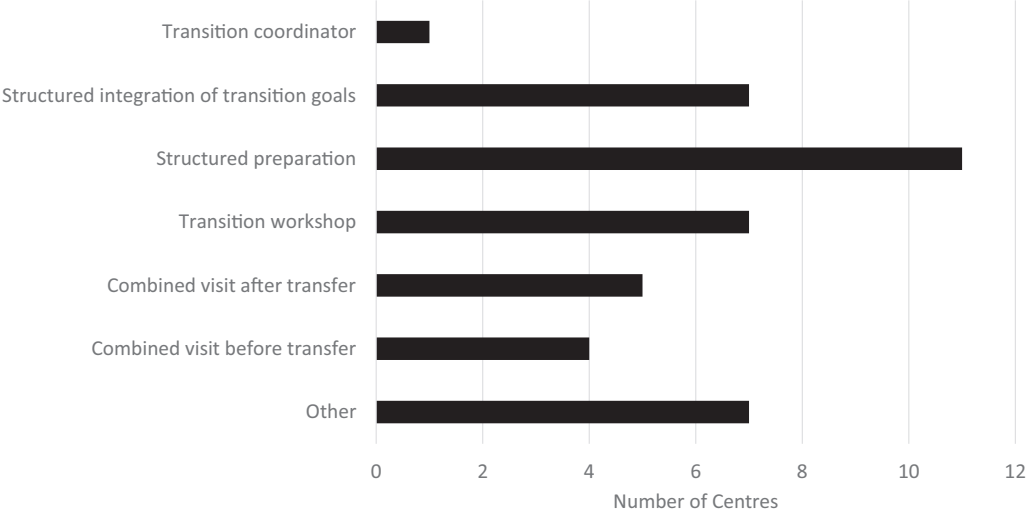

Figure 3. The number of centres that used various transition initiatives (N=42 initiatives).

Table 1
Challenges in transition to adult diabetes care

Theme	Ontario
Transition preparation	• At age 18, individuals may not be ready or mature enough to take ownership of their diabetes care. • Parents may not feel ready for transition. • Poor attendance occurs at transition-education events in pediatric clinics. • It is difficult to engage teens in transition preparation due to competing priorities such as school. • Limited staff resources exist to provide transition-preparation education. • It is challenging to balance the individuals' roles and the parents' roles in diabetes management. • Families continue to contact the pediatric team after transition. • There is a lack of formal transition-care processes. • It is necessary to consider financial coverage for diabetes supplies.
Communication between pediatric and adult teams	• The adult centres may not always receive discharge/transfer letters from the pediatric centres. • Interprofessional team members may not always have the opportunity to contribute to the referral letters sent to adult teams.
Adult diabetes programs' abilities to meet the needs of young adults	• There is a lack of social work support. • There are less frequent visits to diabetes physicians, and not all adult endocrinologists have a young-adult-friendly approach. • If individuals do not come to the clinic prepared, the adult providers may not have the time to get the information. • Adult centres do not all provide the multidisciplinary holistic model of care that individuals are used to in their pediatric/youth clinics. • Fewer staff and resources are available compared to pediatric care.
Loss to follow up	• Some young adults move away for postsecondary education, which makes it challenging to coordinate appointments when they return home for visits and difficult to provide support while they are away. • Parents may no longer take responsibility for their childrens' attendance at adult diabetes clinics. • It is difficult to track whether individuals have connected and remain connected with adult care. • Individuals may need to travel to the nearest adult endocrinologist if one is not available locally. • There is no funding for individuals >18 years to travel from remote First Nations communities to see an adult endocrinologist. • Adult programs are less accommodating than pediatric programs about rescheduling appointments and are difficult for young adults to navigate. • Telemedicine appointments for individuals from First Nations communities are not well attended because in-person meetings are preferred.

rescheduling appointments at adult diabetes clinics may be difficult for young adults to navigate and could create barriers to attendance.

Various other reasons were identified to explain why individuals may be lost to follow up during the transition to adult care. These included patient factors, such as having to coordinate clinic visits during times when individuals who are living away from home return for school holidays and that parents may take less responsibility for their children's attendance. Several system-level factors were identified, including the inability of pediatric providers to ensure that individuals are connected with and continue to be followed by adult diabetes providers. In addition, 1 centre reported that some areas of the province may not have access to adult endocrinologists and that there is no funding for individuals older than 18 years of age from remote First Nations communities to travel to see adult endocrinologists. This centre's representative also perceived that telemedicine appointments are not generally acceptable alternatives.

Discussion

This study describes transition practices across pediatric diabetes centres within a coordinated network in Ontario. We identified that there is no consistent or standard approach to transition care within the network and that perceived deficiencies and gaps in care are significant. There are a large number of pediatric diabetes centres, and they vary considerably in volume and in geographic setting. Many of the smaller centres transfer very few individuals to adult care annually. The vast majority (80% of all centres, representing 95% of all individuals with type 1 diabetes in the province) refer individuals to adult endocrinologists for adult diabetes care.

In previous work, we have reported variability in practice across the PDN centres, in that case, pediatric insulin pump use, but we were unable to identify any centre-level factors associated with the variability (16). In the current study, we did not attempt to associate transition practices with outcomes. We did ask centres whether they had evaluated any of their transition practices. Importantly, only 46% of the transition initiatives described in detail by centres had been formally evaluated. This finding is consistent with the observation made by Wafa et al that there is no common framework for evaluating, comparing and reporting diabetes-transition outcomes (6). The authors suggest Got Transition as an example of a tool that provides a logical approach to evaluating transition practices (6,17,18). Got Transition is an American framework developed by the Maternal and Child Health Bureau and The National Alliance to Advance Adolescent Health that proposes implementation and evaluation of 6 core elements of health-care transition support: establishing a policy, tracking progress, administering transition-readiness assessments, planning for adult care and transferring and integrating into an adult practice (18). This is 1 example of an approach that could be used to examine variation across centres and to inform efforts to improve and reduce disparities in the quality of transition care if they exist.

Transition-related challenges

Some of the perceived challenges described in this study, such as lack of collaboration between pediatric and adult diabetes services and inadequate support and information during transition, have been associated with poor attendance at adult diabetes clinics (19). Young adults report negative emotions and feeling less satisfied when adult diabetes staff are not aware of their emotional needs (19). In this study, many of the reported transition challenges exist because pediatric centres have no mechanism for tracking individuals once they are discharged. This highlights a major system-level deficiency in diabetes care delivery in Ontario. In a large number of pediatric diabetes centres, information technology systems are not integrated, so transferring personal health information and appointment tracking between pediatric and adult care is not feasible. Systematic collection and sharing of these data between pediatric and adult diabetes programs for quality-improvement initiatives and research may facilitate improved transition care and outcomes (20).

Pediatric centres identified that the timing of transition from pediatric to adult care is not ideal and occurs concurrently with major life changes (e.g. end of high school, moving out of

hometown for university/college). It has been recommended that transfer to adult care should occur within the 18- to 21-year age range (21); however, newer guidelines recommend flexibility in the age of transfer to adult care (22,23). Currently, in Ontario, except in certain circumstances, pediatricians cannot be remunerated by the provincial health plan for care provided to individuals older than 18 years of age. These challenges could be mitigated by improved transition preparation, a better focus on specific young-adult needs in adult diabetes clinics and policies that remunerate pediatricians for patients until they are 21 years of age.

Integration of primary care

In this study, primary care physicians were reported to play minimal roles in the transition processes of those whose care is transferred to adult endocrinologists. It is recommended that primary care providers be involved in the transition process (21), but there is little evidence of ways in which the role of primary care providers can be integrated into facilitating effective transitions for youth with chronic conditions (24). There may be the potential for enhanced primary care roles, especially in settings with limited access to adult subspecialty services. At a minimum, pediatric diabetes teams should ask whether individuals have primary care providers who will continue to see them into adulthood (25). If not, they can refer to services in Ontario such as Health Care Connect, which is a public service to help connect patients with primary care physicians or nurse practitioners (26).

We found a perceived need for improved collaboration between pediatric and adult diabetes providers to better integrate the transition process and to ensure that adult providers recognize the unique needs and vulnerabilities of young adults. Similarly, pediatric diabetes providers in Quebec reported that barriers to successful transition included lack of availability of adult providers and multidisciplinary teams in the adult care setting, a perception that the quality of pediatric care is superior to that of adult care, less flexibility in adult-care scheduling, patients' struggles with multiple new adult responsibilities, and insufficient understanding by adult providers of these challenges (11). The authors recommended that adult providers consider special accommodations or changes in their practice settings to ensure that young adults stay engaged and get the needed support during this vulnerable time. This requires engagement at the health-system level to build, support and sustain information-technology infrastructure that can be used to facilitate collaboration between pediatric and adult care teams (27). This is especially important for centres that transfer individuals to outside facilities. There is great potential for an enhanced role of the Ontario PDN to host online resources for patients and providers, to build functional working relationships between pediatric and adult diabetes teams for patient care and to facilitate collaborative quality-improvement initiatives.

Finally, our findings suggest that there are many different approaches to transition care among Ontario PDN centres; this may reflect contextual differences and a lack of evidence to suggest that any particular approach is most effective. We also found that, in general, little attention is paid to integrating primary care providers into the transition process. Implementation of sustainable infrastructure to facilitate standardized data collection as a foundational element of a learning health system is needed. A learning health system incorporates infrastructure on a large scale to share data, create knowledge rapidly and inform decisions to improve health outcomes (28). The wide range of transition approaches used by centres in the PDN poses an opportunity to use this approach to measure meaningful outcomes and to evaluate what works in the real world.

Strengths and limitations

This is the first provincial study to describe transition to adult diabetes care practices. A strength of our study is the 100% response rate, which likely reflects that Ontario PDN centres are engaged and motivated to participate in research and quality-improvement initiatives to improve the quality of care and outcomes for youth living with diabetes. A limitation of our study is that the survey data are self-reported and reflect providers' perceptions of transition care. It is possible that the perceived challenges and barriers reported may reflect the personal opinions of the centre's informants rather than the team's collective opinion. We also did not collect additional data to verify information about perceived challenges and barriers. Another important limitation is that we did not measure the perspectives or transition initiatives that adult centres may have for young adults. It was not feasible to engage adult diabetes centres actively because of the large number of adult providers. However, given that many of the perceived challenges and barriers relate to adult-care systems, future work should focus on collaboration between pediatric and adult diabetes providers to study transition processes.

Conclusions

Despite widespread recognition of the risks associated with transition to adult care and the existence of several recommendations for optimal transition care provision, centres within the PDN identified ongoing gaps and deficits in transition care. There is a unique opportunity within the Ontario PDN to implement and study transition interventions at the provincial level in the context of a coordinated network of diabetes programs. The challenges of transition identified in this study might begin to be addressed by developing a provincial data-collection and sharing system. These data could be used to evaluate, report and compare transition initiatives in local contexts by using existing frameworks such as Got Transition, which includes information on best transition-care practices and a practice-level assessment tool (6,18). This approach would support quality improvement and research efforts to improve transition outcomes in young adults living with diabetes in Ontario and beyond.

Supplementary Material

To access the supplementary material accompanying this article, visit the online version of the *Canadian Journal of Diabetes* at www.canadianjournalofdiabetes.com.

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Author Disclosures

Conflicts of interest: none.

Author Contributions

RS conceptualized and designed the study, designed the data collection instrument, collected the data, carried out the initial analyses, contributed to the analysis, and interpretation of data, drafted the initial manuscript, critically reviewed the manuscript,

and approved the final manuscript as submitted. RC conceptualized and designed the study, provided input to the design of the data collection instrument, contributed to the analysis and interpretation of data, critically reviewed the manuscript, and approved the final manuscript as submitted. AG conceptualized and designed the study, provided input to the design of the data collection instrument, contributed to the analysis and interpretation of data, critically reviewed the manuscript, and approved the final manuscript as submitted.

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