

Improving the transition from pediatric to adult diabetes care: the pediatric care provider's perspective in Quebec, Canada

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ABSTRACT

Objectives The transition from pediatric to adult care is a high-risk period for the emerging adult with diabetes. We aimed to determine adequacy of pediatric transition care structures and explore the pediatric diabetes care provider's perceptions of transition care.

Research design and methods In-depth interviews with pediatric diabetes care providers from 12 diabetes centers in Quebec were conducted. We queried alignment with Got Transition's six core elements of healthcare transition, experiences, and barriers to transition care. Interview transcripts were reviewed for themes.

Results Three centers (25%) reported having any elements of formal and structured transition care preparation and planning. When referrals were within center (n=8), pediatric providers perceived that transition was smoother; information sharing relied heavily on verbal communication rather than documented medical summaries. Barriers included lack of adult providers, less flexibility in adult care scheduling, patient struggles with multiple new adult responsibilities, and insufficient understanding by adult providers of these challenges. There was a perception that the quality of pediatric care was better than adult care. Moving out of the pediatric care geographical region appeared to increase risk for poor follow-up. Patient satisfaction and regular follow-up in adult care were thought to be good measures of transition success. Programs that included overlap between pediatric and adult care were perceived as ideal.

Conclusions Important gaps in transition care practices persist. Efforts should focus on improving education in transition practices for pediatric care providers and establishing formal transition policies and structures at the institutional level.

INTRODUCTION

Emerging adulthood, the developmental stage between ages 18 and 25 years, is a vulnerable period, where individuals are developing their autonomy and self-identity.¹ For those with diabetes, this stage is further complicated by the daily demands of a chronic disease and the additional challenge of transitioning from pediatric to adult healthcare. The transition to adult care occurs at a point in life concurrent

Significance of this study

What is already known about this subject?

► Transition from pediatric to adult diabetes care is characterized by inadequate medical follow-up, poor self-management, and an increased risk of adverse outcomes. Literature on the adequacy of transition care services and the pediatric diabetes care provider's perspectives on transition is limited.

What are the new findings?

► Our study findings suggest significant and persistent gaps in transition care services, a lack of implementation of transition care consensus recommendations with poor uptake of available structured tools into practice, and a lack of knowledge and/or training for pediatric providers in appropriate transition care.

How might these results change the focus of research or clinical practice?

► Efforts to improve transition care should focus on improving education in transition care for pediatric providers, improving collaboration and linkages between pediatric and adult diabetes providers, and developing targeted interventions with a system-level approach.

with numerous physiological and psychosocial changes, including a deterioration in glycemic control, decreased adherence to self-management tasks and to clinic attendance, as well as an increased risk of adverse outcomes.^{2–8} During the transfer to adult care, emerging adults may feel a sense of abandonment and sadness with the loss of the patient-provider relationship as well as uneasiness with the unfamiliar adult medical setting.^{4,9} Thus, the transition to adult care may exacerbate these physiological and psychosocial risks inherent to this developmental stage. For instance, results from the SEARCH for Diabetes in Youth Study demonstrated that after controlling for socio-demographic factors, emerging adults who

Box 1 Summary of Got Transition components^{13 14}**Transition policy**

Practice approach to transition practices, including suggested age for transfer and age for beginning the process, with privacy and consent procedures shared with providers, patients, and families

Transition youth registry

Youth registry to help identify patients at the appropriate time for transition and helps to monitor which steps of the transition process need to be completed

Transition readiness

Transition readiness assessment to help identify gaps in knowledge or skills, providing educational opportunities for improvement in self-management

Transition planning

Includes developing and updating plan of care and transition goals as well as developing a portable medical summary and emergency care plan

Transfer of care

Transfer of care includes arranging transfer to adult care and preparation of a transfer package that contains a medical summary, latest transition readiness assessments, transition goals, and action plans

Transfer completion

Transfer completion involves communication with the adult team or patient to ensure that the patient has been seen in the adult healthcare setting

transferred to adult care were 2.5 times more likely to have suboptimal glycemic control compared with those who stay in pediatric care.⁵

Blum and colleagues define transition as the 'purposeful, planned movement of adolescents and young adults with chronic medical conditions from child-centered to adult-oriented health care systems'.¹⁰ The ultimate goal is to provide healthcare that is coordinated, uninterrupted, and developmentally appropriate and to promote skills in decision-making, communication, autonomy, and self-care.

Based on expert consensus, the American Diabetes Association recently published clinical practice guidelines on healthcare transition for emerging adults with diabetes.¹¹ Further, Got Transition, a US-funded initiative, has put forth a core set of six common components of quality transition care developed as direct extensions of a joint report from the American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and the American College of Physician (ACP).^{12 13} The components include a transition policy, transitioning youth registry, transition readiness and planning, transfer of care, and ensuring transition completion (box 1).¹⁴ A recent US study found fewer than 15% of emerging adults with diabetes reported receiving written transition materials or having a specific visit to discuss transition.¹⁵ A 2007 survey of pediatric diabetes centers in 36 countries found that most centers did not have a structured transition care program.¹⁶ This suggests important deficiencies in transition care, but inferences are limited by a low 16% response rate.¹⁶ We were able to conduct in-depth interviews with key respondents at 12 of 15 pediatric diabetes centers in Quebec in the present study, permitting us to address important knowledge gaps in pediatric care providers' perspectives on transition care.

RESEARCH DESIGN AND METHODS

We conducted an in-depth interview-based qualitative study in Quebec, Canada's second largest province. Quebec has over 8 million residents and has one of the highest incidence rates of diabetes among children in the world (32 per 100 000 per year).¹⁷ Like other provinces in Canada, Quebec has a universal public health insurance coverage plan, through which all residents are insured for hospital services, as well as inpatient and outpatient physician services, including coverage into adulthood for insulin pump therapy that is started before 18 years of age. In Quebec, transfer to adult care is generally mandated to occur at age 18 years.

We contacted the responsible diabetes nurse or physician (pediatrician or pediatric endocrinologist) from each of the 15 pediatric diabetes centers (four tertiary). A member of the research team (SW) conducted in-depth one-on-one semistructured interviews by phone (English or French) between June 2015 and November 2015. Written informed consent was obtained. All interviews were audiotaped and transcribed in their original language. This study was approved by the McGill University Health Centre's Research Ethics Board.

Interview guide

The interview guide was composed of two parts. The first consisted of structured yes or no questions querying alignment with Got Transition's six core elements (box 1).¹⁴ The second included open-ended questions about perceived barriers to successful transition care, optimal methods to transitioning care, and measures of successful transition. The open-ended questions were developed by the research team with expertise in pediatric and adult diabetes care as well as in transition care.

Thematic content analysis

The transcripts were independently read by two evaluators (KD and MN), and data were initially open coded by identifying and categorizing keywords and phrases to generate the initial codes. Our team has experience in conducting qualitative studies addressing diabetes care.^{18,19} The two evaluators met to arrive at a consensus regarding their initial coding. Text responses were compared across the centers, seeking similar or repeated ideas. The final step involved categorizing codes into themes and subthemes. We report themes that were raised during at least half of the interviews.

RESULTS

Participant characteristics and components of transition care

Participants from 12 centers agreed to take part in the study. The participants from the three centers not in the study were from small community centers, each with patient volumes of 30 or less. Only three (25%) of the participating centers had a formal uniform transition policy, regarding the practice approach to transition preparation, age at which transition preparation begins, and the age of transfer (online supplementary file 1). Discussions with patients regarding the practice's transition policies usually took place starting at ages 12–14 years. None of the centers involved youth and/or their families in developing their transition policy, nor were there special provisions for those with intellectual challenges.

Seven centers (58%), including the four academic centers, had a uniform policy solely regarding the age of transfer (i.e., 18 years), while the remainder were flexible (i.e., ages 18–21 years) depending on patient's preferences. If patients were students who were out of the region for periods of the year, then they would be continued to be followed by the pediatric center where the age of transfer was flexible. At four centers (33%), patients on insulin pump therapy were followed beyond age 18 years because of a perceived lack of adult care providers willing to provide care. Only one center (8%) had a transitioning youth registry to aid with transition planning and monitoring transition progress. The age at which patients were offered time alone without the parent/caregiver present varied between centers. Seven centers saw patients alone at age 14 years (58%), two at age 16 years (17%), and one at age 12 years (8%).

There was a near universal absence of formal transition care readiness and planning across, whether university based or community based. Only three (25%) used structured transition readiness and self-care skills assessment tools and regularly developed, updated, and documented patients' progress and goals. The remainder made efforts to facilitate autonomy but did so informally and without the use of structured assessment tools. Further, if future goals for achieving self-care were discussed, it was not routinely documented in the

medical record. Seven of the centers' (58%) discussions tended to focus solely on the actual transfer to adult care. The timing of these discussions tended to occur approximately a year before transfer. Two centers (17%) regularly arranged a 3-month post-transfer follow-up visit to obtain feedback regarding the transition process and the care in the adult medical settings. The remainder did not have a formal system in place for confirmation of attendance at the adult clinic or feedback from patients after transfer.

Thematic analysis

Five key themes emerged: (1) reliance on within-center referrals; (2) barriers to successful transition (lack of available adult care providers and multidisciplinary team in the adult care setting, quality of pediatric care superior to adult care, vulnerability during the transition period, lack of understanding by adult care providers of the challenges emerging adults face, pediatric providers' lack of time for transition planning); (3) overlap between pediatric and adult care; (4) perceived measures of successful transition (patient satisfaction, sustained follow-up in adult care, gap less than 3–6 months on transfer to adult care); and (5) moving out of region as a key vulnerability factor. The themes that achieved saturation across at least half of the centers are presented below.

Theme 1: Reliance on within-center referrals

In eight centers (67%), when transferred to adult care, patients either remained at the same diabetes center or had the same nurses and dietitians as they did in pediatric care. At these centers, there was a perception that the transition to adult care was smoother than would occur without within-center adult clinics. Providers perceived this as a form of transition care; as such no other formal transition preparation or planning occurred. With patient transfer, information sharing between adult and pediatric care relied heavily on informal and indirect methods, including telephone discussions between adult and pediatric care providers and transfer of a shared medical chart without a formal medical summary document.

Theme 2: Barriers to successful transition

Interviewees' perceived barriers to successful transition included both structural (i.e., within the adult and pediatric care settings) and patient-specific factors.

Lack of availability of adult providers and multidisciplinary team in the adult care setting

Six centers (50%) cited a lack of available adult providers and/or an adult care multidisciplinary team; insufficient mental health resources was regarded as an important gap in adult care.

Quality of pediatric care superior to adult care

All interviewees believed that the quality of pediatric care was superior to that of adult care in terms of the amount

of time spent with patients and ease of access to the healthcare team. There was a perception that adult care implied less frequent appointments, less flexibility in scheduling appointments despite competing educational or work commitments, and difficulties in accessing the adult care team for guidance between visits. Interviewees perceived that patients were not seeing the allied healthcare team frequently enough due to less flexibility in booking appointments with the whole healthcare team, necessitating multiple separate appointments.

Vulnerability during the transition period

Participants noted that the period of transition to adult care was one of vulnerability and considered a challenging and high-risk period for the emerging adult with diabetes. Participants identified patients' multiple new responsibilities and competing life priorities as contributors to non-adherence as well as a lack of readiness to assume more responsibilities in their diabetes management.

Lack of understanding and appreciation by adult care providers of the specific challenges emerging adults face during the transition period

Half of the interviewees perceived that adult care providers had a lack of understanding and appreciation of the challenges and new responsibilities emerging adults have during the transition period. There was a perception that adult care providers wrongly expected emerging adults to be fully autonomous by the age of 18 years, irrespective of the patient's developmental stage. As a result, if a patient was not fully autonomous or responsible for his/her care, pediatric providers perceived that there were no specific strategies or approaches in place in the adult care setting for support.

Pediatric providers' lack of time in planning for transition and lack of an identified staff person responsible for transition care

Five (42%) cited difficulties in developing transition care strategies and processes due to a lack of time and human resources. There was an uncertainty as to who should be responsible for instituting a transition care program.

Theme 3: Measures of successful transition

Six interviewees defined successful transition as patient satisfaction. Three believed a gap less than 3–6 months between last pediatric visit and first adult visit was a good measure of successful transition. A marker of successful transition proposed by five was sustained follow-up in adult care at 3–4-month intervals over the first 1–2 years in adult care. Hemoglobin A1c level was not judged to be a very good measure of successful transition, as there were many other factors that could impact it other than the transfer to adult care.

Theme 4: Overlap of care between pediatric and adult healthcare systems seen as ideal method of transition care delivery

The ideal system for transition care was thought to include overlap between pediatric and adult care. Possibilities included a nurse and dietitian common to pediatric and adult care settings, a pediatric endocrinologist working within the adult care setting for the first 2 years following transfer, a young adult clinic with adult and pediatric providers working together, or a transition care coordinator working within both settings who would specifically implement and support the transition process.

Theme 5: Moving out of region

Interviewees indicated that they generally did not know whether patients who moved out of region achieved successful transition. There appeared to be a lack of systematic assistance to both pediatric providers and patients to find diabetes care in the new region. Five (42%) cited a lack of a central source of information about province-wide resources and because there was no formal tracking process in place; interviewees found it difficult to ensure that there was no gap in care when patients moved out of the region.

CONCLUSIONS

Our study systematically examined the transition care practices and perspectives of pediatric providers caring for adolescents with diabetes. We have identified persistent important deficiencies with transition care services, as reported by pediatric care providers, within a publicly funded, universal access healthcare setting. Our findings were consistent across health regions in the province, in both academic and non-academic centers. Pediatric providers in our study recognized the importance of transition care. However, only 25% of our sample reported having any formal and structured transition care preparation and planning at their diabetes centers. Transition care guidelines and consensus recommendations have not been systematically implemented, and there exists poor uptake of available structured tools into practice. Centers that transferred patients to adult clinics within the same center or transferred to a team that included some members of the pediatric team tended to not have any formal transition care processes in place. Barriers perceived as the most important included lack of adult providers, less flexibility in scheduling adult healthcare appointments, patients' struggles with multiple new responsibilities, and adult providers' lack of appreciation of these struggles. Patient satisfaction and regular clinic attendance following transfer were suggested as good measures of transition success. Overlap of care between pediatric and adult care during the transition years was perceived to be the optimal method of transition care delivery. For patients who move out of their local region, pediatric

providers struggled to identify adult providers and voiced difficulties in ensuring patients did not have any gaps in care on transfer.

Despite the lack of formal transition care processes, pediatric providers did not perceive that their current transition practices at the pediatric care level were unsatisfactory and in fact providers felt that barriers to transition care were mainly within the adult care setting. This is in contrast to several studies of emerging adults who have reported a lack of purposeful transition preparation²⁰ and dissatisfaction with the transition process within the pediatric care setting.^{3 4 15} Patients with inadequate transition preparation are at a higher risk for gaps >6 months between the last pediatric and first adult care visit.¹⁵ The discrepancy between what pediatric providers perceive as adequate transition preparation and what they reported being done for transition preparation is concerning. It arguably suggests a lack of knowledge and/or training on appropriate transition care. This is consistent with a recent survey of pediatric diabetes providers in the USA, which found that 68% have not received an introduction to or training in transition care.²¹

Qualitative research has shown that adolescents and emerging adults wish to discuss transition care early and feel that transition preparation is important.²² A recent survey of adolescents with complex care needs found that those who had received anticipatory guidance regarding transition had significantly higher ratings of perceived transition readiness and confidence in successful transition than those who did not receive guidance.²³ In our study, discussions about transition were reported to occur a year before the transfer to adult care and focused solely on the transfer process. This delay in discussion supports previous qualitative research, where at least two-thirds of adolescents with diabetes (ages >16 years) had not yet discussed transition care or their anticipated transfer to adult care with their diabetes team.^{23 24}

An important component of appropriate transition preparation is assessment of self-care skills and transition readiness, which can help guide and track individualized interventions to promote patient education and skill development.^{25 26} Although pediatric providers in our study made an effort to promote autonomy and decision-making skills, assessments were performed inconsistently and without the use of structured tools.

In addition to a lack of formal transition preparation, interviewees reported an overall deficiency in routine documentation for goals and action plans for self-care and decision-making and in preparing medical summaries for transfer. Our findings support those of a study of adult providers in the USA, where 11% reported to consistently receive a medical summary, even though 73% thought it was important to have one and cited not having one as a key barrier to transition care.²⁷ Written communication may help promote continuity of care and can be improved with a standard transition care summary document. For example, the Endocrine Society and Got Transition have both developed various transition care

tools to help facilitate transition, including medical summary templates.^{13 28}

The lack of transition preparation and documentation was the most evident in centers where transfer to adult care occurred within the same centers or where members of the healthcare team remained the same. This was perceived by pediatric providers as a form of transition care with the assumption that no additional transition care components were needed. Findings from several studies suggest that patients who had some overlap in care after transfer had lower rates of hospitalizations and better clinic attendance and glycemic control, compared with those with no overlap.^{2 5 29} With this strong reliance on within-center transfers, it is not surprising that most interviewees in our study thought that some form of pediatric and adult care overlap was an ideal approach to transition care. Targeted interventions, such as joint young adult clinics or transition coordinators, may help with some of the perceived barriers identified by pediatric providers.³⁰

There are several limitations to our study. Interviews were limited to Quebec, Canada. However, Quebec is the second largest province in Canada and we interviewed providers from academic, non-academic, and rural centers, capturing nearly all the centers in the province (80%), likely giving a generalizable representation of transition care practices and perspectives. Our results are based on the pediatric provider's perceptions and were not confirmed by an audit of care or verification of the information of the practices described. To mitigate this limitation, we conducted our interviews with providers who were responsible for their diabetes centers' processes and protocols. Our interviews were telephone-based rather than in-person interviews. This may have limited rapport building; however, the telephone-based interviews likely allowed our interviewees to discuss sensitive information more freely. We obtained only the pediatric provider's perspective and did not conduct interviews with adult care providers or with emerging adults with type 1 diabetes. Despite these limitations, our study provides important information regarding the pediatric provider's perspective on transition care by evaluating transition care structures using the Got Transition framework, a well-known and publicly available framework, allowing for comparisons in other jurisdictions.¹⁴

Summary

In 2002, the AAP, AAFP, and the ACP published joint consensus guidelines calling for transition care to be a basic standard of high-quality medical care.¹² Despite over a decade of increasing awareness of the importance of transition care, significant and persistent gaps in transition care processes were reported by pediatric care providers in Quebec. Our findings highlight the need for a more structured approach to transition care. When emerging adults are supported through the transition period, clinic attendance, adverse outcomes, and loss to follow-ups improve.^{31 32} Although research evaluating

Box 2 Key transition care practices and resources for healthcare providers^{11–13}

Key transition care practices

- ▶ Develop a transition care policy/plan to standardize a practice's approach to transition
- ▶ Begin transition care preparation in early adolescence (i.e., 12–13 years of age)
- ▶ Regularly assess and document adolescents' self-management skills, transition readiness, and disease knowledge using structured assessment tools
- ▶ Prepare a medical summary for patient and adult care provider as well as communicate with adult healthcare provider before transfer
- ▶ Consider developing a practice-based transition care program (a transition education program, specialized transition care clinic, transition care coordinator)

Transition care resources

- ▶ Got Transition (www.gottransition.org)
- ▶ Endocrine Society (<http://www.endocrinetransitions.org/type-1-diabetes/>)
- ▶ National Diabetes Education Program (<https://www.niddk.nih.gov/health-information/health-communication-programs/ndep/living-with-diabetes/youth-teens/transition-adult-health-care/Pages/index.aspx>)

effective models of transition care is limited, several recommendations, mainly based on expert consensus, exist for improving the process, including beginning transition preparation early in adolescence (box 2).^{11–13} Pediatric and adult care practices could begin by evaluating their current resources and approaches to transition and identify ways to incorporate supports. Got Transition, which provides information on best transition care practices, has a practice-level assessment that can be used.¹⁴ Further, incorporating GOT Transition's six core elements may result in practice-level improvements that promote successful transition (box 1).³³ In addition, several diabetes-specific transition care resources are available to pediatric providers, including transition planning checklists and clinical summary templates.²⁸ Assessment tools such as the Transition Readiness Assessment Questionnaire (TRAQ)³⁴ or the Am I ON TRAC for Adult Care (ON TRAC) questionnaire³⁵ are also available to guide pediatric providers in preparing adolescents for transition. Programs such as transition education programs, young adult clinics, and/or transition coordinators may improve outcomes with transition; however, high-quality studies are needed to evaluate these interventions.³¹ Further work is needed to improve collaboration and linkages between pediatric and adult diabetes care providers. For example, diabetes associations can enhance communication between pediatric and adult providers by developing directories of adult providers willing to care for emerging adults with type 1 diabetes. Future research should focus on the transition care issues unique to those emerging adults starting after secondary education. Further, a limitation of our study is that we only obtained the experiences of pediatric providers; as such, future work should explore the emerging adult's and adult care provider's perceptions of transition care to help further elucidate the deficiencies in transition care delivery. Transition care delivery is a complex process. Our findings highlight a need for the development and evaluation of targeted interventions at multiple levels to improve the process.

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