


## RESEARCH ARTICLE

# Youth with diabetes and their parents' perspectives on transition care from pediatric to adult diabetes care services: A qualitative study

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**Abstract**

**Background and Aims:** When youth with diabetes transition from pediatric to adult diabetes care, they are at high risk for loss to follow up and worsening glucose control. We aimed to gain insight on how to improve the transition of youth with type 1 diabetes from pediatric to adult diabetes care from the patients' and parents' perspective.

**Methods:** We conducted focus groups in youth with type 1 diabetes in transition from pediatric to adult diabetes care and their parents, in Calgary, Alberta, between June and August 2014. Eligibility criteria included: (a) type 1 diabetes; (b) aged 15 to 25 years; (c) have or had received care at the pediatric hospital; and, (d) either pre or post-transfer; or, (e) parents of recently transferred youth. Purposive sampling was used, and the theoretical framework used was the Integrated Behaviour Model. Participants were asked about positive, negative, or challenging experiences related to diabetes and transition, solutions to challenges, and tools and strategies to improve and better support transition. Thematic analysis was conducted after focus groups were recorded and transcribed.

**Results:** Three focus groups were conducted: pre-transfer youth with diabetes (4 females and 3 males; median age 17.5 years, IQR 1.3 years); post-transfer young adults with diabetes (2 females and 2 males; median age 23.5 years, IQR 1.2 years); and parents of recently transferred young adults with diabetes (n = 3). Main themes were: (a) communication technology; (b) the need for more transition and diabetes education and preparation during transition; and, (c) the importance and need for social and peer support.

**Conclusion:** This study describes specific areas that may improve diabetes transfer and transition from pediatric to adult diabetes care. This information can help inform clinical care delivery for transition and the development of programs, strategies, and interventions to improve transition care.

**KEYWORDS**

focus groups, transitional care, type 1 diabetes

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## 1 | INTRODUCTION

Diabetes is increasing in the United States, and in 2017, 9.7% of the population were estimated to have this chronic condition.<sup>1</sup> Although most of the attention given to the diabetes epidemic has focused on the increase of diabetes in adults, there is a concerning rise in the prevalence of diabetes in children and youth.<sup>2-7</sup> In less than 10 years, between 2001 and 2009, the prevalence of type 1 diabetes in youth increased by 21%.<sup>8</sup> Type 1 diabetes is the most common form of diabetes in children and youth,<sup>9</sup> and results from the autoimmune destruction of the insulin-producing cells of the pancreas.<sup>9</sup> Preventive measures are necessary to stop this epidemic, and until approaches are available, management strategies that address the unique care needs of youth with diabetes are equally important. One such area is the transition of youth with diabetes from pediatric to adult care.

Transition is “the purposeful, planned movement of adolescent adults with chronic physical and medical conditions from child-centered to adult-oriented systems”.<sup>10</sup> Transition is not a single event; rather, it is a process that includes the *transfer* of care from pediatric to adult health care services (Figure 1). At our center, the transition process starts at age 14 years and transfer from pediatric to adult care services occurs between the ages of 17 to 18 years.

The transition period from pediatric to adult diabetes care has been identified as a potentially vulnerable and challenging period for youth and families.<sup>11,12</sup> Diabetes is a particularly complex condition, requiring a daily commitment to nutrition, monitoring of blood glucose, and adherence to medications, with self-management being a cornerstone of care in adolescence.<sup>13</sup> In addition to their medical needs, this age group has multiple concurrent competing priorities (ie, school, sports teams, relationships, identity, autonomy, among others) and developmental changes. Coupled with the physical, psychological, and social changes, youth with diabetes in transition face significant challenges as they deal with the daily complexity of this chronic condition and substantial changes in their care as they transfer from pediatric to adult diabetes care services.<sup>12,14</sup>

During the transition period, up to 60% of youth with diabetes drop out of medical care post-transfer.<sup>11,15,16</sup> This loss to follow-up is associated with worsening glycemic control and with avoidable hospitalizations.<sup>11,15,16</sup> This period is also associated with poor self-care behaviors and mental health symptoms.<sup>17,18</sup> Youth with diabetes are also five times more likely to die than their age-matched peers.<sup>19</sup> Unfortunately, current health care services may be failing to meet the unique needs of youth with diabetes.<sup>11,15-18,20,21</sup>

Several strategies to address this problem have shown, at best, some promising results, but there is still substantial room for improvement.<sup>12,22,23</sup> Strategies have varied and have included transition coordinators, transition clinics, and group education sessions, with this literature recently being summarized in a systematic review.<sup>23</sup> Transition trials thus far have been unsuccessful in showing improved follow up rates post transfer.<sup>24-26</sup> In the development of tools and strategies to improve diabetes transition care, it is important to have the input of key stakeholders, namely patients and their families, prior to their development and implementation, rather than relying solely on

physician or other health care provider's feedback alone. While a few studies have documented the experience of young adult with diabetes, these tend to only include those individuals post-transfer and in a private payer health care setting.<sup>20,27</sup> Here, in contrast to other studies, we have purposely included a contemporary cohort of youth and young adults at varying stages of transition (ie, pre and post-transfer), as well as parents, to gather a variety of participants' perspectives and experiences.<sup>20,27</sup> Furthermore, in contrast to previous studies conducted in private payer systems, ours was conducted in a single payer system in Canada.<sup>20,27</sup> Notably, our strategy would build on previous literature which showed that a transition coordinator modestly improves diabetes transition care in the Canadian setting.<sup>28</sup> As such, the objective of this study was to gain insight on how to improve the transition of youth with type 1 diabetes from pediatric to adult diabetes care from the patients' and parents' perspective.

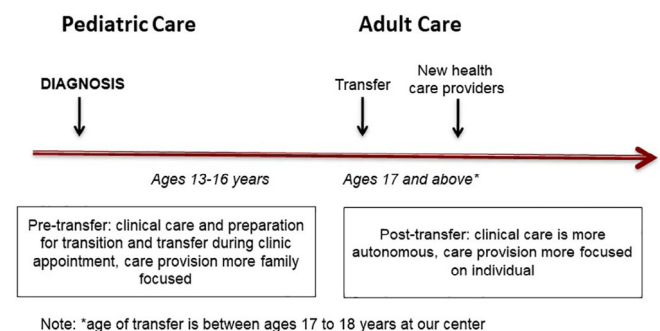
## 2 | METHODS

### 2.1 | Study design

We conducted a qualitative descriptive study.<sup>29</sup> Qualitative description seeks to elicit and capture perspectives through qualitative methods such as in focus groups.<sup>29</sup> We conducted three focus groups: pre-transfer youth with diabetes (group 1); post-transfer young adults with diabetes (group 2); and, parents of recently transferred young adults with diabetes (group 3). We purposely included these groups as we considered it important to have the input of youth with type 1 diabetes at varying stages of transition (ie, pre-transfer and post-transfer from pediatric to adult diabetes care) as well as their parents, being key stakeholders. We used the Consolidate Criteria for Reporting Qualitative Research (COREQ) as the reporting framework for this study.<sup>30</sup>

### 2.2 | Study population and setting

This study was conducted in Calgary, Alberta, a large urban city, population >1.2 million, in which the Alberta Children's Hospital



**FIGURE 1** A schematic diagram of the transition and transfer from pediatric to adult diabetes care. Transition is the entire process, which includes transfer

**TABLE 1** Characteristics of youth and young adults with type 1 diabetes participating in the study

Characteristic	
Age (years)	
Median	18 years
Interquartile range	6.3 years
Range	15.9 years to 24.5 years
Sex	
Females n, (%)	6 (55%)
Males n, (%)	5 (45%)
Type 1 Diabetes n (%)	11 (100%)
English speaking n (%)	11 (100%)

Abbreviations: n = number.

**TABLE 2** Summary of key findings associated with each theme

Themes	Subthemes and key findings
Communication technology	<ul style="list-style-type: none"> <li>- Lack of communication technology use in transition</li> <li>- Participants saw this as a major gap</li> <li>- Use of communication technology as an opportunity to improve transition (ie, texting appointment reminders, asking questions regarding their care, etc.)</li> </ul>
Education and preparation	<ul style="list-style-type: none"> <li>- Diabetes education and preparation could be improved prior to transition</li> <li>- Perception and/or experience of not having education or preparation for transition</li> <li>- Perception and/or experience of not having education or preparation about adult care</li> </ul>
Social and peer support	<ul style="list-style-type: none"> <li>- Social and peer support deemed important</li> <li>- Sharing experiences had positive impact</li> </ul>

catchment includes Calgary, the Southern portion of the province of Alberta, as well as neighboring parts of adjacent provinces (Eastern British Columbia and Western Saskatchewan). Purposive sampling was used to recruit participants. Eligibility criteria included: (a) a diagnosis of type 1 diabetes; (b) age 15 to 25 years old; (c) were receiving or had received care at the Alberta Children's Hospital; and, (d) either pre or post-transfer from pediatric to adult diabetes care in Calgary, Alberta; or, (e) parents of recently transferred youth that met eligibility criteria. Participants were excluded if they did not meet eligibility criteria or could not provide informed consent. The Alberta Children's Hospital diabetes program and the adult diabetes care program provides comprehensive, multidisciplinary diabetes care; however, at the time of the focus groups, the transition process included only a brief educational program delivered during regular pediatric clinical care visits, and no transition coordinator was in place. The transition process started at age 14 as per the national transition guidelines.<sup>18,31</sup> Discussions with youth and families around increased autonomy, self-care, and organization of adult healthcare services, and transition topics such as sexuality, driving, drugs, alcohol, finances, and living away from home were part of the curriculum for their regular medical

**TABLE 3** Themes and potential applications within clinical practice and/or transition programs

Theme	Potential applications within clinical practice and/or transition programs
Communication technology	<ul style="list-style-type: none"> <li>- Use of email, texting</li> <li>- Online forums, Facebook groups, blogs, vlogs</li> <li>- Apps</li> <li>- Virtual patient networks</li> <li>- Website with content related to transition</li> </ul>
Education and preparation	<ul style="list-style-type: none"> <li>- Self assessment knowledge tools</li> <li>- Transition readiness tools</li> <li>- Seminars or courses for emerging adults and parents</li> <li>- Case based scenarios</li> <li>- Consideration conducting education and preparation sessions outside of clinical appointments</li> </ul>
Social and peer support	<ul style="list-style-type: none"> <li>- Online forums, Facebook groups, blogs, vlogs</li> <li>- Social events, outings</li> <li>- Volunteering in groups</li> <li>- Camps, conferences, courses</li> <li>- Sports days</li> <li>- Group education with activities for participant interaction</li> </ul>

follow-up visits. An electronic transition checklist was used by all the pediatric clinics to ensure transition topics were covered prior to transfer. Transfer from pediatric to adult care services occurs at 17 to 18 years of age at our center.

The focus groups presented here were done as part of a larger research project, prior to the implementation of a new transition program which included a transition coordinator role within our clinics. Focus groups were conducted between June and August 2014. Participants who had previously consented in clinic to be approached for research studies were contacted. Staff contacted, via telephone or during clinic visits, eligible youth, young adults, and their parents and invited them to participate.

### 2.3 | Focus group procedures

We developed a semi-structured focus group guide based on a literature search, an environmental scan, review of professional guidelines, and consultations with nine pediatric and adult diabetes care providers including endocrinologists, diabetes educators, nurses, dieticians, and psychologists.<sup>18,23,32</sup> The focus group guide included open ended and broad questions to elicit details about the perspectives and experience of youth, young adults, and parents with transfer and transition. Focus group guide items included: positive experiences with diabetes within the last 6 months related to transition, negative or challenging experiences within the last 6 months related to diabetes and transition, solutions to challenges, and tools and strategies to improve and better support transfer and transition (see Supporting Information).

Rigor was enhanced by having focus groups moderated by the same female investigator (KAM), with experience and training in conducting qualitative research. This ensured consistency of the delivery of the

focus group guide and that all participants had the opportunity to voice their experiences and perspectives. Focus groups were conducted in the diabetes center, and an additional staff member from pediatric or adult diabetes clinics co-moderated the focus groups. The researchers all have a background in diabetes and chronic disease, and experience working with youth and families. Focus group moderators were not previously known to or involved in the care of the study participants. Participants were informed of the objective of the study prior to the start of the focus group. The Integrated Behaviour Model was used to guide data collection and analyses by reviewing and re-reviewing themes within the framework.<sup>33</sup> This model was used because of the various factors involved in health behavior in people with chronic diseases such as diabetes. Notes were taken to capture key points and observations about interactions and the group discussion. Focus groups were 60 minutes in duration and were audiotaped and transcribed verbatim by a single transcriptionist. All data were anonymized and securely stored. Twenty-five-dollar gift cards were provided to participants.

### 2.3.1 | Analysis

Two team members, experienced in qualitative research methods, guided the analytic process using conventional qualitative content analysis.<sup>34</sup> Transcripts and notes were read multiple times, independently and in duplicate, to identify common words, phrases, stories, etc., and these commonalities were highlighted, coded, organized, and then grouped together using spreadsheets.<sup>35</sup> Related codes were categorized into themes. The individuals then met, compared findings, and discussion ensued with the research team until consensus was reached on the final themes. Decisions were tracked and recorded for audit purposes.

### 2.3.2 | Ethical considerations

This study was approved by the University of Calgary (REB14-1158) institutional ethics review board. All participants (and a parent or legal guardian for any participants under the age of 18 years) provided written informed consent.

## 3 | RESULTS

Seven youth (four females and three males) with type 1 diabetes who were pre-transfer participated in group 1 (median age 17.5 years, interquartile range 1.3 years), four young adults (2 females and 2 males) with type 1 diabetes who were post-transfer participated in group 2 (median age 23.5 years, interquartile range 1.2 years), and three parents of youth with type 1 diabetes who had transferred from pediatric to adult care participated in group 3 (Table 1).

Three main themes on transfer and transition from pediatric to adult diabetes care emerged: (a) communication technology; (b) the

need for more transition and diabetes education and preparation; and (c) the importance and need for social and peer support (Table 2).

### 3.1 | Theme 1: Communication technology

All participants discussed communication technology and importantly, the absence of the use of communication technology during the transfer from pediatric to adult diabetes care. Participants voiced this as a negative aspect of the transition process as other “care” services known to them employ communication technology. One example used by a participant was how dentist offices use texting for appointment reminders. Participants described the need for increased use of communication technology to improve and enhance contact with diabetes clinic (eg, reminders for appointments and lab work) and communication with the team (eg, for support, assistance when diabetes issues arise, and to stay on track with self-management).

“I think a text message or an email would sort of remind you to keep on track.” [Group 1]

“[current pump nurse] is literally 24/7, I can text her or email her and she'll reply” [Group 2]

“maybe like a text ... cause that's how they [youth with diabetes] run the world, that's how they run their whole lives, through texting and messaging.” [Group 3]

Notably, here, the participants identified a gap during the transition process and a solution, that is, the use of communication technology, to improve the transition process (ie, texting, email, etc.).

### 3.2 | Theme 2: Transition and diabetes education and preparation

Diabetes education, including self-management, is a cornerstone of adult diabetes care as it provides people the information and skills to lead a healthy life with diabetes. One of the aims of transition is to shift care of diabetes from parents or guardians to self-care management. A main theme that emerged was the need and desire for increased education and preparation pre-transfer to adult diabetes care. Participants voiced gaps in two areas in which they felt ill-prepared. These areas included: (a) diabetes knowledge; and, (b) preparation and knowledge about transition and adult care.

“...and I know at the Children's they were like you need to learn to do carb counting but my Mom did everything for me. She still helps me, but I think now, having an educational class to make sure that us as 17-year-olds actually do know how to manage our diabetes on our own.” [Group 2]

"I don't remember much talk about [transition] at all. I think it was maybe a couple sessions beforehand and I probably didn't listen to it because I didn't want it to become reality." [Group 2]

"I felt like maybe like a refresher course or something probably coulda helped more." [Group 2]

Participants suggested educational topics including "back-to-basics" on type 1 diabetes management, like carbohydrate-counting, sick day management, nutrition, and education on insulin pumps. They also suggested that the ideal time for type 1 diabetes education would be just before transferring from pediatric care. Thus, there is an opportunity to improve transition care by increasing diabetes teaching prior to transfer as well as re-assessing how well preparation about transition and adult care is occurring.

### 3.3 | Theme 3: Social and peer support

Youth with diabetes and parents highlighted the importance of a peer, or group of others to share experiences and provide social support. Visits with health care providers (ie, physicians, nurses, dieticians) were not adequately meeting the needs of individuals with diabetes.

"Kinda gives me a bit of ease knowing that she's keeping an eye." [Group 1]

"I feel like ya know and I think that ya know, it is helpful to be able to talk to someone that at least understands what you are going through." [Group 3]

"[Child's] friends know so that they know what to look for and same with [child's significant other] .... [significant other] helps [child] stay in check." [Group 3]

This suggests that at a younger age, the need for support is often met by their parents or guardians. However, as they mature and aim for independence from their parents, transition youth also seek or want support elsewhere. In this case, they recognized the importance of receiving this from individuals who share the same experiences of living with diabetes.

## 4 | DISCUSSION

The transition period for youth and young adults with diabetes is a challenging and vulnerable time because in addition to the daily complexity of this chronic condition, and substantial changes in their care as they transfer from pediatric to adult care, there are many significant physical, psychological, and social changes youth experience as a part of their normal development.<sup>14</sup> As such, we aimed to gain insight into how to improve the transition process from pediatric to adult

diabetes care. Our focus groups of youth and young adults before and after transfer, as well as parents, identified main themes related to transition, including the need for increased use of communication technology in the process, the need for increased transition and diabetes education and preparation, and the importance of social and peer support. These findings are important, with potential implications to clinical care delivery and transition strategies and programs (Table 3).

Our study adds patient and parent voices in supporting the need of more communication technology. Both youth and young adults with type 1 diabetes, as well as parents, described the absence of communication technology use as an important gap in transition care. This gap was in relation to health services delivery (ie, appointment reminders, support) and communication (ie, diabetes care, knowledge, content questions). Importantly, previous studies have not identified this important theme.<sup>20,27,36</sup> In today's digital age, cell phones or smartphones, texting, emails, internet, and social media are avidly used by this age group. Hence, for a population who has embraced new technologies, it is compelling to use such technologies to improve transition care.<sup>37,38</sup> Adolescents with a chronic disease who used a web-based and text-delivered disease management and skill-based intervention improved their disease management skills, health-related self-efficacy, and patient-initiated communications.<sup>39</sup> Similarly, the Maestro project, a transition program including a transition coordinator who regularly called or emailed transitioning youth, also leveraged technology with a website. This program demonstrated a reduction in the loss to follow up (40% vs 11%). Due to the multi-faceted nature of the program, the effect of the website use is unknown, but was one of the components of this successful program.<sup>28</sup>

In this study, some youth and families felt they did not receive adequate preparation and others perceived no preparation for transfer and transition was provided, despite these topics being covered during clinical visits. This is consistent with findings from an American study of post-transition young adults with diabetes.<sup>21</sup> From a health care provider's perspective, barriers to providing adequate preparation may include limited time in clinical encounters, competing priorities, and/or not providing the type of information youth and families want (ie, the differences in adult vs pediatric care delivery) or in a manner that is useful to them (ie, verbal vs other forms of communication).<sup>40,41</sup> Possible patient barriers to receiving adequate transition preparation such as competing clinical priorities (ie, hypoglycemia, obtaining a driver's license), personal changes (ie, changes in living situation or schooling), and/or lack of readiness may exist as well. Generic transition readiness measures have been developed such as the California Healthy and Ready to Work Tool, the Self-Management Skills Assessment Guide, the Transition Readiness Assessment Questionnaire, and the TRxANSITION Scale, and this field is still evolving, with the development of new instruments and the need for validation in diverse groups.<sup>42</sup> Finally, participants expressed the importance of and need for social and peer support. Type 1 diabetes is a particularly complex condition requiring a daily commitment by an individual with diabetes to manage and monitor their diet (ie, content, amount of food, etc.), activity, blood glucose reading, and insulin doses (ie,

calculation and administration), with self-management being a key component of care.<sup>13</sup> Youth with diabetes are also experiencing physical, psychological, and social changes in addition to managing a chronic condition as they transfer from pediatric to adult diabetes care services.<sup>43-45</sup> A supportive person, group, or network could positively enhance the transition process.<sup>46-48</sup> As mentioned earlier, the MAESTRO program included social activities, but the independent effect of such activities are not known.<sup>28</sup> Such social engagement with others with diabetes may occur through volunteering and peer mentoring activities. Volunteering and peer mentoring have been demonstrated in youth to be effective for diabetes prevention, and in adults, to improve glycemic control and diabetes self-management, but have not been assessed in the transition period.<sup>46-48</sup>

Strengths of this study include the inclusion of a contemporary cohort of participants; the inclusion of youth with diabetes at varying stages of transition (ie, pre-transfer and post-transfer) and parents of individuals with type 1 diabetes that had recently transferred, concurrently; and, the inclusion of participants from a broad geographic region. Importantly, valuable insights into diabetes transition care were gained that may be used to inform future strategies and programs.

There are also some limitations to this study. First, data were not collected to the point of saturation.<sup>49</sup> This limitation might be mitigated by the fact that consistent themes emerged from the focus groups but other themes may still be possible. Second, detailed quantitative information (ie, laboratory results, clinical characteristics) was intentionally not requested, as our study team felt that asking participants for access to their clinical data may deter youth with diabetes from participating (ie, for instance, if their glycemic control was not ideal, they may perceive that they would be scrutinized and avoid participating). Also, we did not consider gender in our sampling nor in the analyses. Importantly, diabetes may affect mothers more deeply than fathers.<sup>50</sup> Furthermore, mothers may be more likely to attend clinic appointments and take responsibility for completion of diabetes related care tasks, including during transfer and transition.<sup>50,51</sup> There is also the possibility of recall bias in the post-transfer group due to time lapse between their transfer and focus groups, and it would have been ideal to include member checking (ie, returning transcripts to participants).

In terms of future studies, further work should also include the perspectives of parents of pre-transfer youth as well as endocrinologists, diabetes educators, family physicians, psychologists, program managers, and office staff (ie, check-in staff or administrative assistants to garner how these youth may differently interact with the health system).

## 5 | CONCLUSION

In summary, our findings support the inclusion of the use of communication technologies, improved transition and diabetes education, social and peer support in the development, and implementation of

programs and strategies to improve transition from pediatric to adult diabetes care. A program or strategy which prepares and supports youth and families and that ensures smooth transfer and transition would be ideal. Importantly, such programs or strategies would minimize adverse health events and maintain or improve quality of care for youth with diabetes and their families through this important phase of their lives.

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## CONFLICT OF INTEREST

The authors report no conflicts of interest in this work.

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All authors reviewed and approved the manuscript.

Sonia Butalia had full access to all the data in the study and takes complete responsibility for the integrity of the data and the accuracy of the data analysis.

## TRANSPARENCY STATEMENT

Sonia Butalia confirms that this manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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## REFERENCES

1. Xu G, Liu B, Sun Y, et al. Prevalence of diagnosed type 1 and type 2 diabetes among US adults in 2016 and 2017: population based study. *BMJ*. 2018;362:k1497. <https://doi.org/10.1136/bmj.k1497>.
2. Jarosz-Chobot P, Polanska J, Szadkowska A, et al. Rapid increase in the incidence of type 1 diabetes in Polish children from 1989 to 2004, and predictions for 2010 to 2025. *Diabetologia*. 2011;54(3):508-515.
3. The Diamond Project Group. Incidence and trends of childhood type 1 diabetes worldwide 1990–1999. *Diabet Med*. 2006;23(8):857-866.
4. Patterson CC, Dahlquist GG, Gyürüs E, Green A, Soltész G. Incidence trends for childhood type 1 diabetes in Europe during 1989–2003 and predicted new cases 2005–20: a multicentre prospective registration study. *Lancet*. 2009;373(9680):2027-2033.
5. EURODIAB ACE Study Group. Variation and trends in incidence of childhood diabetes in Europe. *Lancet*. 2000;355(9207):873-876.
6. Onkamo P, Väänänen S, Karvonen M, Tuomilehto J. Worldwide increase in incidence of Type I diabetes—the analysis of the data on published incidence trends. *Diabetologia*. 1999;42(12):1395-1403.
7. Forlenza GP, Rewers M. The epidemic of type 1 diabetes: what is it telling us? Current opinion in endocrinology. *Diabetes & Obesity*. 2011;18(4):248-251.
8. Dabelea D, Mayer-Davis EJ, Saydah S, et al. Prevalence of type 1 and type 2 diabetes among children and adolescents from 2001 to 2009. *JAMA*. 2014;311(17):1778-1786.
9. American Diabetes Association. Standards of medical care in diabetes—2013. *Diabetes Care*. 2013;36(Supplement 1):S11-S66.
10. Blum RWM, Garell D, Hodgman CH, et al. Transition from child-centered to adult health-care systems for adolescents with chronic conditions: a position paper of the Society for Adolescent Medicine. *J Adolesc Health*. 1993;14(7):570-576.
11. Nakhla M, Daneman D, To T, Paradis G, Guttmann A. Transition to adult care for youths with diabetes mellitus: findings from a universal health care system. *Pediatrics*. 2009;124(6):e1134-e1141.
12. Wafa S, Nakhla M. Improving the transition from pediatric to adult diabetes healthcare: a literature review. *Can J Diabetes*. 2015;39(6):520-528.
13. Canadian Diabetes Association Clinical Practice Guidelines Expert Committee. CDA 2013 clinical practice guidelines for the prevention and management of diabetes in Canada. *Can J Diabetes*. 2013;37(suppl 31):S1-S212.
14. Garvey KC, Markowitz JT, Laffel LM. Transition to adult care for youth with type 1 diabetes. *Curr Diab Rep*. 2012;12(5):533-541.
15. Kipps S, Bahu T, Ong K, et al. Current methods of transfer of young people with type 1 diabetes to adult services. *Diabet Med*. 2002;19(8):649-654.
16. Gerstl E-M, Rabl W, Rosenbauer J, et al. Metabolic control as reflected by HbA1c in children, adolescents and young adults with type-1 diabetes mellitus: combined longitudinal analysis including 27,035 patients from 207 centers in Germany and Austria during the last decade. *Eur J Pediatr*. 2008;167(4):447-453.
17. Hendricks M, Monaghan M, Soutor S, Chen R, Holmes CS. A profile of self-care behaviors in emerging adults with type 1 diabetes. *Diabetes Educ*. 2013;39(2):195-203.
18. Peters A, Laffel L. Diabetes care for emerging adults: recommendations for transition from pediatric to adult diabetes care systems. *Diabetes Care*. 2011;34:2477-2485.
19. Public Health Agency of Canada (2011). Diabetes in Canada. <http://www.phac-aspc.gc.ca/cd-mc/diabetes-diabete/face-eng.php>. Accessed December 11, 2014.
20. Garvey KC, Telo GH, Needleman JS, Forbes P, Finkelstein JA, Laffel LM. Health care transition in young adults with type 1 diabetes: perspectives of adult endocrinologists in the U.S. *Diabetes Care*. 2016;39(2):190-197.
21. Garvey KC, Beste MG, Luff D, Atakov-Castillo A, Wolpert HA, Ritholz MD. Experiences of health care transition voiced by young adults with type 1 diabetes: a qualitative study. *Adolescent Health, Medicine and Therapeutics*. 2014;5:191-198.
22. Findley MK, Cha E, Wong E, Faulkner MS. A systematic review of transitional care for emerging adults with diabetes. *Journal of Pediatric Nursing*. 2015;30(5):e47-e62.
23. Schultz AT, Smaldone A. Components of interventions that improve transitions to adult care for adolescents with Type 1 diabetes. *J Adolesc Health*. 2017;60(2):133-146.
24. Sequeira PA, Pyatak EA, Weigensberg MJ, et al. Let's empower and prepare (LEAP): evaluation of a structured transition program for young adults with type 1 diabetes. *Diabetes Care*. 2015;38:1412-1418.
25. White M, O'Connell MA, Cameron FJ. Clinic attendance and disengagement of young adults with type 1 diabetes after transition of care from paediatric to adult services (TrACeD): a randomised, open-label, controlled trial. *The Lancet Child & Adolescent Health*. 2017;1(4):274-283.
26. Spaic T, Robinson T, Goldbloom E, et al. Closing the gap: results of the multicenter Canadian randomized controlled trial of structured transition in young adults with type 1 diabetes. *Diabetes Care*. 2019;42(6):1018-1026.
27. Ritholz MD, Wolpert H, Beste M, Atakov-Castillo A, Luff D, Garvey KC. Patient-provider relationships across the transition from pediatric to adult diabetes care: a qualitative study. *Diabetes Educ*. 2014;40(1):40-47.
28. Van Walleghe N, MacDonald CA, Dean HJ. Evaluation of a systems navigator model for transition from pediatric to adult care for young adults with Type 1 diabetes. *Diabetes Care*. 2008;31(8):1529-1530.
29. Sandelowski M. Whatever happened to qualitative description? *Res Nurs Health*. 2000;23(4):334-340.
30. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International J Qual Health Care*. 2007;19(6):349-357.
31. McManus MA, Pollack LR, Cooley WC, et al. Current status of transition preparation among youth with special needs in the United States. *Pediatrics*. 2013;131(6):1090-1097.
32. Canadian Diabetes Association Clinical Practice Guidelines Expert Committee. Type 1 diabetes in children and adolescents. *Can J Diabetes*. 2013;37:S153-S162.
33. Montañó D, Kasprzyk D. Theory of reasoned action, theory of planned behavior, and the integrated behavioral model. In: Glanz K, Rimer BK, K V, eds. *Health Behavior and Health Education: Theory, Research, and Practice*. 4th ed. San Francisco, CA: Wiley; 2008:95-125.
34. Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005;15(9):1277-1288.
35. Stockdale Margaret S (2002). Analyzing focus group data with spreadsheets, University of Alabama, Department of Health Sciences. <https://www.thefreelibrary.com/Analyzing+focus+group+data+with+spreadsheets.-a096267483>. Accessed April 17, 2015.
36. Fernandes SM, O'Sullivan-Oliveira J, Landzberg MJ, et al. Transition and transfer of adolescents and young adults with pediatric onset chronic disease: the patient and parent perspective. *J Pediatr Rehabil Med*. 2014;7(1):43-51.
37. Andone I, Blaszkiewicz K, Eibes M, Trendafilov B, Montag C, Markowetz A. How age and gender affect smartphone usage. *Proceedings of the 2016 ACM International Joint Conference on Pervasive and Ubiquitous Computing: Adjunct, Heidelberg, Germany 2971451: ACM*; 2016:9-12. <https://doi.org/10.1145/2968219.2971451>.
38. Statistics Canada (2017). Life in the fastlane: how are Canadians managing?. <https://www150.statcan.gc.ca/n1/en/daily-quotidien/171114/dq171114a-eng.pdf?st=Hee8cA85>. Accessed April 8, 2019.

39. Huang JS, Terrones L, Tompane T, et al. Preparing adolescents with chronic disease for transition to adult care: a technology program. *Pediatrics*. 2014;133(6):e1639-e1646.
40. Agarwal S, Garvey KC, Raymond JK, Schutta MH. Perspectives on care for young adults with type 1 diabetes transitioning from pediatric to adult health systems: a national survey of pediatric endocrinologists. *Pediatr Diabetes*. 2017;18(7):524-531.
41. Nakhla M, Bell LE, Wafa S, Dasgupta K. Improving the transition from pediatric to adult diabetes care: the pediatric care provider's perspective in Quebec, Canada. *BMJ Open Diabetes Res Care*. 2017;5(1):e000390.
42. Schwartz LA, Daniel LC, Brumley LD, Barakat LP, Wesley KM, Tuchman LK. Measures of readiness to transition to adult health care for youth with chronic physical health conditions: a systematic review and recommendations for measurement testing and development. *J Pediatr Psychol*. 2014;39(6):588-601.
43. Sparud-Lundin C, Ohrn I, Danielson E. Redefining relationships and identity in young adults with type 1 diabetes. *J Adv Nurs*. 2010;66(1):128-138.
44. Rasmussen B, Ward G, Jenkins A, King SJ, Dunning T. Young adults' management of type 1 diabetes during life transitions. *J Clin Nurs*. 2011;20(13-14):1981-1992.
45. Hanna KM. A framework for the youth with type 1 diabetes during the emerging adulthood transition. *Nurs Outlook*. 2012;60(6):401-410.
46. Eskicioglu P, Halas J, Sénéchal M, et al. Peer mentoring for type 2 diabetes prevention in first nations children. *Pediatrics*. 2014;133(6):e1624-e1631.
47. Santos RG, Durksen A, Rabbani R, et al. Effectiveness of peer-based healthy living lesson plans on anthropometric measures and physical activity in elementary school students: a cluster randomized trial. *JAMA Pediatr*. 2014;168(4):330-337.
48. Steinhart MA, Mamerow MM, Brown SA, Jolly CA. A resilience intervention in African American adults with type 2 diabetes: a pilot study of efficacy. *Diabetes Educ*. 2009;35(2):274-284.
49. Saunders B, Sim J, Kingstone T, et al. Saturation in qualitative research: exploring its conceptualization and operationalization. *Qual Quant*. 2018;52:1893-1907.
50. Fornasini S, Miele F, Piras EM. The consequences of type 1 diabetes onset on family life. An integrative review. *J Child Fam Stud*. 2020;29(5):1467-1483.
51. Allen D, Channon S, Lowes L, Atwell C, Lane C. Behind the scenes: the changing roles of parents in the transition from child to adult diabetes service. *Diabet Med*. 2011;28(8):994-1000.

## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

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