





BMJ Open Quality Implementation and evaluation of a longitudinal diabetes educational programme for adolescents

Kristina Loreta Pabedinskas ¹, Jennilea Courtney,² Nicholas Barrowman,^{1,2} Sarah Zankar,¹ Christine Richardson,³ Liz Stevens,⁴ Ellen B Goldbloom ^{1,4}, Sarah E Lawrence,^{1,4} Caroline Zuijdwijk,^{1,4} Margaret L Lawson ^{1,4}, Marie-Eve Robinson,^{1,4} Saunya Dover,³ Alexandra Ahmet ^{1,4}

To cite: Pabedinskas KL, Courtney J, Barrowman N, *et al*. Implementation and evaluation of a longitudinal diabetes educational programme for adolescents. *BMJ Open Quality* 2023;**12**:e002361. doi:10.1136/bmjopen-2023-002361

► Additional supplemental material is published online only. To view, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2023-002361>).

Received 23 March 2023
Accepted 12 July 2023



© Author(s) (or their employer(s)) 2023. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

¹Faculty of Medicine, University of Ottawa, Ottawa, Ontario, Canada

²Children's Hospital of Eastern Ontario Research Institute, Ottawa, Ontario, Canada

³Division of Endocrinology and Metabolism, Children's Hospital of Eastern Ontario Research Institute, Ottawa, Ontario, Canada

⁴Division of Endocrinology and Metabolism, Children's Hospital of Eastern Ontario, Ottawa, Ontario, Canada

Correspondence to
Dr Alexandra Ahmet;
aahmet@cheo.on.ca

ABSTRACT

Introduction International guidelines recommend *structured and continuous* educational programmes to expand diabetes knowledge and self-efficacy in youth. To address these recommendations within a paediatric diabetes clinic, we conducted a three-phase quality improvement project aimed at improving adolescents' confidence in diabetes self-management skills.

Methods In phase 1, the Diabetes Learning Centre (DLC), an educational programme for adolescents with type 1 diabetes (T1D) ages 13–17 years, was developed and implemented. Programme feasibility was evaluated through programme attendance rates. Phase 2 aimed to guide ongoing programme development and optimisation. DLC attendees rated their baseline confidence in overall and individual T1D self-management skills on a 5-point Likert scale. Patient characteristics were summarised using descriptive statistics and the association between patient characteristics and overall confidence in T1D self-management was evaluated. Phase 3 used patient surveys to evaluate patient satisfaction and reported change in confidence in self-management skills following DLC attendance.

Results In phase 1, 232 (81%) of eligible adolescents attended the DLC during the study period. In phase 2, median overall confidence in diabetes management on a Likert scale (0–4) was 3, representing 'quite confident', although confidence was low in some essential self-management skills. Higher confidence was associated with lower HbA1c ($p < 0.001$). In phase 3, 77 (85%) of participants reported high levels of satisfaction with the DLC. 106 (82%) of completed worksheets were associated with improved confidence in the diabetes self-management skill addressed.

Conclusions Implementation of a longitudinal T1D educational model was feasible with good uptake in an existing T1D programme. While confidence at baseline was quite high for overall T1D self-management, it was low in some essential self-management skills, highlighting the need for this programme and specific educational gaps. Adolescents reported improvements in confidence and high levels of satisfaction following DLC attendance. Our model provides a replicable programme template to address longitudinal education needs.

INTRODUCTION

Management of type one diabetes (T1D) is lifelong and complex, requiring individuals

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Education for adolescents with type 1 diabetes is essential and can improve diabetes knowledge and self-efficacy; however, it is challenging to systematically integrate this into routine diabetes care as recommended by international guidelines.

WHAT THIS STUDY ADDS

⇒ A longitudinal educational programme can be associated with high attendance rates and can be implemented with high levels of patient satisfaction. The need for such a programme is highlighted by the low confidence in some essential diabetes self-management skills reported by our population.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ This study describes the implementation of a model for longitudinal diabetes education that can be used at other centres.

to develop and practice numerous self-management skills to maintain optimal glycaemic control and prevent acute and long-term complications.¹ Given its childhood onset, most individuals with T1D are not initially responsible for their own diabetes management.² The transition into adolescence, and then early adulthood, is associated with increased responsibility for self-care and ultimately, independent T1D management. This transition may be associated with deterioration in glycaemic control.^{3–5} Factors contributing to this worsening of glycaemic control include lifestyle changes and suboptimal adherence to diabetes treatment regimens.^{6–8}

Self-efficacy—an individual's confidence in their ability to perform specific tasks required to reach a desired goal—is an important factor in predicting self-care behaviours and glycaemic control in adolescents and young adults with T1D.^{9 10} Adolescents with lower



self-efficacy have been found to have lower self-reported adherence to their diabetes regimen and higher haemoglobin A1c (HbA1c) compared with those with higher self-efficacy, suggesting that the degree to which an adolescent adheres to their diabetes self-management tasks may be influenced by their confidence in their ability to do so.^{9 10} Higher self-efficacy in adults with T1D, has been associated with better self-perceived health and social functioning.¹¹

Provision of support during the transition period of adolescence may improve confidence in diabetes self-management, and thereby, adherence to treatment and glycaemic control. One obvious and effective strategy to accomplish this is diabetes education tailored to an adolescent's emerging autonomy. Studies have shown that educational interventions targeted at children and adolescents with T1D result in improved diabetes knowledge, self-management skills, self-efficacy and glycaemic control.^{12–15}

In response to the growing recognition of the importance of education, the International Society for Pediatric and Adolescent Diabetes (ISPAD) published a series of recommendations for diabetes education in children and adolescents.¹⁶ These guidelines outline universal principles for diabetes education, stating that every person with diabetes has a right to comprehensive expert-structured education that is continuous and repeated, easily accessible, adaptable and able to be personalised.¹⁶ A 2016 review of 36 diabetes education programmes assessed how closely various educational interventions followed ISPAD clinical practice guidelines.¹³ Only 14 of the 36 programmes met >50% of ISPAD education recommendations, with deficiencies noted in both programme duration and accessibility.¹³ Therefore, while there are clear recommendations for comprehensive and structured education for adolescents with T1D, most clinical programmes have not been able to develop and implement interventions to fulfil these. The failure to follow these recommendations is likely at least in part related to the lack of published feasible and effective longitudinal diabetes education models that address this need.

At the Children's Hospital of Eastern Ontario (CHEO), our previous diabetes education model involved intensive family-centred didactic sessions immediately after diagnosis and then 'ad hoc' education when areas of deficiency were identified. For adolescents who were diagnosed with diabetes during childhood, their parents would have been the focus of initial education given the child's age and developmental stage at diagnosis. As such, many adolescents were not systematically taught the self-management skills required for independent T1D management and transition to adult care, as recommended by ISPAD. Recognising this shortcoming, the CHEO Diabetes Team sought to develop a structured, longitudinal educational programme for all adolescents with T1D to support continued education following diagnosis that would align with ISPAD guidelines, with

the goal of improving adolescents' diabetes related self-efficacy—their confidence in diabetes self-management skills.

We undertook a quality improvement initiative to conceive, implement and evaluate a new educational programme, the Diabetes Learning Centre (DLC), that provides accessible, continuous and personalised diabetes education in the clinic setting. To understand our population's self-efficacy and learning needs at baseline, we also evaluated adolescents' self-reported confidence in T1D self-management skills prior to DLC participation and explored potential predictors of confidence. Here, we present this three-phase quality improvement project. In phase 1, we describe the conception and process of implementing the DLC at CHEO. In phase 2, we describe the evaluation of our population's baseline self-efficacy. In phase 3, we describe the evaluation of patient satisfaction with the programme and self-reported change in confidence related to participation in the DLC.

METHODS: PHASE 1 Needs assessment

In 2017, a CHEO Diabetes Team retreat, facilitated by our hospital quality improvement team, was held to identify areas for improvement within the T1D programme. We identified the need to better prepare adolescents for transition to adult care and the absence of a structured, longitudinal educational programme consistent with ISPAD guidelines.¹⁶ We also identified the need to address long waiting room times within our T1D clinic between check-in and face-to-face contact with the physician as an opportunistic window to provide educational programming. A multidisciplinary working group was formed with the goal of developing an educational programme to address both the transition and educational needs of our population while better capitalising on time that patients are typically waiting to be seen in clinic. The working group included a paediatric endocrinologist, two certified diabetes educators—registered nurse and registered dietitian—and a diabetes social worker.

Programme development

In the context of limited physical space, personnel and financial resources available, the working group sought to establish an educational programme that could be delivered year-round at the time of routine T1D clinic visits with multiple patients able to attend at once, while still supporting the personalised learning needs of each individual. In addition, it was observed that any delay within the T1D clinic (eg, patients arriving late, delays in uploading technology, urgent issues arising during a visit) often resulted in adolescents waiting to see the physician. The working group therefore sought to capitalise on this 'wasted' clinic time spent waiting to see the physician within our programme design.

A longitudinal educational programme, facilitated by diabetes educators and with educational materials

that could easily be individualised, was conceived by the working group and presented to the CHEO Diabetes Team to receive their input. In order to facilitate personalised learning and to support active rather than passive learning, it was decided that the DLC curriculum would be delivered through worksheets (available in both English and French) that are focused on providing information and evaluating the adolescent's understanding of key diabetes self-management topics (eg, diabetic ketoacidosis prevention, management of hypoglycaemia, insulin dose adjustments, illness management, driving with diabetes, alcohol and diabetes, travelling with diabetes, management of physical activity, carbohydrate counting). Within the DLC, the diabetes educator would act as a resource for the adolescents completing the worksheets, answering their questions, supporting completion of the worksheet as needed, and reviewing the worksheet to ensure that the material was understood. Through the support of the diabetes educator, adolescents of different ages and developmental stages would be able to learn using the same resources. As most adolescents can work independently on their worksheets, only requiring diabetes educator involvement at the completion of the worksheet to consolidate the information, this would also facilitate the attendance of more than one adolescent at a time in the DLC despite having only one supervising diabetes educator present. This model would also allow adolescents to complete worksheets on different topics during the DLC in order to meet their independent learning needs. Following approval of this education model by the CHEO Diabetes Team, and with the support of the hospital quality improvement team, clinic workflows were evaluated and a plan for integration of the DLC into routine care was created and optimised through a second CHEO Diabetes Team retreat. The plan for integration involved attendance of the DLC either while patients were waiting in the diabetes clinic to see the physician, eliminating 'wasted time' in the waiting room, or following completion of their physician visit with timing of attendance determined by clinic flow on the given day.

Curriculum and resource development

Topics for worksheets were derived from the Endocrine Society Provider Assessment of Patient Skill Set list, which includes topics that have been identified as important to review prior to an adolescent's transition to adult care.¹⁷ It was decided that each worksheet would contain background information about the specific diabetes self-management topic, followed by related short answer or multiple-choice questions to engage the adolescent and to consolidate and assess their knowledge. As tablets would be available to use in the DLC, each worksheet was complemented by additional resources that could be accessed by adolescents while in the DLC, such as handouts or website links (online supplemental file 1—Exercise and injections worksheet; online supplemental file 2—Driving and diabetes worksheet).

Each worksheet was developed by members of the working group or CHEO Diabetes Team, shared with the broader CHEO Diabetes Team for feedback, and then piloted with both English and French speaking adolescents with T1D who evaluated the worksheets for clarity as well as usefulness of the information and related questions. Each worksheet was piloted by three to five adolescents and worksheets were modified in response to their feedback. Twenty-three worksheets were created. This model allows for more worksheets addressing new topics to be added over time. The worksheet format also allows for easy transition to a virtual format.

Programme implementation

Starting in May 2019, at each routine T1D clinic visit at CHEO, patients ages 13–17 years were also scheduled to attend the DLC. The DLC was physically located in a conference room within the T1D clinic, facilitated by a diabetes educator and could be attended by up to five adolescents at a time. Each visit to the DLC lasted approximately 30 min and was attended independently by the adolescent while they were awaiting, or directly following, their physician appointment. The DLC was run on most T1D clinic days with rare closures during times of staffing absences. The DLC was run within our existing staffing and resources and facilitated by a shift in diabetes educator focus on clinic days.

The diabetes educator's role within the DLC was to support each adolescent's learning by identifying education topics, answering their questions, providing content clarification when needed and by discussing learning points with them after completion of the worksheets. This structure was chosen to foster active and personalised learning, as well as assessment of knowledge or skill at each DLC visit. The completed worksheets and answer key were provided to the adolescent at the end of each DLC visit serving as a resource for future reference.

Adolescents completed one to three worksheets per visit. Worksheet topics for each DLC session were selected based on each adolescent's learning needs as identified by the adolescent, diabetes educator or physician. A concurrent quality improvement initiative within our clinic, pretransition visits, provides formalised assessment of learning needs for adolescents around their 16th birthday. This initiative allows for systematic evaluation of knowledge and skill, and identification and documentation of topics in need of attention through the DLC for adolescents approaching transition.¹⁸ Within the T1D clinic electronic medical record (EMR), there is a customised diabetes flowsheet where identified learning needs and worksheet completion and proficiency are captured, tracked and used to help inform the focus of future DLC visits. Completion proficiency of the worksheet was rated as 'can do this alone', 'some help needed', 'lots of help needed' or 'unable to complete' within the flowsheet. Adolescents who were unable to complete a worksheet alone are encouraged to repeat the worksheet at future visits.

As a result of the COVID-19 pandemic, the programme was paused from March 2020 until March 2022 due to a change to a virtual platform for patient care and a temporary loss of clinic resources. The programme was resumed in April 2022, initially through a virtual platform, and then in-person once most of our clinics returned to in-person care.

DLC attendance

To evaluate programme feasibility, DLC attendance rates prior to the COVID-19 pandemic were assessed. DLC attendance was documented within the EMR—Epic (Epic Systems Corporation, Wisconsin). An Epic report was obtained to determine the total number of patients 13–17 years of age, who attended the DLC between 1 May 2019 and 1 February 2020, and the total number of patients between the ages of 13 and 17 years who were seen within the CHEO T1D clinic within the study dates.

METHODS: PHASE 2

Participants

All adolescents with T1D ages 13–17 years old who attended their first DLC visit at CHEO between 1 May 2019 and 1 March 2020, were approached for participation in phase 2 of the quality improvement project. 11 March 2020, marked the beginning of the pandemic related clinic changes at our centre. Adolescents were excluded if they did not speak English or French or were unable to independently participate in the DLC or complete questionnaires (eg, those with an underlying comorbidity such as severe intellectual disability). Adolescents with learning disorders were supported in the DLC by the diabetes educator and were invited to participate in this phase of the project.

Assessment design

To understand our population's current self-efficacy and learning needs and to guide ongoing programme development and improvement, we developed a questionnaire to assess participants' self-reported confidence in T1D self-management skills prior to the DLC. The New World Kirkpatrick Model,¹⁹ a framework which guides the evaluation of the effectiveness of educational programmes on four levels, was used to inform the design of the questionnaire. Specifically, we considered *Level 2: Learning*, where one seeks to measure how effectively the information of a programme was absorbed by its participants, and which can be measured by the degree to which participants acquire confidence—or self-efficacy.¹⁹ In this regard, we reviewed existing tools that have been validated for evaluation of diabetes related self-efficacy. Though none were suitable to address the specific self-management skills addressed in the DLC, these validated tools informed the development of the questionnaire.²⁰ We revised the content of the questionnaire based on feedback from a methodologist at the CHEO Research Institute. It was then piloted with adolescents within our T1D clinic and further revised for clarity and language.

The questionnaire asked participants to rate their confidence in overall diabetes management and with respect to eleven specific diabetes self-management skills (addressed in the DLC) on a 5-point Likert scale (online supplemental file 3—DLC questionnaire). The five points on the scale were: 'not at all confident', 'slightly confident', 'moderately confident', 'quite confident' and 'extremely confident'. This Likert scale was modelled after those used in other studies that have evaluated self-efficacy in patients with T1D.²⁰

To evaluate possible predictors of confidence, demographic and diagnosis-related characteristics were extracted for each participant from the EMR, including age, sex, duration of diabetes, type of insulin regimen (injection, pump), use of continuous glucose monitoring (CGM) and HbA1c. Parental involvement in diabetes management was also self-reported by participants on their questionnaire.

Data analysis

Baseline characteristics were summarised using frequency and percentage for discrete variables and median and IQR for continuous variables. For each participant, mean confidence was calculated by taking the mean of all available Likert scale values for individual diabetes self-management skills. Association of confidence with participant demographic and diagnosis-related characteristics was assessed using Spearman correlation to evaluate possible predictors of confidence. Statistical significance was defined by a two-sided p value less than 0.05. A cross-sectional census of characteristics of the adolescent T1D clinic population (ages 13–18 years) was compared with the study sample to determine whether it was representative. However, because the study sample was a subset of the adolescent T1D clinic population, standard statistical tests (which assume independence of samples) could not be applied. Instead, qualitative comparisons are drawn. All analyses were performed using R V.4.0.5.²¹

METHODS: PHASE 3

Context

Due to the COVID-19 pandemic, which resulted in a transition to virtual care and a loss of diabetes team resources, the DLC was paused from March 2020 to March 2022. It initially resumed on a virtual platform in April 2022, which limited the number of adolescents able to attend as the diabetes educator could support only one adolescent at a time virtually, before returning to the group in-person model described above in February 2023. To evaluate the DLC following this pause in delivery, phase three involved a patient survey administered following each DLC visit from April 2022 until June 2023.

Participants

All adolescents in the T1D clinic ages 16–18 years were invited to participate in the DLC from April 2022 to June 2023, including completion of patient surveys as part of phase 3 of the quality improvement study. The

age group was limited to 16–18 years due to a loss of diabetes resources that persisted beyond the pandemic, with a plan to gradually extend the programme to again include younger adolescents as resources returned to baseline.

Assessment design

Prior to DLC initiation, the New World Kirkpatrick Model¹⁹ was used to design a longitudinal survey to evaluate the DLC at *Level 2: Learning*—change in confidence (as described in phase 2 above)—and *Level 1: Reaction*—the degree to which participants are satisfied with a programme. The original plan (prior to the COVID-19 pandemic), was to assess change in confidence by asking participants to rate their confidence in diabetes self-management skills after 1, 2 and 3 years of DLC participation using the 5-point Likert scale from the baseline questionnaire, while participant satisfaction would be evaluated on a 5-point Likert scale on each annual survey. However, to account for the 2-year pause in the DLC programme, the survey was modified during phase 3 to be administered at the end of each DLC visit and to specifically ask about change in confidence in the self-management skill(s) addressed by the worksheets completed during that visit. To describe the population, self-reported demographic and diagnosis-related characteristics were also collected through the survey for each participant including age, sex, type of insulin regimen (injection, pump), use of CGM, HbA1c and glucose management indicator (GMI). The modified survey was piloted with two patients prior to implementation (online supplemental file 4—DLC follow-up survey).

The survey was administered to all adolescents attending the DLC at the end of their visit through REDCap (Vanderbilt University, Tennessee). The diabetes educator provided the adolescents with their diabetes data including HbA1c and GMI to facilitate survey completion. Attendance of the DLC was documented in the EMR—Epic. An Epic report was obtained to determine the number of attended DLC visits from April 2022 to June 2023.

Data analysis

Participant characteristics were summarised using frequency and percentage for categorical variables and median with IQR for continuous variables. Worksheets completed, patient satisfaction and patient confidence in each topic for which they completed a worksheet were summarised using frequency and percentage.

Patient involvement

Patients were involved in all phases of the study. In phase 1, patients were asked to pilot the worksheets used in the DLC and to provide feedback on their clarity and relevance. In phases 2 and 3, patients piloted and provided feedback on the clarity of the questionnaires.

RESULTS

Phase 1

DLC attendance

Two hundred and eighty-eight adolescents between the ages of 13 and 17 years were seen in the T1D clinic from May 2019 to February 2020. Of those, 232 (80.5%) adolescents completed a first DLC visit.

Twenty per cent of eligible adolescents did not attend the DLC during the study period. All adolescents who were eligible for the DLC were also eligible for concurrent mental health screening and a proportion were eligible for transition preparation programming, both of which would have taken place in lieu of the DLC, impacting DLC attendance. The specific proportion of potential attendees impacted by this was not measured.

Phase 2

Participant characteristics

Of the 232 eligible adolescents, 216 (93.1%) consented to participate in phase 2 of the quality improvement project, with 215 (92.7%) included in the study due to one unusable questionnaire. **Table 1** describes the demographic and diagnosis-related characteristics of our cohort.

Table 2 shows that the study sample is similar to the cross-sectional census of the adolescent T1D clinic population (all patients 13–18 years). Small differences are apparent in the distribution of age, insulin regimen and use of CGM (statistical comparison not performed due to non-independence of samples).

Confidence in self-management skills

Median overall confidence in diabetes management on a 5-point (0–4) Likert scale was 3, representing ‘quite confident’. This was moderately correlated with mean ratings of individual diabetes self-management skills ($r=0.54$, $p<0.001$). The majority of participants reported being ‘quite confident’ in most individual self-management skills. For ‘treating a low blood sugar’, ‘counting carbohydrates in a meal or snack’ and ‘driving safely with diabetes’ (participants 16 years and older), the majority of participants reported being ‘extremely confident’ whereas the majority of participants reported being ‘not at all confident’ with ‘managing diabetes safely if drinking alcohol’ and ‘using mini dose glucagon’ (**figure 1**).

Predictors of confidence

The correlation of patient characteristics with confidence was evaluated to determine any possible predictors of confidence. Higher confidence in overall diabetes management was weakly associated with lower HbA1c (Spearman’s correlation coefficient -0.25 ; $p<0.001$) (**table 1**). Confidence in overall diabetes management was not significantly associated with other patient characteristics.

Phase 3

Participant characteristics and DLC attendance

Between April 2022 and June 2023, 84 completed DLC visits were reported in Epic and 91 surveys were

**Table 1** Participant characteristics and association with overall confidence

Participant characteristics	Number (per cent) or median (IQR)	Spearman correlation with overall confidence
Sex		0.06 (p=0.42)
Female	97 (45.1%)	
Age (years)	14.9 (13.9, 15.9)	0.00 (p=0.98)
Duration of diabetes (years)	5.8 (2.9, 8.9)	-0.07 (p=0.32)
Insulin regimen		0.00 (p=1.00)
Injection	105 (48.8%)	
Pump	110 (51.2%)	
CGM		0.12 (p=0.09)
Yes	112 (52.1%)	
No	103 (47.9%)	
Parental involvement	4 (1.9%)	-0.07 (p=0.28)
Never	25 (11.6%)	
Rarely	59 (27.4%)	
Sometimes	77 (35.8%)	
Very often	47 (21.9%)	
Always		
HbA1c (%)	7.9 (7.1, 8.8)	-0.25 (p<0.001)

Characteristics of study participants and association with overall confidence in diabetes self-management skills. n=215. CGM, continuous glucose monitoring; HbA1c, haemoglobin A1c.

completed. There were seven surveys completed for visits not documented in Epic. Forty-two (46%) visits occurred virtually and 49 (54%) visits occurred in-person. Thirty-five (38.5%) participants had attended 1 DLC visit, 21 (23.1%) attended 2 visits, 27 (29.7%) attended 3 or more times and 8 (8.8%) did not respond to the question. Forty-one (45.1%) were female, median age 16.0 years (16.0, 17.0), 51 (56.0%) used insulin pumps, 81 (89.0%) used CGM, median HbA1c 7.1% (6.5, 8.1) and median GMI 7.3% (6.5, 8.1). HbA1c data were available for 50 (54.9%) participants and GMI for 56 (61.5%) participants.

Worksheets completed

Adolescents completed a mean of 1.57 worksheets at each visit. The most frequently completed worksheet was 'driving safely with diabetes', completed by 30 (33.0%) adolescents. The second and third most frequently completed worksheets were 'going to university/college with diabetes', completed by 18 (19.8%) adolescents, and 'managing diabetes safely if drinking alcohol' and 'managing physical activity with diabetes', both completed by 13 (14.3%) adolescents.

Confidence in self-management skills

A total of 130 worksheets were completed by participants. When asked to report on change in confidence for the self-management skill addressed by the worksheet, 106 (81.5%) responses demonstrated improvement in confidence—60 (46.2%) 'a bit more confident' and 46 (35.4%) 'a lot more confident'. Twenty-four (18.5%) responses

indicated no change in confidence and no worksheets were associated with a decrease in confidence. **Figure 2** shows self-reported change in confidence for each self-management skill.

Patient satisfaction

Seventy-seven (84.6%) adolescents reported being quite or extremely satisfied with their DLC visit and only 1 (1.1%) was 'not at all satisfied' (**table 3**). Sixty-four (70.3%) adolescents reported being quite or extremely satisfied with their DLC worksheets and no adolescents were 'not at all satisfied' (**table 3**).

DISCUSSION

We describe the conception, implementation and evaluation of a longitudinal educational programme for adolescents with T1D designed to improve self-efficacy and to meet international clinical practice guidelines for diabetes education. To our knowledge, this is the first educational programme described in the literature that involves structured and individualised learning throughout adolescence as part of routine diabetes care. Given the clear need to support transition readiness for adolescents with T1D and a lack of recommendations around how to facilitate their longitudinal learning, we have presented our programme structure as an example of an educational programme that requires minimal resources to implement and that uses existing checklists for transition readiness as a first step to knowledge translation. We have also demonstrated the feasibility of the programme within our

Table 2 Comparison of study population and overall T1D clinic adolescent population

Variable	Study population (n=215)	T1D clinic population (n=386)
Age (years)		
Median (IQR)	14.9 (13.9, 15.9)	15.0 (14.0, 17.0)
Mean (SD)	15.0 (1.2)	15.2 (1.4)
Missing	0	0
Gender, n (%)		
Male	118 (54.9)	207 (53.6%)
Female	97 (45.1)	179 (46.4%)
Missing	0	0
Duration of diabetes (years)		
Median (IQR)	5.8 (2.9, 8.9)	5.8 (2.8, 9.3)
Mean (SD)	6.1 (3.9)	6.3 (4.2)
Missing	0	9
HbA1c (%)		
Median (IQR)	7.9 (7.1, 8.8)	7.9 (7.0, 9.0)
Mean (SD)	8.1 (1.6)	8.2 (1.7)
Missing	0	18
Insulin regimen, n (%)		
Injection	105 (48.8)	206 (53.5)
Pump	110 (51.2)	179 (46.5)
Missing	0	1
CGM, n (%)		
Missing	0	31
Characteristics of study participants and a cross-sectional census of the adolescent T1D clinic population. CGM, continuous glucose monitoring; HbA1c, haemoglobin A1c.		

T1D clinic. The programme was implemented within our existing resources and staffing and through the outcome of attendance rates during phase 2, we demonstrated high patient engagement during the study period. Finally, while our programme and its evaluation were disrupted by the pandemic, we were able to resume the DLC in April 2022 and in phase 3 we demonstrated high rates of patient satisfaction and of patient reported improvement in diabetes related confidence.

In the second phase of our study, we sought to understand our population's learning needs. Our evaluation demonstrated that prior to implementation of the DLC, adolescents' median overall confidence in diabetes management on a Likert scale (0–4) was 3, representing 'quite confident'. This correlated with the mean confidence rating of the individual self-management skills for each adolescent, such that adolescents who reported higher overall confidence in diabetes self-management also reported themselves to be more confident in

individual self-management skills. This is consistent with the diabetes self-efficacy literature with Iannotti and colleagues previously having demonstrated high correlation between individual items on a self-efficacy rating instrument as well as between scores on the self-efficacy instrument and overall diabetes self-management.²² The finding of fairly high overall diabetes management self-efficacy is also in keeping with previous literature.^{22–24}

While it is possible that confidence level is reflective of actual knowledge, it is also possible that participants do not recognise their own knowledge gaps. Importantly, nearly 60% of adolescents reported that their parents were 'very often' or 'always involved' with their diabetes, suggesting that many of the adolescents have not yet had to test their knowledge or skill through independent management of their diabetes.

Despite the overall higher confidence in diabetes related management, 'managing diabetes safely if drinking alcohol' and 'using mini dose glucagon' were identified as areas of low confidence. Additionally, 'making insulin dose adjustments' and 'managing ketones', two essential diabetes related skills, were identified as areas of low or moderate confidence for many adolescents. This demonstrates the importance and necessity of a structured longitudinal educational programme, such as the DLC, to fill these educational gaps and give adolescents the opportunity to self-identify and address areas of low confidence. Despite participants reporting that they were 'quite confident' in their overall diabetes related skills, there remains room for improvement, with previous studies generally demonstrating poor metabolic outcomes in adolescent and transitioning T1D populations.^{4 5 25} Phase 3 of our study supports this, with adolescents reporting improved confidence in diabetes self-management skills addressed within the DLC despite their high baseline confidence.

We also assessed the relationship between several patient characteristics and confidence to evaluate for any possible predictors of confidence in diabetes management and found that only lower HbA1c was weakly associated with higher overall confidence. This is consistent with previous studies that have shown an association between confidence in self-management skills and better glycaemic control.^{9 22 26 27} This may be mediated by improved adherence as several studies have demonstrated an association between greater self-efficacy and better adherence to diabetes management.^{8–10 22 27} Additionally, the lack of association of confidence with other characteristics is in keeping with the literature which reports variable associations of self-efficacy with age, duration of diabetes, sex and insulin regimen.^{23 24 28 29} Altogether, given that no patient characteristics except HbA1c were associated with confidence in diabetes management (and as this association was weak), this supports providing diabetes education via the DLC to all adolescents within the clinic as they could all possibly benefit.

Interestingly, the median HbA1c and GMI for participants in phase three was lower than the HbA1c at baseline in phase 2. Given that this information was self-reported

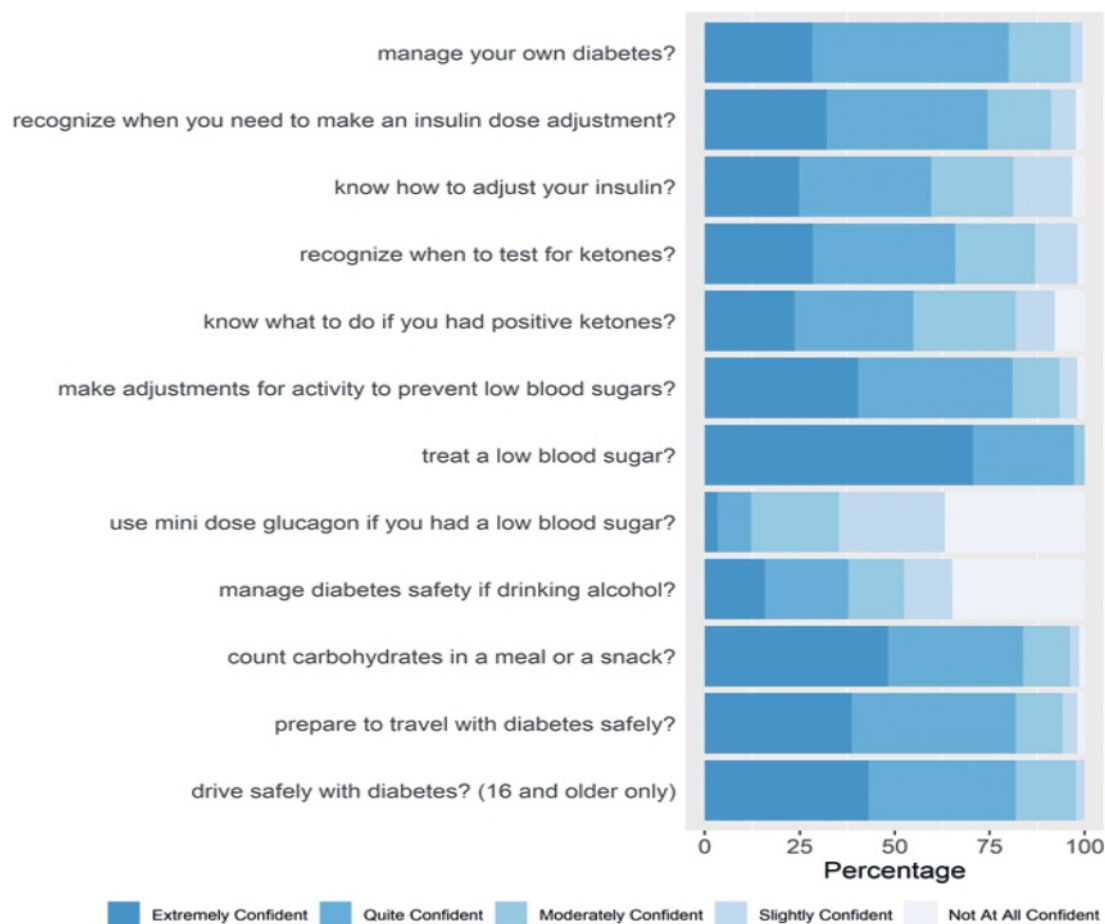


Figure 1 Confidence in diabetes related skills. Likert responses to ‘How confident are you in your ability to ...’. Response rate for mini dose glucagon 95%, managing diabetes safely if drinking alcohol 76% and driving safely with diabetes 20% of the total study population. Response rate for all other skills 97%–100%.

(though supported by a diabetes educator for accuracy), this might reflect biased reporting with individuals with better glycaemic control being more likely to report their glycaemic data. This may also reflect the period of time where DLC visits were conducted virtually as in contrast to high attendance rates using an in-person platform, there were many patients who would not attend their virtual DLC visits. Those who did attend may have been more likely to be engaged in their diabetes management which might contribute to better glycaemic control.

A limitation of our evaluation of DLC feasibility in phase 1 was the fact that we did not capture statistics about reasons for not attending the DLC among the 19.5% of eligible patients that did not attend. However, while specific data were not collected, we know that a proportion did not attend because they were completing concurrent age-related programming in lieu of the DLC, with a smaller proportion attributed to missed diabetes clinic visits and to occasional DLC closures rather than patients choosing not to participate. Furthermore, given that the study was designed to look at long-term impact, adolescents between the ages of 17 and 18 years of age were not included in phases 1 and 2; however, when compared with our entire adolescent T1D population (13–18 years),

our study population was similar. An additional limitation of the evaluation of the feasibility of the DLC was the single outcome measure of programme attendance used, though as outlined above, the implementation without additional resources or staffing also supports the feasibility of the DLC.

The DLC programming and evaluation was interrupted due to the COVID-19 pandemic, which was associated with staffing changes and a shift to virtual care. This setback affected the delivery of the DLC and weakened our ability to show long-term sustainability and impact of the educational programme. However, over the 9-month study period in phase 2, we were able to demonstrate both evidence of clear learning gaps prior to programme implementation, supporting the need for an individualised learning programme, and successful implementation of such a programme, with participation from the majority of our adolescent patients. Additionally, with some modifications, the DLC structure was amenable to delivery via a virtual platform before in-person care resumed at our centre, highlighting programme versatility and adaptability. However, should there be a need to provide the DLC on a virtual platform in the future, more work would need to be done to determine if improvements could be

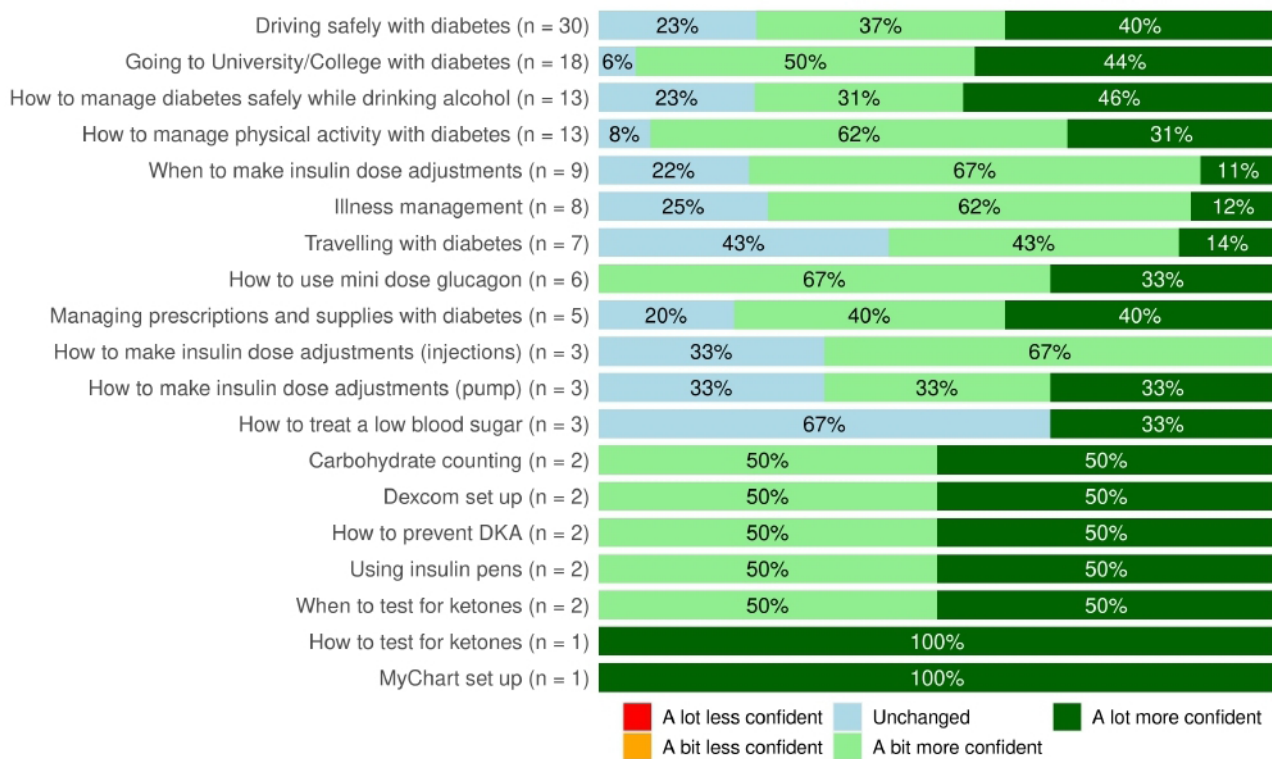


Figure 2 Change in self-reported confidence in diabetes self-management skills by worksheet. Likert responses to ‘After completing the worksheet, how has your confidence in the topic/skill changed?’. n=number of worksheets completed.

made to allow for multiple adolescents to attend and be supported by a single diabetes educator at the same time. Similarly, we observed that virtual DLC visits—which needed to be scheduled separately from routine clinic appointments—were frequently not attended, and so we would aim for the visits to be integrated with physician visits given the higher rates of attendance with the in-person platform when adolescents attend the DLC during their routine clinic visit. Despite losing diabetes educator resources within our clinic in phase 3, we were able to continue to provide the programme to adolescents who were approaching transition to adult care. Moreover, though the longitudinal evaluation of the DLC was impacted by the COVID-19 pandemic, with resumption of the programme in April 2022, we were able to demonstrate high patient satisfaction with the DLC and the associated worksheets in phase 3 of our study, supporting the continued use of this model for patient education. We also demonstrated that most adolescents

reported improved confidence in self-management skills addressed within the DLC, supporting the programme as a useful tool for learning.

Strengths of the second phase of our study include our relatively large sample size and high participation rate, allowing for outcomes that are generalisable to our overall adolescent T1D population. While 19.5% of eligible adolescents did not attend the DLC during the study period, we were able to demonstrate that our study population is representative of our total adolescent patient population and therefore would not anticipate our results would change should those additional adolescents be included. Additionally, by designing our own questionnaire, we were able to directly assess confidence in essential self-management skills specifically addressed within our educational model, some of which are not included on previously validated self-efficacy surveys such as the Self-Efficacy for Diabetes Scale³⁰ and Self-Efficacy for Diabetes Self-Management tool.²² A limitation of the

Table 3 Patient satisfaction

	Degree of satisfaction				
	Extremely satisfied	Quite satisfied	Moderately satisfied	Slightly satisfied	Not at all satisfied
DLC visit	27 (29.7%)	50 (54.9%)	10 (11.0%)	0 (0%)	1 (1.1%)
DLC worksheets	15 (16.5%)	49 (53.8%)	14 (15.4%)	0 (0%)	0 (0%)

Patient satisfaction with the DLC visit and the DLC worksheets. Likert responses to ‘How satisfied are you with ...’. n=91. DLC visit data not available for three participants and DLC worksheet data not available for 13 participants.
 DLC, Diabetes Learning Centre.

second phase of our study includes the lack of evaluation of adherence to diabetes regimen which may have had an impact on the association between HbA1c and confidence. However, at least one previous study has shown that both self-efficacy and adherence to diabetes management are each independently associated with HbA1c.²⁷ Moreover, it has been suggested that self-efficacy is in fact mediating the relationship between adherence and metabolic control—in which case an independent assessment of adherence would be unnecessary.⁹

A strength of phase 3 of our study is the evaluation of factors directly relevant to our patient population when considering the efficacy of the DLC, including patient satisfaction and self-reported change in confidence. This evaluation demonstrated high patient satisfaction with the DLC, with patient satisfaction increasingly being recognised as an essential component of effective clinical interventions.³¹ It also demonstrated high levels of self-reported change in confidence, over 80% across all worksheets. Interestingly, only the ‘treating a low blood sugar’ worksheet was associated with less than 50% improvement in confidence. However, in phase 2, the majority of patients reported feeling ‘extremely confident’ at baseline for this skill. As such, the lack of improvement may be related to the high baseline confidence. Limitations of phase 3 are as follows. First, our data for clinic attendance depended on documentation within our EMR; there were seven more surveys completed than reported DLC visits suggesting over 100% survey completion rate. This discrepancy can be explained by missed documentation of DLC attendance within the EMR. Given that documentation of the DLC is part of our routine workflow, we are confident that the majority of DLC visits were captured and, as such, survey completion rate was at or close to 100%. Another limitation is that the entire phase 2 population was not included in the programme evaluation as this was conducted after a pause in the DLC due to the pandemic. However, given the surveyed participants’ ages and because at least 48 (53%) of adolescents attended the DLC more than once, this suggests that many of the adolescents who participated in phase 3 would have attended the DLC prepandemic as part of the original phase 2 cohort. An additional limitation is that only adolescents ages 16–18 years were included in phase 3 due to limited resources. However, we were still able to highlight that this educational model is acceptable to patients and positively impacted confidence in diabetes self-management skills. Moreover, the plan is to extend the programme to include all patients 13 years and older when resources return to their pre-pandemic baseline, allowing an opportunity to evaluate the impact in this younger cohort. During phase 3, change in confidence was only assessed immediately following worksheet completion. Moving forward, it would be important to see if the improvement in confidence was sustained over time. Finally, given the pandemic related pause in DLC delivery, we were unable to comment on its impact on clinical markers such as metabolic control.

CONCLUSION

We present a longitudinal educational programme for adolescents with T1D that integrates diabetes education into routine care and strives to meet international clinical practice guidelines for structured, continuous, personalised, accessible and adaptable diabetes education.¹⁶ We demonstrate high rates of patient satisfaction and self-reported improvements in confidence in diabetes self-management skills addressed within the programme, suggesting that over time, this programme will help to bridge gaps in knowledge in areas important for independent diabetes management, and to improve adolescents’ self-efficacy, which is associated with better adherence and glycaemic control.

Twitter Marie-Eve Robinson @CHEOSTRONG

Acknowledgements We would like to thank Alicia Klaassen and Brittany Bosse for their support as research assistants, Kaylee Eady, PhD, for support with methodology while developing our research protocol, Ewa Sucha, MSc, for her support with statistical analysis, the CHEO Research Institute’s Students Undertaking a Paediatric Programme of Research Training (SUPPORT) Programme for study recruitment, Ontario Ministry of Health and Long-Term Care for Late Career Nursing award that allowed for nursing time to create resources for the Diabetes Learning Centre, and the adolescents in the Children’s Hospital of Eastern Ontario diabetes clinic who participated in this quality improvement initiative.

Contributors KLP designed the study with AA, led the data acquisition, drafted the initial manuscript, interpreted the data, revised the manuscript and produced the final version of the manuscript with AA. JC contributed to development of the study protocol, revised the manuscript and approved the final version for publication. NB led the data analysis, revised the manuscript and approved the final version for publication. SZ led data acquisition along with KLP, revised the manuscript and approved the final version for publication. CR and LS contributed to development of the study protocol, led participant recruitment, contributed to data acquisition, revised the manuscript and approved the final version for publication. EBG, SEL, CZ and MLL provided input into the implementation of the Diabetes Learning Centre (DLC), revised the manuscript and approved the final version for publication. M-ER and SD revised the manuscript and approved the final version for publication. AA led the development and implementation of the DLC with CR and LS, with input from the Children’s Hospital of Eastern Ontario Diabetes Team, designed the study with KLP, interpreted the data, revised the manuscript critically for important intellectual content and produced the final version of the manuscript with KLP. AA is the guarantor and accepts full responsibility for the work performed throughout the study, had access to the data and controlled the decision to publish.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests The authors declare the following financial interests/personal relationships which may be considered as competing interests: M-ER: Ascendis Biopharma and Ipsen Biopharmaceuticals study grants to institution, and Ultragenyx and Ipsen Biopharmaceuticals consultancy fees to institution. SEL and CZ: Tandem Diabetes Care study grant to institution. MLL, EBG and CZ: Medtronic study grant to institution. EBG is a member (current Chair) of the Epic International Specialty Steering Board for Pediatric Endocrinology - this is an unpaid, elected (by peers) position.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Ethics approval The protocol for both phases 2 and 3 was submitted to the CHEO Research Ethics Board for review and was exempted as a quality improvement project.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request.

Supplemental material This content has been supplied by the author(s). It has not been vetted by BMJ Publishing Group Limited (BMJ) and may not have been

peer-reviewed. Any opinions or recommendations discussed are solely those of the author(s) and are not endorsed by BMJ. BMJ disclaims all liability and responsibility arising from any reliance placed on the content. Where the content includes any translated material, BMJ does not warrant the accuracy and reliability of the translations (including but not limited to local regulations, clinical guidelines, terminology, drug names and drug dosages), and is not responsible for any error and/or omissions arising from translation and adaptation or otherwise.

Open access This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>.

ORCID iDs

Kristina Loreta Pabedinskas <http://orcid.org/0000-0003-4413-9066>

Ellen B Goldbloom <http://orcid.org/0000-0002-6582-2924>

Margaret L Lawson <http://orcid.org/0000-0002-2370-9552>

Alexandra Ahmet <http://orcid.org/0000-0002-3226-8322>

REFERENCES

- Diabetes Canada Clinical Practice Guidelines Expert Committee. Diabetes Canada 2018 clinical practice guidelines for the prevention and management of diabetes in Canada. *Can J Diabetes* 2018;42(Suppl 1):1-325.
- Rankin D, Harden J, Barnard K, *et al*. Barriers and Facilitators to taking on diabetes self-management tasks in pre-adolescent children with type 1 diabetes: a qualitative study. *BMC Endocr Disord* 2018;18:71.
- Rosolowsky E, Yaskina M, Couch R. Pediatric type 1 diabetes: patients' and Caregivers' perceptions of Glycemic control. *Can J Diabetes* 2018;42:302-7.
- Lotstein DS, Seid M, Klingensmith G, *et al*. Transition from pediatric to adult care for youth diagnosed with type 1 diabetes in adolescence. *Pediatrics* 2013;131:e1062-70.
- Clements MA, Foster NC, Maahs DM, *et al*. Hemoglobin A1C (HbA1C) changes over time among adolescent and young adult participants in the T1D exchange clinic Registry. *Pediatr Diabetes* 2016;17:327-36.
- Cameron FJ, Garvey K, Hood KK, *et al*. ISPAD clinical practice consensus guidelines 2018: diabetes in adolescence. *Pediatr Diabetes* 2018;19 Suppl 27(Suppl 27):250-61.
- Westen SC, Warrnick JL, Albanese-O'Neill A, *et al*. Objectively measured adherence in adolescents with type 1 diabetes on multiple daily injections and insulin pump therapy. *J Pediatr Psychol* 2019;44:21-31.
- Du Pasquier-Fediaevsky L, Tubiana-Rufi N. Discordance between physician and adolescent assessments of adherence to treatment: influence of HbA1C level. *Diabetes Care* 1999;22:1445-9.
- Griva K, Myers LB, Newman S. Illness perceptions and self efficacy beliefs in adolescents and young adults with insulin dependent diabetes mellitus. *Psychology & Health* 2000;15:733-50.
- Littlefield CH, Craven JL, Rodin GM, *et al*. Relationship of self-efficacy and Bingeing to adherence to diabetes regimen among adolescents. *Diabetes Care* 1992;15:90-4.
- Aalto AM, Uutela A, Aro AR. Health related quality of life among insulin-dependent diabetics: disease-related and Psychosocial correlates. *Patient Educ Couns* 1997;30:215-25.
- Hampson SE, Skinner TC, Hart J, *et al*. Effects of educational and Psychosocial interventions for adolescents with diabetes mellitus: a systematic review. *Health Technol Assess* 2001;5:1-79.
- Colson S, Côté J, Gentile S, *et al*. An integrative review of the quality and outcomes of diabetes education programs for children and adolescents. *Diabetes Educ* 2016;42:549-84.
- Mercuri N, Caporale J, Moreno I, *et al*. Changes induced by recreational and educational activities in children with diabetes. *Diabetes Spectr* 2009;22:231-7.
- Johnson B, Norman P, Sanders T, *et al*. Working with insulin, Carbohydrates, Ketones and exercise to manage diabetes (WICKED): evaluation of a self-management course for young people with type 1 diabetes. *Diabet Med* 2019;36:1460-7.
- Phelan H, Lange K, Cengiz E, *et al*. ISPAD clinical practice consensus guidelines 2018: diabetes education in children and adolescents. *Pediatr Diabetes* 2018;19 Suppl 27(Suppl 27):75-83.
- Endocrine Society. Transitions of care: type 1 diabetes. 2019. Available: <https://www.endocrine.org/improving-practice/transitions/t1d> [Accessed 14 Oct 2022].
- Marr A, Tsampalieros A, Courtney J, *et al*. Patient and family perspectives of a pre-transition visit in a Paediatric tertiary care diabetes clinic. *BMJ Open Qual* 2022;11:e001563.
- Kirkpatrick J, Kirkpatrick W. *Kirkpatrick's four levels of training evaluation*. Alexandria: ATD Press, 2016.
- Rasbach L, Jenkins C, Laffel L. An integrative review of self-efficacy measurement instruments in youth with type 1 diabetes. *Diabetes Educ* 2015;41:43-58.
- R Core. R: a language and environment for statistical computing. Vienna, Austria: R Foundation for Statistical Computing, 2021. Available: <https://www.R-project.org/>
- Iannotti RJ, Schneider S, Nansel TR, *et al*. Self-efficacy, outcome expectations, and diabetes self-management in adolescents with type 1 diabetes. *J Dev Behav Pediatr* 2006;27:98-105.
- Winsett RP, Stender SR, Gower G, *et al*. Adolescent self-efficacy and resilience in participants attending a diabetes camp. *Pediatr Nurs* 2010;36:293-6.
- Ott J, Greening L, Palardy N, *et al*. Self-efficacy as a mediator variable for adolescents' adherence to treatment for insulin-dependent diabetes mellitus. *Children's Health Care* 2000;29:47-63.
- Wood JR, Miller KM, Maahs DM, *et al*. Most youth with type 1 diabetes in the T1D exchange clinic Registry do not meet American diabetes Association or international society for pediatric and adolescent diabetes clinical guidelines. *Diabetes Care* 2013;36:2035-7.
- Grey M, Boland EA, Davidson M, *et al*. Short-term effects of coping skills training as adjunct to intensive therapy in adolescents. *Diabetes Care* 1998;21:902-8.
- Hughes AE, Berg CA, Wiebe DJ. Emotional processing and self-control in adolescents with type 1 diabetes. *J Pediatr Psychol* 2012;37:925-34.
- Battaglia MR, Alemzadeh R, Katte H, *et al*. Brief report: disordered eating and Psychosocial factors in adolescent females with type 1 diabetes mellitus. *J Pediatr Psychol* 2006;31:552-6.
- Chih A-H, Jan C-F, Shu S-G, *et al*. Self-efficacy affects blood sugar control among adolescents with type I diabetes mellitus. *J Formos Med Assoc* 2010;109:503-10.
- Grossman HY, Brink S, Hauser ST. Self-efficacy in adolescent girls and boys with insulin-dependent diabetes mellitus. *Diabetes Care* 1987;10:324-9.
- Doyle C, Lennox L, Bell D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open* 2013;3:e001570.