


Designing and implementing an outpatient management pathway for patients with newly diagnosed insulin-dependent diabetes mellitus

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Summary

Objective: Recently, our team transitioned to an outpatient diabetes education model for patients with newly diagnosed insulin-dependent diabetes mellitus (IDDM) after concerns arose regarding inconsistent education provided in the hospital, as well as additional emotional stress attributed to hospitalization. To optimize this model, an improvement initiative was implemented to redesign the outpatient care processes, refine patient education content and identify ideal educational strategies. Specific aims were to (a) achieve family self-management, (b) reduce stress and (c) ensure family and provider satisfaction with the outpatient pathway.

Research design and methods: Using a multidisciplinary team and formal quality improvement (QI) methods, we redesigned content and format of the pathway based on results from key measures and Plan-Do-Study-Act (PDSA) cycles. Primary outcome measures included self-efficacy, stress and satisfaction.

Results: We achieved our goal self-management skills, while maintaining high satisfaction for patients and providers throughout the implementation and refinement of the pathway. Key pathway components include refined education content, interactive educational tools and close collaboration with social work. Multiple PDSA cycles and pathway modifications were completed, including early social work involvement and simplification of education resources; however, we found modifying the stress experienced by parents to be a challenge. The majority of the stress relates to factors that are difficult to modify, specifically emotional burden and interpersonal distress, and is rarely attributed to regimen- or physician-related distress.

Conclusion: During the transition to an outpatient pathway, we achieved our satisfaction and self-management goals but were unsuccessful in achieving our goals for minimizing stress associated with a new diagnosis of a chronic illness.

KEYWORDS

ambulatory care facilities, education, psychological stress, type 1 diabetes mellitus

1 | INTRODUCTION

Type 1 diabetes mellitus (T1DM) is one of the most common chronic illnesses in childhood. At the time of diagnosis, a significant amount of education is needed to equip children and their parents with the knowledge and skills necessary for managing diabetes. Historically paediatric patients with newly diagnosed T1DM have been hospitalized to receive this education, and prior to discharge, the family was required to demonstrate the ability to check blood sugars, give insulin and know what to do in the case of hypoglycaemia or hyperglycaemia.

In our setting, the floor nurse assigned to the child with newly diagnosed diabetes typically provided this critical education at the bedside. We observed that education content and format were not always consistent from nurse to nurse and often required re-education at the follow-up outpatient visits. In addition, we noted significant family and patient emotional and psychological stress associated with the hospitalization process itself. As a result, we evaluated our approach to teaching diabetes management skills in the inpatient setting and determined that we needed to make improvements to enhance the quality of our programme.

Reports in the literature from institutions that transitioned their paediatric T1DM management education programme to the outpatient setting identified that outpatient education programmes are as effective as inpatient education programmes at preventing short-term diabetes-related problems, as well as promoting knowledge, family functioning and quality of life for children and their families.¹ In addition, these institutions found no differences in long-term glycaemic control and studies suggest that the outpatient model may empower patient autonomy and lead to faster transition to insulin pump therapy for diabetes management.^{2,3}

Given the literature support for the overall safety of an outpatient education model for patients with newly diagnosed T1DM, and our desire to reduce variation and avoid unnecessary hospitalization and psychological stress, we implemented an improvement initiative on November 1, 2016. Our target population was comprised of patients with newly diagnosed T1DM ages 3 and older who presented without diabetic ketoacidosis or nausea/vomiting. Eligible patients had no communication barriers that would impede outpatient education, no behavioural issues that would make outpatient diabetes education difficult and no transportation issues that would preclude a family from making it to their scheduled appointment.

Our overall initiative aim was to develop, implement and refine an effective and safe outpatient diabetes management pathway to standardize learning content, promote self-management and reduce the emotional impact of a new chronic illness diagnosis in the first 6 weeks after diagnosis. Specifically, within 6 weeks of diagnosis, we aimed to have 100% of parents with Maternal Self-Efficacy for Diabetes Management Scale (MSED) scores >40, Perceived Stress Scale (PSS) scores of <15, and report being at least "satisfied" with the outpatient curriculum.

2 | METHODS

A multidisciplinary team was formed consisting of a certified diabetes educator (CDE)/nurse coordinator, a CDE/registered dietitian, a diabetes social worker, paediatric endocrinologists, parents of children with newly diagnosed T1DM and a quality improvement (QI) consultant. To optimize the outpatient diabetes education process and meet our aims, we utilized QI methods and tools to develop the initial education content and format, design and redesign outpatient care processes to execute the pathway, refine patient education content and identify ideal educational strategies, techniques and timing.

Phase 1 focused on designing the initial education curriculum content and format. Content for the 3-day outpatient diabetes education pathway, including criteria for eligible patients, was adapted from the existing curriculum provided in both the inpatient and the outpatient settings at the University of North Carolina Children's Hospital. The sequence for outpatient content was divided based on information urgency. Day 1 focused on practical skills and nutrition and occurred within 1-2 days of the diagnosis of T1DM. Skills addressed included practicing and demonstrating blood sugar checks and insulin injection, and practicing both glucagon administration and urine ketone checks. During the nutrition section, hands-on food models, food labels and portion-controlled plates/bowls aided learning about carbohydrate counting. Day 2, occurring within 3-4 days of Day 1, focused on practical skills such as using phone/tablet applications for advanced diabetes management. Day 3, coordinated with the 6-weeks follow-up visit with the endocrinologist, involved parent and adolescent patient goal development.

The format for the education consisted of individual patient and family sessions provided by a CDE in the paediatric diabetes outpatient clinic. Coordinating multiple education days required frequent communication between the on-call physicians, educators and scheduling staff. At the first visit, the family received a binder with all of the education material, as well as relevant contact information for their diabetes providers.

Phase 2 focused on the implementation, study and revision of the education pathway and related care delivery processes. Using formal QI methods and tools, and informed by quantitative and qualitative data, we conducted multiple Plan-Do-Study-Act (PDSA) cycles to optimize the content and format of the pathway and redesign care processes to accomplish the pathway recommendations. Integral to the PDSA cycles was the patient and family input into the pathway curriculum content and format. In addition to educational content, we refined our processes for key aspects of care including knowledge attainment and self-management skills.

The outcome measures selected for this initiative included self-efficacy scores, stress scores and patient-family satisfaction. To assess these outcomes, one parent and any adolescent patient 14 years or older completed a survey at the 6 weeks post-diagnosis appointment. This survey included the Perceived Stress Scale (PSS, 10 questions) for parents and adolescents, Self-Efficacy for Diabetes Self-Management (SEDM, 10 questions) for adolescents, Maternal

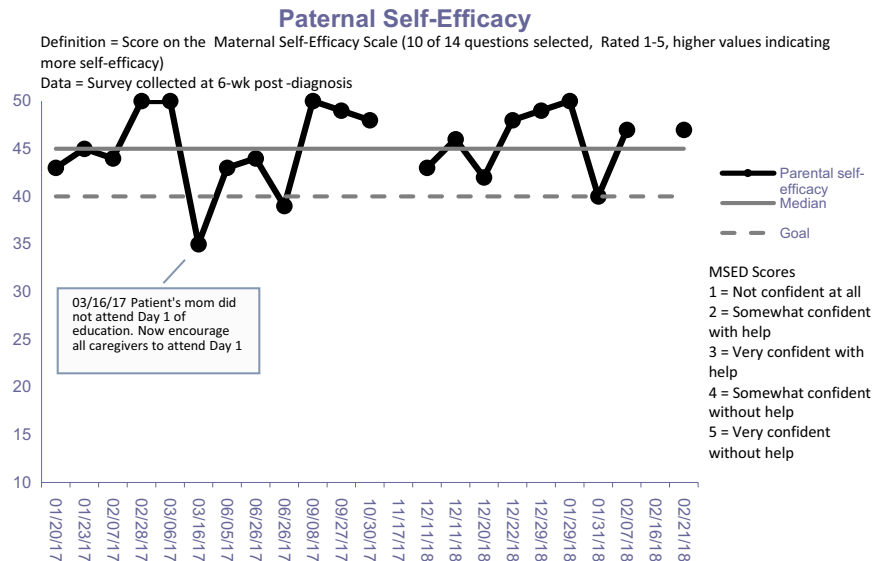


FIGURE 1 Parental self-efficacy

Self-Efficacy for Diabetes Management Scale (MSED, 10 questions) for parents and a question about the overall satisfaction of the outpatient diabetes education curriculum. Four questions from the MSED were not included, as our team felt they focused on skills that are not critical to master in the first 6 weeks after diagnosis. The parent and adolescent scores were recorded separately, and parental responses ultimately became the primary outcome monitored, given the infrequent rate of diagnosis of T1DM in adolescents 14 and older.

To assess adoption of key processes, we measured self-management goals, the presence of a school plan and meetings with our dietitian and diabetes social worker. School absences, unplanned readmissions and ED visits were monitored as balancing measures, and investigated for opportunities to improve the pathway and test changes in PDSA cycles. Each individual patient was evaluated for opportunities for ongoing quality improvement efforts.

Outcomes and process measures were studied using a time series design. Individual patients were the basis for each PDSA cycle. Run charts with a median line and a goal line were used to monitor improvement. Any patient noted to be outside of our goal parameters was evaluated by the multidisciplinary team at our monthly meeting for opportunities for improvement.

The UNC Institutional Review Board (IRB) approved this project.

3 | RESULTS

Data collected for parent and adolescent patient-reported self-efficacy, stress and satisfaction began with the implementation of the outpatient diabetes programme. An individual data point in our figures represents an individual patient/family. Analysis of the results from the first three patients through the pathway revealed that parent self-efficacy and satisfaction were consistently at, or above our targets, with 100% of self-efficacy scores >40 by 6 weeks after diagnosis (Figure 1), and 100% of parents satisfied

or very satisfied with outpatient education pathway. Stress evaluations, however, identified a subset of families with parental and adolescent PSS scores >15. These results along with qualitative feedback from our diabetes educators and social worker regarding concerning stress levels, identified a gap in our pathway and highlighted the need to target interventions to reduce emotional stress in these patients and families.

Over the 13-month improvement period, 23 patients received education via the outpatient pathway, out of 63 patients diagnosed with insulin-dependent diabetes mellitus (IDDM) during that time. We obtained complete data sets for all patients, with the exception of a child that had come off insulin by the time of the 6-weeks follow-up appointment, and a parent who was Spanish speaking only, as our surveys were only available in English.

Enhancing our pathway to include stress reduction interventions became a primary focus of our QI initiative. As we made modifications to the pathway, we continued to monitor parent and adolescent patients, which demonstrated wide variations in parental perceived stress. A High Stress Protocol (HSP) was developed, tested, modified and implemented. Key components of the protocol include criteria to trigger the protocol; processes to notify the social worker, communicate with the family and perform a full psychosocial evaluation including food security and social determinants of health; as well as identification of resources for families in need. Although families with high stress at baseline often benefitted from referral to behavioural health providers a few months after diagnosis, we found that in the initial 6 weeks after diagnosis, these families are very focused on survival mode, including blood sugar checks, insulin shots and multiple doctor's appointments. During that time, our social worker found most families felt most supported when they understood the role of the social worker and were able to receive help navigating concrete tasks, such as paperwork for school and for the Family and Medical Leave Act (FMLA). On many occasions, families reported this support helped reduce their stress in the immediate period after diagnosis.

Parental Diabetes Distress Scale Regimen-Related Distress

Definition = Average Score on Regimen Related Questions of the Modified Diabetes Distress Scale (five questions)

Data = Survey collected at 6-wk post-diagnosis

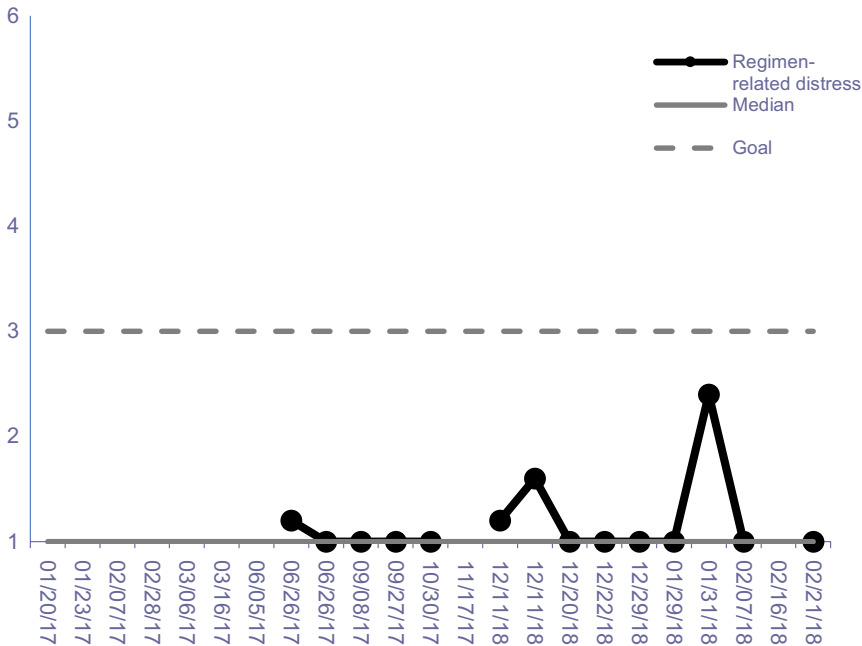


FIGURE 2 Parental regimen-related distress on the Diabetes Distress Scale

Six months of experience with evaluating stress using the Perceived Stress Scale (PSS) provided valuable insight into the global stress experienced by adolescent patients and families in the first 6 weeks after diagnosis of T1DM. However, the scale could not differentiate the source of stress and lacked the granularity the team needed to understand whether the stress might be modifiable by changes to our outpatient diabetes education curriculum. As a result, we investigated other surveys and changed our stress assessment tool to the Diabetes Distress Scale (DDS) for our adolescent patients, and a modified version of the DDS for parents. The DDS is a validated tool to evaluate diabetes-related emotional distress, as related to four areas: emotional burden, physician-related distress, regimen-related distress and diabetes-related interpersonal distress.⁴ The subcategories relevant to the outpatient education pathway, such as regimen-related and physician-related distress, were evaluated for continued improvement and found to rarely contribute to overall levels of distress (Figure 2). The subcategories of emotional burden and diabetes-related interpersonal distress we believed represented more intrinsic distress (such as underlying anxiety disorder) and other difficult-to-modify social categories. However, these were categories we continued to target with interventions in collaboration with support of our licensed clinical social worker, including individual and family therapy, mental health referrals and collaboration with social support resources. Qualitatively, we found that adolescents/parents with higher baseline anxiety prior to diagnosis had high emotional burden in the first 6 weeks after diagnosis of T1DM, which matched our clinical observations. Despite our efforts to minimize the emotional burden throughout the duration of

this initiative, we continued to have families reporting distress levels above our target in this subcategory (Figure 3).

A few months into our outpatient pathway, formal feedback from parents and educators identified that Day 1 of the curriculum was overwhelming for families. After exploring options, the curriculum was modified and tested. Successful changes that we implemented included the addition of a 4th day of education focused on nutrition. The content for Day 1 was revised to Introduction to Diabetes and Survival Essentials, and Day 2 curriculum addressed Nutrition and Meal Planning. Verbal feedback from providers and parents demonstrates increased satisfaction with the new 4-day curriculum.

Ongoing monitoring for unplanned ED visits and admissions for diabetes-related concerns identified the need for further improvements to our pathway. The team conducted an analysis of a Day 1 visit for a patient who presented to the emergency department the next day due to persistent ketosis. We identified a gap in the communication between the diabetes provider and the diabetes educator. A successful PDSA cycle was conducted, which tested a closed-loop communication process at education visits, and the pathway was subsequently modified. There have been no return ER visits for other patients due to diabetes complications since that time.

A few months into our outpatient pathway, we encountered a patient with significant baseline anxiety, who otherwise met eligibility for the outpatient management pathway. We attempted the outpatient pathway, but her severe needle phobia prevented blood glucose checks and insulin administration. As a result, she required hospitalized for insulin administration, including a transfer to an

Parental Diabetes Distress Scale Emotional Burden

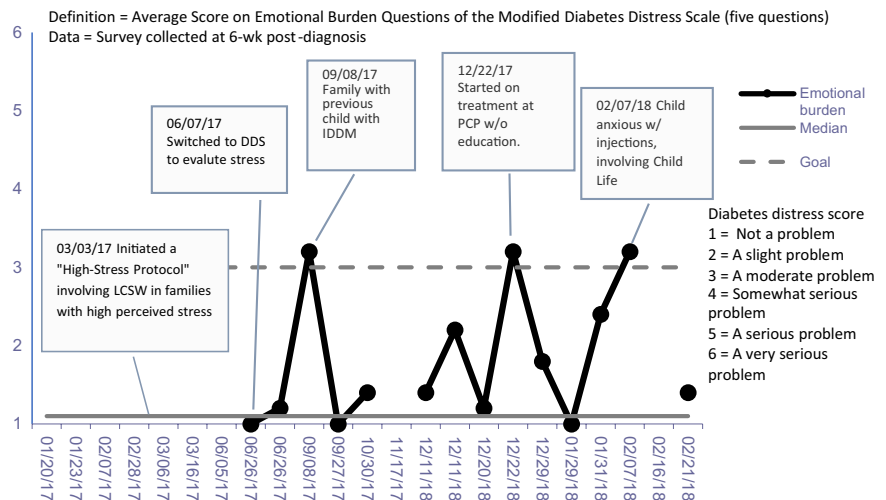


FIGURE 3 Parental emotional burden on the Diabetes Distress Scale

inpatient psychiatric unit to address this severe needle phobia. This admission prompted an evaluation of our eligibility criteria for outpatient management, and a significant history of anxiety, needle phobia or refusal to check blood sugar or give insulin were added to the outpatient eligibility exclusion criteria. Since making this pathway modification, we have not had further issues with patients with severe needle phobia, and we continue to assess this as part of our eligibility process. We did have a few of our younger patients who found the initial diabetes management, including finger pricks and insulin injections, quite distressing, which prompted an evaluation of our use of our Child Life colleagues. We modified our pathway to require involvement of Child Life early in the first appointment for all children under 8 years old. Since making this modification, we have had subjective improvement in experience for our young patients.

Formal feedback from patients and parents indicated opportunities to improve our format through the addition of child-friendly education tools, especially games, toys and electronic resources. We explored many options, including an original smart phone application that allowed children to learn about carbohydrates. Although initially well received by patients and parents, this electronic app was not sustainable because of the cost to maintain it on the app store. Another teaching tool utilized is a stuffed animal bear, who has an interactive smart phone app, which allows young patients to practice site rotation as they mimic insulin injections for the bear. Feedback from parents and children was positive for this learning tool, and after a grant provided funds to supply this to all young patients, this became standard practice in our outpatient curriculum. Finally, our diabetes educator developed an innovative diabetes board game for general education in our clinic, which we then began to use for patients with newly diagnosed diabetes. This board game helps to identify individual patient/parent knowledge strengths and gaps and allows the diabetes educators to re-emphasize education in weak areas, helping to customize ongoing education. Feedback from parents, patients and educators during testing of the board game

was overwhelmingly positive, and the pathway was modified to include the diabetes board game for all new patients in the last day of education, 6 weeks after diagnosis.

As part of the outpatient pathway, we asked that the parents of our patients call the on-call endocrinologist to report blood sugar results for the first three nights after diagnosis, to determine insulin dose adjustments to match the patient's insulin requirements. As the patient number increased, it was noted by the on-call providers that families were not always calling in as scheduled, and it was difficult to keep track of scheduled call-in times. A modification to the pathway included adding a note in the electronic medical record to indicate the expected call-in days. If one of these days was missed, the on-call team would follow-up with a phone call to the family the next day. With this modification, there has been more consistent communication with patients over the first few days after diagnosis.

As the outpatient education pathway grew, it became difficult for the diabetes educators to coordinate 4 days of education for each patient in the first 6 weeks after diagnosis. This adversely affected provider satisfaction. A PDSA cycle was performed, which included recruitment of an administrator to centralize the scheduling process. Feedback from all providers was overwhelmingly positive. The pathway was modified to include this administrator as central to the success of the pathway. See Table 1 for a list of key improvement areas.

4 | DISCUSSION

We successfully developed an outpatient pathway for patients with newly diagnosed insulin-dependent diabetes, the first of its kind at our institution, using quality improvement tools and techniques. We achieved our target self-efficacy, self-management and satisfaction goals through the development, implementation and optimization of a standard specialty team-based pathway, and related care delivery processes.

TABLE 1 Key improvement areas and specific interventions

Key improvement areas	Specific interventions
Customized stress management	High Stress Protocol (HSP)
Curriculum intensity	Addition of a 4th session and redistribution of content
Assessment of stress	Change of stress assessment tool to the Diabetes Distress Scale (DDS)
Child-friendly education format	Use of diabetes stuffed animal with smart phone application for education about insulin administration and site rotation. Development of diabetes board game for patients and their families to play with CDE as method of interactive education
Pathway criteria	Modified exclusion criteria to include anxiety indicators
Blood sugar reporting for insulin adjustments	Use of note in the electronic medical record patient chart to notify all healthcare providers of expectation for family
Coordination of appointments	Single central scheduler for all four education days

Our aim for reducing reported stress for patients with newly diagnosed IDDM was not achieved, despite multiple interventions and pathway modifications. We believe that a certain degree of emotional stress is anticipated in the setting of a new diagnosis of a chronic medical illness, as has been reported in other chronic medical conditions such as epilepsy⁵ and ulcerative colitis,⁶ and the emotional burden distress we measured using the DDS may reflect this intrinsic burden. This intrinsic stress is complex, individual-specific, and regardless of the approach to education during the initial weeks following diagnosis, may not be completely modifiable. One of our patients had a brother previously diagnosed with IDDM, and his parents had above-goal scores on the emotional subscale of the DSS. This suggests that this previous knowledge about the hardships of a chronic illness contributed to the stress felt by this family at the time of the second diagnosis.

During our initiative, we discovered that an outpatient pathway for new onset diabetes requires a substantial increase in the number of hours dedicated to diabetes education. Initially, this affected educator satisfaction due to the increased workload. Fortunately, due to the success of our pathway, our institution supported the hiring of another educator. For another group thinking about starting their own outpatient pathway, a plan for obtaining early institutional support for the entire programme, including staffing, clinic space, and supplies to maintain the programme, will need to be secured in order to allow success going forward.

Although we did not formally assess the provider experience of this outpatient pathway, we informally monitored this at our monthly meetings, by starting every meeting off with feedback from our educators. There were certainly times when the workload was much more than the previous inpatient pathway, as noted above, but

modifications to the pathway improved this over time. In addition, the consistent message received from all providers, including physicians and educators, was that the outpatient pathway was more satisfactory than the previous inpatient pathway, because it provided controlled and consistent education, and resulted in a clear benefit to patients and families.

Reviewing our patient panel, we discovered that many of our patients with newly diagnosed diabetes required hospitalization on the weekends due to logistical, instead of medical reasons (such as diabetic ketoacidosis). Lack of certified diabetes educator availability on weekends and holidays and access to sufficient clinic space for extended educational visits were identified as the two key factors leading to these hospitalizations. As we continue to optimize our pathway, we will explore the possibility of having an on-call diabetes educator for weekend education in the future, which will require clinic space and institutional support for weekend/holiday coverage. In addition, the rise of telemedicine may offer additional opportunities to reduce burdens for families, by offering remote education sessions, without the need to come to the hospital and take extended time off work.

Of note, early in our pathway development, we initially only monitored patients who were diagnosed with type 1 diabetes. Six months into our pathway, we decided to add in patients with insulin-dependent type 2 diabetes, as sometimes it can be hard to differentiate these patients, and these patients require the same scope of education. In addition, our captured data were limited by the need for frequent, often brief, hospitalizations for many of our patients, due to diagnosis on the weekends. Although any patient who came into the hospital was not formally tracked by our quality improvement measures, these patients were often quickly transitioned to

the outpatient curriculum. Any patient who required hospitalization is not presented here, as hospitalization is hypothesized to be a confounding stressor.

Given the success we found in the outpatient pathway, we plan to update and modify the pathway for patients with newly diagnosed IDDM who required hospitalization. A key goal will be to streamline the education received from the bedside nurse during their hospital stay. We anticipate this curriculum will focus on the essential information presented in the outpatient "Day 1" curriculum, with a plan for a quick transition into the remaining outpatient education days.

Despite our inability to modify the emotional burden of stress in the first 6 weeks after diagnosis, the outpatient education pathway for patients with newly diagnosed insulin-dependent diabetes was extremely well received by providers and families alike. We anticipate there will be a continued trend towards outpatient education, as insurance companies and hospital systems push to limit unnecessary hospitalizations. In addition to cost benefits, we feel our improvement work shows the outpatient model has additional benefits of improving self-efficacy and satisfaction for families during this difficult time. We hope the lessons learned through our quality improvement initiative may be applicable to other paediatric endocrinology practices looking to make this transition.

CONFLICT OF INTEREST

Nothing to declare.

AUTHOR CONTRIBUTION

ES collected the clinical data, analysed and interpreted the data and drafted the manuscript. EE participated in data acquisition, aided in analysis and interpretation of the data and revised the manuscript. NJ participated in data acquisition, aided in analysis and interpretation of the data and revised the manuscript. MM participated in data acquisition, aided in analysis and interpretation of the data and revised the manuscript. CB participated in data acquisition, aided in analysis and interpretation of the data and revised the manuscript. KC participated in data acquisition, aided in analysis and interpretation of the data and revised the manuscript. CWK provided guidance to ES in data acquisition, quality improvement conception and design, analysis and interpretation of data and revised the manuscript.

ETHICAL APPROVAL

By submitting to this journal, the authors confirm the manuscript meets the highest publication ethical standards from all authors and coauthors.

DATA ACCESSIBILITY

All data created during this research is available upon request from the authors.

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