



Parent Perspectives on Educational and Psychosocial Intervention for Recent-Onset Type 1 Diabetes in Their School-Age Child: A Qualitative Study

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OBJECTIVE | The recent-onset period of type 1 diabetes (T1D) in early school-age children should include comprehensive, parent-focused T1D education as well as family-centered resources and support to help with adjustment. Here, we present parent/caregiver perspectives on specific areas of concern during the recent-onset period of T1D and their preferred timing for different topics related to T1D education.

METHODS | Parents/caregivers of 5- to 9-year-old children with T1D completed a card-sorting task and qualitative interview to describe ongoing areas of concern and preferred educational topics during the first year after T1D diagnosis.

RESULTS | Thirteen parents/caregivers (aged 35.1 ± 6.9 years) of a child with T1D (aged 8.9 ± 0.8 years, 11.3 ± 7.0 months post-diagnosis) completed the card-sorting task, and 11 completed the qualitative interview. Parents/caregivers endorsed four preferred stages of education: basic education and T1D survival skills during month 1 post-diagnosis, application and practice of T1D skills from months 1–3, access to community supports to cope with anxiety and distress from months 3–6, and support to build autonomy and manage burnout beyond month 6 post-diagnosis. Parents/caregivers endorsed four main themes for ongoing concerns: anxiety, autonomy, distress, and support.

CONCLUSION | Parents endorsed four time points for education and psychosocial services within the first year of a T1D diagnosis. Parents/caregivers may benefit the most from psychosocial interventions 3–6 months post-diagnosis, once they have had sufficient time to develop basic T1D management skills. These findings support the need for regular parent psychosocial screening and access to scalable psychosocial interventions in the first year post-diagnosis of T1D.

Globally, 78,000 youth are diagnosed with type 1 diabetes (T1D) each year (1), but annual rates suggest a 21% increase in diagnoses in the past decade (2). Families of children diagnosed with T1D must quickly learn diabetes management skills and make broad lifestyle adjustments to keep their child healthy. However, adjusting to T1D is challenging for many families. Approximately one-third of parents experience psychological distress shortly after their child's T1D diagnosis, and 19% of parents report long-term distress 1–4 years post-diagnosis (3). Addressing parent distress during the recent-onset period may be important because research shows associations between higher parent distress, fewer blood glucose checks, and children's suboptimal glycemic control (4), which could also translate into greater risk for T1D-related complications for children in the future (5,6).

Although the current goal for T1D therapy is to help youth achieve an A1C $<7.0\%$ (53 mmol/mol) or as low as safely attainable, the majority of youth with T1D do not meet this target (7), and many follow trajectories of increasing A1C over time (8–14). In particular, there is evidence that school-age children may begin to demonstrate trajectories of increasing A1C soon after diagnosis (15,16). Unfortunately, there is also evidence that suboptimal glycemic trends in the first 2 years post-T1D diagnosis may predict long-term challenges for youth in achieving their glucose targets (17,18), suggesting a need for interventions to prevent and reverse early adverse changes in T1D self-management and A1C in school-age children.

To date, most behavioral and psychosocial interventions in pediatric diabetes have targeted adolescents (19–23), with

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only one intervention targeting school-age children (24). However, there are no interventions specifically targeting families of school-age children in the recent-onset period of T1D, and we would assert that this gap may exist because there is limited formative research to guide intervention development specific to these families. Thus, to address this gap, we collected parent/caregiver perspectives on potential T1D educational topics to improve treatment engagement and A1C in families of 5- to 9-year-old children with recent-onset T1D. Specifically, we asked parents/caregivers to identify the relevance and ideal timing of specific educational topics for the first 12 months of T1D. We then conducted qualitative interviews with parents/caregivers to learn more about their experiences during the first year after their child's T1D diagnosis and any ongoing concerns they might have.

Research Design and Methods

Subjects and Procedures

This study was conducted within the context of the TACKLE T1D (Treatment Adherence and Control in Kids: A Longitudinal Evaluation) study (Ro1 DK100779), a multisite, prospective, longitudinal study examining factors that affect treatment engagement and children's glycemia during the first 3 years post-T1D diagnosis. Parents/caregivers were recruited from a Midwestern children's hospital-associated network of pediatric diabetes clinics. Eligibility criteria included parents/caregivers who were English-speaking, and who were a legal guardian of a child who was diagnosed with T1D between the ages of 5 and 9 years and using intensive insulin therapy, with the child's T1D diagnosis occurring within the past 24 months. Families were ineligible if their child did not have T1D, had a severe psychiatric disorder or comorbid chronic condition (e.g., renal disease), or was taking a medication that could affect glycemic control (e.g., systemic steroids). We attained local institutional review board approval before recruitment. Parents/caregivers provided written informed consent and attended a one-time study visit where they completed all study activities. Parents/caregivers received \$20 for completing this visit.

Measures

Psychosocial Questionnaires

Parents/caregivers completed the Hypoglycemia Fear Survey-Parent (HFS-P [25]), a 26-item measure of parent hypoglycemia fear; the Center for Epidemiological Studies Depression Scale Revised (CESDR [26]), a 20-item measure of parent depressive symptoms; the Problem Areas in Diabetes-Parent Revised (PAID-PR [27]), an 18-item measure of parent-perceived diabetes distress; and the Test for

Diabetes Knowledge (TDK-5 [28]), a 29-item measure of diabetes self-management knowledge. We report total scores for each measure, where higher scores indicate greater symptomatology or knowledge. Of note, scores ≥ 16 on the CESDR indicate clinically elevated depressive symptoms (26); however, the other measures do not have consistent clinical cut points.

Card Sorting Task

We asked parents/caregivers to sort 55 preprinted cards into six possible categories: 1 month, 3 months, 6 months, 9 months, or 12 months post-diagnosis and never/not relevant, reflecting when parents/caregivers might prefer to receive education about the card topic during the first year after their child's T1D diagnosis. The card topics related to T1D self-management, including self-care, parenting skills, parent/caregiver psychological well-being, adjustment to chronic illness, quality of life, family factors (e.g., communication and family conflict), T1D knowledge, coping skills, and social support. We also provided parents with up to five blank cards to add any relevant topics they perceived were missing from the existing cards. Parents/caregivers sorted cards manually using baskets labeled with each time point. In turn, a research assistant manually recorded parents' responses in real time and later transferred the data to an Excel spreadsheet to calculate the percentage of times each card was sorted into each category.

Qualitative Interview

We asked each parent/caregiver nine open-ended questions using a structured interview guide to obtain additional information about their experiences during the recent-onset period. (See Supplementary Material.) Parents further indicated whether information provided by the health care team during the first year post-diagnosis was helpful, unhelpful, or confusing and responded to a question about any ongoing concerns they had for their child with T1D. We audio-recorded and transcribed each interview. Two researchers independently coded transcripts for de novo themes repeated by at least three parents/caregivers. In case of discrepancy, the researchers finalized themes through consensus.

Results

Thirteen parents/caregivers completed the card-sorting task, 11 completed the qualitative interview ($n = 2$ missing because of technology/recording error), and 9 completed the study surveys ($n = 4$ lost to follow-up). The majority of parents/caregivers were mothers and between 30 and 41 years of age. Children were between 6 and 9 years of age and 5–22 months (mean 9.67 ± 6.48 months) post-T1D diagnosis at the time of the study visit.

TABLE 1 Parent Survey Results

Survey	Mean ± SD	Minimum, Maximum
CESDR*	5.2 ± 4.0	0, 11
PAID-PR	20.7 ± 14.0	6, 38
HFS-P	63.9 ± 8.8	46, 75
TDK-5	27.9 ± 2.3†	22, 29

*0% of parents reported scores ≥16, which is the clinical cutoff. †Mean number of correct answers out of a total of 29 questions.

Parent Surveys

On the CESDR, parents/caregivers endorsed low levels of depressive symptoms (mean score 5.2 ± 4.0, possible range 0–60), and no one scored above the clinical cutoff (CESDR ≥16) for depressive symptoms. On the PAID-PR, parents/caregivers also reported low levels of diabetes distress (mean score 20.7 ± 14.0, possible range 0–72). In contrast, parents/caregivers reported moderate levels of hypoglycemia fear (mean score 63.9 ± 8.8, possible range 25–125). Notably, parents/caregivers identified engaging in two potentially adaptive behaviors sometimes to very often: 1) “Always carry fast-acting sugar” and 2) “Check my child's blood sugar often when he/she is at school or activities.” Parents also identified two common worries occurring sometimes to very often: 1) “Worry my child will have a low blood sugar while sleeping” and 2) “Worry my child will have a low blood sugar when away from me and in someone else's care.” Parents reported high knowledge of diabetes self-management (TDK-5 mean score 27.9 ± 2.3, possible range 0–29) (Table 1).

Card Sorting Task

Parents tended to divide topics into four main stages of education across the 12 months post-T1D diagnosis (Table 2). Parents requested the topics “basic education” and “T1D survival skills” during the first month post-T1D diagnosis (Stage 1). Between 1 and 3 months post-diagnosis (Stage 2), they indicated that education should shift from basic T1D knowledge to the application of this knowledge in daily life. Between 3 and 6 months post-diagnosis (Stage 3), parents commonly endorsed a desire for information regarding community supports and how to manage T1D-related fears. At 6 months post-diagnosis and beyond (Stage 4), parents expressed an interest in learning how to safely promote their child's T1D autonomy and strategies for managing burnout. In addition, parents identified some topics that they would have liked to have received multiple times during the first year post-diagnosis. These topics included promoting adjustment to

T1D, T1D survival skill refreshers, recent T1D technologies, and handling major life transitions (e.g., starting school). All card sort items and parent-requested time points are provided in the Supplementary Materials.

Qualitative Interviews

Researchers identified 23 de novo codes repeated by at least three different parents. Then, using thematic analysis, these codes were fit into four overarching themes: anxiety, autonomy, distress, and support.

Anxiety

Parents reported that sending their child back to school after being diagnosed with T1D was scary and also described school transitions or changes in school providers as stressful.

“Sending him back [to school] was kind of scary and confusing, too The first time you had to go back was really nerve-wracking.” (Participant TK06)

Parents described sick-day care as confusing, overwhelming, and frustrating and endorsed worrying about their child becoming sick.

“I'm scared of him getting sick. I'm scared of my other child bringing home something from school and then him getting [sick], so I'm super cautious with him I try not to get around him if I'm sick. It's scary.” (Participant TK28)

However, even on typical days, parents reported extreme fears about high and low blood glucose, and many endorsed concerns about acute and long-term health complications of high or low blood glucose levels.

“Our biggest concern is highs. At what point is a high damaging his organs It is a reality because I know someone currently in organ failure from type 1 diabetes.” (Participant TK27)

“I worry about her at night, her blood sugar will drop, and I won't hear her pump go off.” (Participant TK14)

Parents described ongoing difficulty trusting other adults to care for their child with T1D, the steps they have taken to train certain adults in T1D, or how they have chosen to limit their child's activities because of their mistrust.

“She can only go over to my dad's house to stay the night. They're the only people that I actually trust to make sure

TABLE 2 Summary of Card-Sorting Task Items and Parent/Caregiver Preferred Educational Stages

Month	Educational Stage	Card-Sorting Items
0-1	1. Basic Education and T1D Survival Skills	<ul style="list-style-type: none"> • How often to check blood glucose during the day and night • Appropriate blood glucose range for my child • Recognizing symptoms of high and low blood glucose • How to treat high and low blood glucose levels • How to count carbohydrates and appropriate foods • How and when to measure ketones • Frequency of T1D clinic visits • How to use glucagon • Knowledge of T1D management supplies • How to avoid diabetic ketoacidosis • Causes of T1D
1-3	2. Application and Practice	<ul style="list-style-type: none"> • How to talk to my child about diabetes • Access to services and support networks • Application of basic T1D knowledge in daily life • Managing T1D when my child is sick • Eating a balanced diet that fits within carbohydrate needs • What questions to ask primary care provider • Managing difficult mealtime and sleep behaviors • Balancing T1D self-care with daily life • Building confidence in my ability to manage daily T1D tasks • Managing disruption to family patterns and relationships • Establishing consistent eating schedules • What T1D tasks everyone in the family can help with • When to ask about devices that may be right for your child • What affects A1C value and target A1C range • Types of physical activities best for my child
3-6	3. Emotional Support	<ul style="list-style-type: none"> • Fear of nighttime low glucose and treating nighttime lows • Fear of hypoglycemia during physical activity • Teaching child strategies to manage anxiety about T1D tasks • How to educate teachers, extended family, and friends about T1D • Fostering open family communication for T1D management • Addressing parent grief, hopelessness, guilt, helplessness, and isolation • Introducing/helping my child adjust to new treatments • Integrating T1D management into typical developmental activities • Managing misbehaviors/noncompliance with diabetes self-care • Talking to my child's T1D team about health-related concerns
6+	4. Building Autonomy and Managing Burnout	<ul style="list-style-type: none"> • How and when to appropriately transition T1D tasks to child • Teaching my child how to talk to peers about diabetes • Managing concerns about leaving my child in the care of others and trusting other adults • Managing concerns about long-term T1D complications • Refreshers on basic T1D management • Managing sibling tension and marital distress related to T1D • Handling parent and child burnout
12	Repeating	<ul style="list-style-type: none"> • Maintaining T1D self-care during major transition periods • Information about recent T1D treatments and technologies • T1D interfering with fostering my child's autonomy • Balancing the attention I give to my child with T1D and other relationships

that she had proper dosage and things like that." (Participant TK17)

Finally, parents expressed anxiety about managing costs associated with T1D, including current difficulties with insurance coverage of and gaining access to T1D technologies

and uncertainty about being able to afford insulin and T1D supplies in the future.

"I was crying by the end of the phone calls going back and forth with insurance. Nobody could tell me anything that I needed to know, what they covered, nobody knew anything." (Participant TK17)

"The future, because of coverage for her with insurances, and what it is going to be like for her as an adult or a parent . . . Are we saving enough money for her to be able to pay for her insulin if by chance insurance doesn't cover it?" (Participant TK12)

Autonomy

Another overarching theme from parent interviews was child autonomy for T1D self-management. During the initial diagnosis period, many parents reported changing their parenting styles and restricting their child's independence. However, as time passed, parents also expressed frustration when their child struggled to take on more responsibility for T1D tasks, they were unsure of how to effectively foster their child's independence, and they worried that their child could develop long-term complications if he or she did not achieve adequate self-care independence.

"His forgetfulness to remember to bring his bag with him everywhere he goes, to remember that he has to take a shot after he eats because there's still a lot of reminding, and I'm trying to figure out, like, when is a good time for him to really understand that this is yours, and you have to take care of it." (Participant TK10)

"I'm afraid that when she gets older, that she's not going to want to manage it how we're managing it now because she'll be on her own." (Participant TK18)

Closely related to these feelings, parents described the emotional toll T1D may exact on children now and in the future, and they reported a need to help their children normalize their experience of T1D and learn how to handle difficult peer interactions.

"Why are you beeping? Are you beeping? Do you have a phone? Are you playing a video game? He fields a lot of questions from the outside world that they don't understand him." (Participant TK27)

"So, I guess just getting him to feel normal about it or confident about it when he leaves there. Like, yes, this happened to you, but this doesn't mean that you're any different or, like, just really working on that confidence right at the gate because I think he was just really scared and had no idea what was going on." (Participant TK10)

"I'm afraid more of the emotional side of it is going to affect her. When she gets older, it's going to change her. When she gets into adolescent years, and she might not be able to do things that other kids maybe want to be doing; stuff like that is what I worry about." (Participant TK18)

Distress

Parent-reported distress was common. Indeed, parents described that their entire world was dominated by diabetes and that T1D self-care tasks and misperceptions about how difficult and uncertain T1D self-care would be made the early diagnosis period very stressful.

"... the anxiety and the pressure and the stress and the guilt. This is completely life-altering. And once you have become accustomed to this new normal, you are not going to be able to rest well, to sleep well, to deal with life well, because you don't know how you are supposed to handle certain things until you have experienced them." (Participant TK12)

Moreover, across the first year post-diagnosis, many parents described feeling guilt, grief, hopelessness, helplessness, frustration, isolation, loneliness, stress, and burnout, and they described putting all of their attention on diabetes because of the relentlessness of daily T1D management.

"The emotional toll I would say. People always ask me how he is doing, and I say, 'Medically really good, and emotionally it's just hard that there is no break.' It is 24/7. It is when you are on vacation. It is when you're at school. Whatever you're doing, it is with us." (Participant TK19)

Parents reported that miscommunication or a lack of communication with their child's school or health care team was a source of distress, and in particular, they noted distress and confusion resulting from the use of too much jargon.

"Yeah, with the DKA [diabetic ketoacidosis] or whatever it is. That was super confusing when they were running it by me when she was diagnosed that night. It didn't make sense to me until the second or third group, and that's when one of the nurses who we've worked with several times now pulled up pictures on YouTube of what she was talking about and was able to show me and break it down and made it all click in my head." (Participant TK17)

Support

Parents endorsed the importance of support to cope with feelings of distress and T1D-related challenges. Unfortunately, parents were often unsure of where to find adequate support initially.

"I struggled with guilt, loneliness, helplessness. I didn't understand the disease enough at first to be able to talk clearly, to be able to express my anxiety, frustrations, and

concerns with somebody that didn't know it either. So, it was also really frustrating to not be able to communicate my feelings because I didn't know the words to use." (Participant TK12)

They stressed the importance of 24/7 support from their child's health care team, as well as support they received from school nurses, teachers, coaches, counselors, psychologists, and extended family. They also stressed the importance of interacting with other families living with T1D through support groups, peer advocacy, and online forums.

"When you call someone at 3:00 in the morning to ask a question, it may seem like a silly question, but it's not a silly question." (Participant TK16)

"We kind of went over[board] having support. I think that's a big one; it was just support. Another thing is maybe, like, how to help him at school or teachers and how you talk to other people about diabetes and managing, and the things that he needs." (Participant TK06)

Parents highlighted the importance of supports that normalized their child's experience living with T1D and connected him or her to peers who also have T1D. Plus, they requested more resources to support the whole family, including siblings.

"He's this bright, kind, amazing child who has so many different wonderful components to him, and we have to remember to support all of those different areas, not just the pancreas that doesn't want to work." (Participant TK19)

"His older sister was really struggling afterward, and she said it wasn't related, but I think it's pretty coincidental And I know she mentioned how much attention he was getting I would ask people about it, and it seemed like all the support was for him or for us but nothing for the siblings." (Participant TK06)

Finally, parents consistently stated that they would like more support to learn about T1D technologies, including when and how to select the best devices for their child, and frequent updates on any new technologies.

"Information about treatments and technology for T1D. Gosh, I can't get enough, like I want [to] know more It would be nice to have some type of constant communication from the hospital saying, 'This is a new treatment that is in the news that you should be aware of. This is a new technology, and here is a brief highlight of it.'" (Participant TK12)

Discussion

Based on a novel card-sorting task and qualitative interviews, parents of school-age children provided an ideal timeline for addressing specific diabetes education topics in the first year post-T1D diagnosis and described four primary areas of ongoing concern.

Not surprisingly, parents reported the importance of learning basic T1D education and survival skills in the first month post-T1D diagnosis (Stage 1: Basic Education and T1D Survival Skills). This finding is supported by previous qualitative studies, in which parents reported that their main concerns shortly after diagnosis were adapting to life with T1D and learning daily T1D management skills (29,30). In addition, this finding is consistent with current practice guidelines for diabetes self-management, which call for extensive education at the time of diagnosis, followed by regular refresher sessions to build on knowledge in a developmentally appropriate format (5).

In typical practice, families learn basic T1D management skills during the first few days or weeks after diagnosis during an inpatient hospital stay or through outpatient workshops. Current evidence suggests that both methods of education may be similarly effective, although outpatient education programs may offer reduced costs for youth who do not require acute hospitalization (31,32).

Between 1 and 3 months post-diagnosis, parents' card-sorting responses suggest a shift toward wanting education to help them better apply T1D management skills in their everyday life (Stage 2: Application and Practice). Similarly, in previous qualitative studies, parents commonly described large-scale disruption of their daily living activities soon after their child's diagnosis as a result of their focus on learning T1D self-management skills (29,30). Although by no means did parents in our study report a full return to "normal" between 1 and 3 months post-diagnosis, parents generally indicated the desire for information and resources to help them build their confidence in their T1D self-management skills and reestablish previous daily routines and life balance.

Interestingly, while existing qualitative studies report that parents often immediately perceive their child's diagnosis as traumatic (30,33), parents in our study reported an interest in receiving information and resources on managing the emotional toll of T1D between 3 and 6 months post-diagnosis (Stage 3: Emotional Support) and an interest in learning strategies to manage burnout and develop their child's T1D self-care autonomy between 6 and 12 months post-diagnosis (Stage 4: Building Autonomy and Managing

Burnout). In this way, parents' timeline for educational topics deemed relevant for later in the recent-onset period seems to match the limited available longitudinal data on parent functioning in the recent-onset period from research indicating that parents' level of diabetes distress and hypoglycemia fear may peak at 6 months post-diagnosis (34).

Parent/caregiver survey data suggest that we recruited a sample that was not experiencing many depressive symptoms or feeling highly distressed by their child's T1D. We believe that this finding may promote the generalizability of our results because it suggests that the parents/caregivers who participated in our project were likely not seeking treatment and therefore could give a neutral estimation of the appropriate timing for specific T1D educational topics or resources.

However, the parents/caregivers who participated did report moderate levels of hypoglycemia fear, and these were generally consistent with the levels reported by a different sample of parents of young school-age children with recent-onset T1D (35). Moreover, parents' reports of fear appear to line up with several of their qualitative responses and with our four major qualitative themes of anxiety, autonomy, support, and distress.

Taken together, we believe these results may highlight the need for a dynamic and ongoing approach to T1D education in the recent period and beyond. At the most basic level, a dynamic approach to education may include 1) frequent refreshers on T1D survival skills, 2) regular screening for youth and parents' emotional concerns and adjustment problems at quarterly clinic visits, and 3) timely distribution of resources to help families seek treatment for any emotional concerns or adjustment problems from institutional or community partners or to learn about new T1D therapies and technologies. Indeed, this basic level of dynamic education would be consistent with current practice guidelines (5) and may be easily scalable with the availability of several low-cost and validated measures of parent and youth fear of hypoglycemia, family conflict, and psychological symptoms.

However, on a larger scale, a dynamic educational approach could involve all of these components plus in-clinic deployment of new or previously developed adjunctive interventions to help reduce parenting stress (36), family conflict (37–39), and hypoglycemia fear (40) and promote quality of life (21). It is also possible that a larger dynamic education program could incorporate interventions targeting T1D treatment engagement. In fact, there is already evidence to support the feasibility of deploying family-based interventions to improve T1D treatment engagement

within clinics (41) and to provide these interventions via telehealth (42). There is also evidence supporting the feasibility and acceptability of care ambassador and peer mentoring programs, which may provide a cost-effective and targeted approach to supporting and educating families during the new-diagnosis period (43–46). For example, in one study recruiting families in the first 6 months after a T1D diagnosis and testing a peer mentoring intervention, parents reported increased community support and confidence for T1D self-management and fewer negative perceptions about the impact of diabetes (45,46). Finally, a larger dynamic educational approach may offer families ongoing support during life transitions (e.g., starting school and starting adolescence) and support for siblings of youth in the recent-onset period of T1D.

We believe the use of a novel card-sorting task to collect detailed information from parents about the timing of education topics during the first year post-T1D diagnosis and our inclusion of parents' qualitative responses represent areas of strength for this study. Our card-sorting task proved to be easy to implement and efficient and may be a useful strategy for collecting similar data in the future. Moreover, our qualitative data add significantly to the literature. Few studies have focused on learning about parents' perspectives across the entire first year post-diagnosis, and thus, what we need are qualitative foundational data to direct the focus of clinical research in the future.

This study should also be interpreted in light of its limitations. We report only qualitative data from a small sample of parents within a single Midwestern hospital system. Thus, it is possible that findings may not generalize to other geographic regions or parents and need to be replicated and confirmed. We asked parents only about topics during the first year post-T1D diagnosis, so findings may have limited impact on T1D education beyond the recent-onset period. Moreover, because we only collected data from one parent, we cannot describe how other family members may experience the recent-onset period, suggesting that we may need a follow-up study that includes more family respondents (e.g., all caregivers and siblings of the child with T1D) to obtain a more holistic family perspective. Finally, our data on parent/caregiver preferences for when to receive T1D education topics reflects their individual experiences, which may not translate to when providing this information could have the biggest impact on T1D-related outcomes. Therefore, a future study will need to explore the impact of using this proposed timeline for T1D education on families' psychosocial and health-related outcomes.

To conclude, our findings support a four-stage framework for delivering T1D education, support, and resources to

families of school-age youth within the first year post-T1D diagnosis. In addition, our data suggest that clinics should use a dynamic T1D educational approach that, at the most basic level, involves regular T1D refresher sessions, parent and youth psychosocial screening, and timely distribution of treatment resources and information about new T1D technologies. At a larger scale, it may also be feasible and acceptable to support clinic-deployed psychosocial and behavioral interventions to help families who evidence problems with treatment engagement and/or screen positive for psychosocial concerns.

As future areas of research, it may be helpful to pose similar questions about T1D educational needs to families further out from their T1D diagnosis, to continue to develop and test low-cost and flexible approaches to providing T1D education and treatment (e.g., mHealth/eHealth and peer mentoring programs), and to conduct implementation trials to identify effective educational programs and interventions for the recent-onset period that are also scalable for widespread clinic use.

DUALITY OF INTEREST

No potential conflicts of interest relevant to this article were reported.

AUTHOR CONTRIBUTIONS

A.M.M. and A.D.M. analyzed the data based on qualitative themes and wrote the manuscript. K.G. and M.A.C. reviewed/edited the manuscript. S.R.P. participated in the project design, contributed to the results and discussion, and reviewed/edited the manuscript. S.R.P. is the guarantor of this work and, as such, had full access to the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analyses.

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