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Young Children with Type 1 Diabetes: Recent Advances in Behavioral Research

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Abstract

Purpose of Review This review provides a recent update of behavioral research pertinent to young children with T1D and addresses current priorities and future directions.

Recent Findings Rates of type 1 diabetes (T1D) in young children (ages 1–7) are continuing to rise. Since 2014, changes to diabetes care and management have impacted young children and reinforced the need for increased attention and interventions to support diabetes management, especially in caregivers who are primarily responsible for their young child's diabetes management.

Summary T1D is associated with unique physiologic challenges in young children, with constant management demands elevating parental diabetes-related stress and fear of hypoglycemia. Diabetes technology use has significantly increased in young children, contributing to improvements in glycemic levels and parent and child psychosocial functioning. Yet despite the positive outcomes demonstrated in select clinical behavioral interventions, research with this young child age group remains limited in scope and quantity.

Keywords Young children · Type 1 diabetes · Parenting · Diabetes technology · Behavioral interventions

Introduction

Rates of type 1 diabetes (T1D) are continuing to rise, and 18% of new diagnoses occur in children ages 9 and younger [1]. In 2014, *Current Diabetes Reports* published a review of diabetes management in young children with T1D, highlighting challenges of T1D management, current research within this population, and opportunities for future research and clinical care [2]. Since 2014, numerous changes in the clinical diabetes landscape have impacted young children. Research has reinforced the importance of maintaining glucose levels in a tight target range for youth with T1D of all ages [3]. Current glycemic goals recognized by the American Diabetes Association (ADA) and the International Society of Pediatric and Adolescent Diabetes (ISPAD) recommend that young children maintain an A1c level < 7.0% when possible and without risk of severe hypoglycemia [3, 4]. Further, young children with T1D are the fastest adopters of diabetes technologies, including insulin pumps and continuous glucose monitors (CGMs) [5, 6], with significant implications for both glycemic indicators and parent and child psychosocial functioning. However, recent data from the T1D Exchange found a mean A1c of 8.2% in children less than 6 years of age [5], suggesting this age group would benefit from increased attention and interventions to support diabetes management.

Many challenges to diabetes management in young children identified in the 2014 article still remain [2]. Parents

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continue to take primary responsibility for diabetes management in young children. Diabetes management is complicated by normative development in toddlers and preschoolers, including rapid physical and neurological development, difficulty verbalizing thoughts and feelings, frequent and unpredictable physical activity, picky eating, and behavioral challenges and fears [2]. Additionally, many clinical T1D management programs do not offer tailored patient education specifically designed to meet the needs of young children. Given these unique management and developmental considerations, parents of young children have been increasingly targeted for behavioral interventions. In the USA, some of these newer intervention trials were funded in response to a 2013 Request for Applications by the National Institutes of Health (NIH) and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) calling for interventions to improve diabetes management in families with young children with T1D [7]. The goal of this article is to review new research with young children with T1D (typically ages 1–7) that has been published since 2014, with an emphasis on technology use and behavioral interventions.

Parental Initial Adjustment

Following their young child's T1D diagnosis, parents typically oversee all aspects of their young child's comprehensive T1D regimen [8]. Given this immense responsibility, parents may experience diabetes-related distress, a negative emotional response to the burdens of managing their young child's diabetes regimen, during the initial months following their child's diagnosis and beyond [9]. Qualitative research suggests that many parents report difficulty returning to normalcy after diagnosis due to feeling "on guard all of the time" and hesitancy to trust other caregivers to manage their young child's diabetes regimen [10]. Mothers often report higher distress soon after their child's T1D diagnosis compared to fathers [11]. Social support during the initial diagnosis period may be protective for parents and associated with decreased stress. Specifically, our recent research found that more family support predicted less stress in mothers, and more partner support predicted less stress in fathers [12].

Physiologic Challenges

Early-onset T1D places young children at an increased risk for neurocognitive impacts. Using both comprehensive neurocognitive testing and high-resolution structural magnetic resonance imaging (MRI), Mauras and colleagues found that young children with T1D did not differ from their counterparts without T1D in assessments of cognition and executive functioning, but children with T1D had observed differences in brain matter growth [13]. Slower brain development was associated with higher cumulative hyperglycemia and glucose variability among young children with T1D [13]. Another study observed similar structural findings, yet also found subtle cognitive differences in children with T1D compared to children without T1D, including in participants who had been recently diagnosed with T1D (T1D duration in study ranged from 0.1 to 7.9 years). This study also found a trending association among DKA and severe hypoglycemia history and IQ scores. This research suggests that glycemic indicators may have detrimental impacts on the developing brain [14]. In a longitudinal study, Kirchhoff and colleagues observed differences in cognitive function between youth with T1D and their similarly aged relatives without diabetes, with the decreased cognitive function being associated with both increased hyperglycemia and earlier age of onset of T1D, which can cause challenges to the developmental trajectory of cognitive processes [15, 16].

Young children are at increased risk for diabetic ketoacidosis (DKA) at T1D onset [17, 18]. DKA at diagnosis of T1D has been associated with higher A1c levels over time and a negative impact on cognitive functioning [19, 20]. Aye and colleagues found that DKA at diagnosis in young children was associated with lower cognitive scores as assessed by IQ tests, the Detectability and Commission subtests of the Conners' Continuous Performance Test II, and the Dot Locations subtest of the Children's Memory Scale ($M_{\text{time since diagnosis}} = 2.8$ years) [20]. Development of or improvements to public health educational programs focused on helping families and primary care physicians detect early signs of T1D and DKA may be beneficial to reduce the negative impact on young children's cognitive development [21].

Given developmental expectations for young children, including limited language abilities and unpredictable eating and activity patterns, there are often more concerns for hypoglycemia than in older children with T1D [22]. Further, young children often take smaller, more precise doses of insulin and have higher sensitivity to insulin than older youth [2]. Recent research has found that parents may intentionally maintain their young children's blood glucose at higher levels to avoid low blood glucose levels and the adverse effects of hypoglycemia [22, 23]. Parental fear of hypoglycemia may interfere with achievement of updated glycemic targets that recommend tighter glycemic ranges [24], which is problematic given the aforementioned research linking chronic hyperglycemia with negative cognitive impacts. As noted earlier, since the publication of the 2014 review, the recommended target A1c for young children (children ≤ 6) changed from < 8.5 to $< 7\%$, which reflects the current goal for all individuals with T1D regardless of age. The A1c goal was changed with the aim of avoiding long-term vascular complications, hyperglycemia, and hypoglycemia to ensure children have the highest chance of a healthy life with minimal diabetes-related complications, especially looking toward adulthood. While this more conservative A1c goal may be more difficult for families to reach, the International Society of Pediatric and Adolescent Diabetes note the lowered target is intended as an aspirational goal, as people who with a lower target goal range for glycemic levels tend to have lower A1c levels [3, 25, 26].

Nutrition

Dietary quality and parent management of mealtime behaviors are important aspects of diabetes management in young children [27]. Research has found that while parents of young children generally know what healthy eating entails, they do not always follow healthy eating patterns because of barriers to feeding and dietary intake [28]. Our nutrition research evaluating breakfast dietary quality in a sample of young children with T1D found that less than half met dietary recommendations for protein and fat (46% each), and even fewer met dietary recommendations for carbohydrates (23%) [29]. Parent-identified challenges to feeding their child with T1D a healthy diet may include (1) cost and availability of healthy foods, (2) picky eating tendencies in young children, (3) desire to maintain same food options as siblings and peers, and (4) difficulties getting younger children to try new foods. It is not surprising that behavior at mealtimes can be stressful for parents. Younger child age has been associated with more frequent mealtime behavior problems, which are associated with elevated glycemic levels in young children with T1D [30]. Parents also report experiencing worry about administering insulin before meals as appetites vary, particularly in this young child age group [28].

In recent years, research has identified beneficial techniques used around mealtimes to maintain in-range glycemic levels. Seckold and colleagues found that glycemic targets were more likely to be met when children were given insulin before meals and followed a consistent eating schedule for meals, rather than grazing throughout the day [31]. Implementing effective approaches such as providing support to parents of young children with problematic eating behaviors via trained counselors or parent coaches [32••], focusing on the nutritional make up of children's meals [33], and maintaining routines around meal times [31] also may help improve glycemic levels in young children.

Physical Activity

Ensuring physical activity is performed in a safe, and healthy manner is an additional challenge of T1D management in young children, as parents may be fearful of hypoglycemia brought on by physical activity [34]. While minimal research on physical activity has been conducted with young children, physical activity is beneficial in maintaining healthy weight and glycemic levels in older children and adolescents with T1D [35]. National guidelines by the Physical Activity Guidelines Advisory Committee recommend that most young children engage in 3 hours of light, moderate, and/or vigorous activity per day, and ISPAD recommends children with T1D complete the same amount of exercise as children in the general population [35, 36]. Yet, Tully and colleagues (2018) examined physical activity in a small sample of young children ages 3–7 with T1D and found that the sample spent most of their day in sedentary behavior and were less active than published samples of young children without T1D [34].

Psychosocial Functioning

T1D management in young children is often described as all-encompassing and unrelenting, and parents of children with T1D endorse significant burdens associated with T1D management [37]. Harrington and colleagues analyzed survey data from 597 young children <7 years of age with T1D, finding that the following burdens were endorsed by over half of all parents: (1) worry about low blood sugar, (2) worry about future complications, (3) feeling upset when diabetes management is "off track," and (4) negative impact on sleep quantity and quality [38]. These burdens can have a negative impact both on family functioning (e.g., family well-being, family conflict) and on individual parental psychosocial functioning (e.g., mood, stress, quality of life).

Studies suggest that parental adjustment is associated with young children's T1D outcomes and quality of life [39]. In one study, higher levels of parenting stress contributed to lower diabetes-related quality of life in both parents and children [40]. Our research demonstrated that key child protective factors (e.g., initiative, self-control, and attachment) were associated with more optimal parental functioning (e.g., lower depression and stress symptoms) and higher child quality of life [41]. Additionally, Jaser and colleagues found that sleep quality in young children with T1D is associated with parental sleep and well-being [42]. Thus, parental psychosocial functioning appears to be a key factor in the well-being of young children with T1D.

Due in part to developmental limitations for child self-report in young children, research to date has mainly relied on parental report of child psychosocial functioning, with fewer investigations exploring adjustment or quality of life of young children themselves. In one study, parents rated young children with T1D as having lower health-related quality of life compared to a comparison group of children without T1D [43]. Yet, in other studies, parent ratings provided evidence of diabetes-related resilience by demonstrating no difference in health-related quality of life or functioning between young children with or without T1D [44]. Developmentally tailored measures to assess parent and child functioning in this unique population of young children are needed, and some new measures have emerged in recent years. For example, Enlow and colleagues developed and validated the Parent-Preschoolers Diabetes Adjustment Scale to evaluate caregiver adjustment to the challenges and demands of parenting a young child with T1D [45].

Parental Coping and Resilience

While overseeing their child's T1D management is a complex and intensive task for parents, many parents display resilience. Pierce and colleagues found that most parents of young children with T1D engaged in positive coping strategies [39], including defining a "new normal" for their family, engaging in creative problem-solving, and benefit finding (positive perceptions in the face of adversity). Expanding on the advantage of benefit finding in their later work, this group also found that benefit finding was correlated with higher parental diabetes self-efficacy [46]. Parental diabetes self-efficacy, defined as parents' perceived ability to oversee diabetes care tasks, is an important component of managing diabetes for a young child [47]. In our unpublished data from a stepped care behavioral intervention [48], we found that parental diabetes self-efficacy improves over the first year and a half after diagnosis, and long-term parental diabetes self-efficacy was predicted by parental psychosocial functioning at diagnosis [49]. However, there is limited research examining interventions to promote parental diabetes self-efficacy and further investigation is warranted.

Other Caregivers

Responsibilities for managing a young child's diabetes are often shared with other caregivers—such as teachers, day care providers, and nurses—corroborating the idea that T1D management in young children is a team effort [50–52]. In a recent study of kindergarten teachers, most rated their T1D knowledge and ability to assist with diabetes tasks as fair, and many identified opportunities for improved institutional support and communication with parents and health care providers [50]. Similarly, pre-kindergarten and kindergarten school nurses reported confidence in their ability to care for children with T1D [52]. Daycare poses additional considerations for parents. In fact, some parents reported that daycare utilization was significantly impacted by diabetes-related financial stress and need for flexibility related to managing their child's diabetes [53]. Further, parents of children with more diabetes-related complications (diabetes-related unconsciousness or seizures) and higher fear of hypoglycemia expressed increased concerns for their child's functioning in daycare or school [51]. For some families, recent advances in diabetes technologies have increased ease of sharing diabetes responsibilities with other caregivers, but not all young children have the same opportunities for access and use. Halipchuk and Sawatsky call for increased use of flexible insulin regimens in toddlers, such as basal-bolus regimens or insulin pumps, to help facilitate insulin administration in daycares and schools [54].

Technology

Diabetes technologies, such as insulin pumps and CGMs, are evolving tools for diabetes management, and use of these technologies in young children has significantly increased in recent years [55]. Recent data from the T1D Exchange indicate that CGM use in children less than 6 years old has increased over 40% from 2011 to 2016 [56] and insulin pump use nearly doubled, with the highest rates of use in the youngest patients [43, 57]. Hybrid closed loop systems, which automatically adjust insulin delivery according to glucose levels aside from mealtime boluses, are relatively novel in young children, with a recent trial indicating that they are feasible and safe to use [58]. Household sociodemographic factors have significant impacts on access and consistent use of diabetes devices [59]. Families with private insurance are more likely to use a CGMs, and young children with a longer T1D duration, an annual household income of > $75,000, a parent with college education, and using a CGM are more likely to use a pump [60, 61]. Further, these technology advances have exacerbated racial disparities in diabetes treatment, with non-Hispanic White children being more likely to be prescribed and use insulin pumps and CGMs than non-Hispanic Black and Hispanic children [62].

Research has demonstrated that diabetes technologies improve glycemic levels and may reduce the burden of diabetes management in young children and their parents [63, 64]. Several studies have shown that children using a CGM have fewer sleep disturbances [65, 66••, 67]. Further, Burckhardt and colleagues found that CGM use may provide a greater sense of freedom for children and their parents (e.g., being able to spend time away from home) and improve communication between parents and other caregivers (e.g., teachers) [68]. Similarly, parents of young children using hybrid closed loop systems reported spending less time performing diabetes activities, resulting in feeling reassured and perceived improvements in their child's quality of life [66••].

While there is increased use and identified benefits of CGMs and pumps, challenges still arise for young children and their parents. Children have reported that CGMs and pumps were painful to insert and wear, specifically reporting skin adhesive difficulties and extra discomfort when wearing both devices [60, 65]. Other burdens reported by parents include incomplete glycemic data due to connectivity issues [65, 66••], financial barriers to ongoing use (e.g., insurance stopped covering, too expensive) [60], and battery performance [66••].

There are mixed findings regarding the impact of technology on parents' sleep and regarding parents' impressions of glucose data interpretation and device alarms. Our work found greater parent sleep disturbances related to CGM use due to nighttime blood glucose monitoring [67], while Burkhardt and colleagues found that parents reported improved sleep quality after initiating CGM in their young children [68]. Similarly, with CGMs offering continuous and extensive blood glucose data, some parents have found this information overwhelming and difficult to interpret, while others have found being able to visualize their child's blood glucose levels, trends, and patterns relieving [65, 68]. Moreover, Musolino and colleagues found that alarms from diabetes technologies related to glucose excursions were either perceived by parents as intrusive (i.e., causing anxiety), or reassuring (i.e., creating peace of mind) [66••]. It is important to note that evolving capabilities of diabetes technology influence parental experiences. Similarly, many studies report on older versions of technologies, which may account for some of the inconsistencies seen in the literature (e.g., CGM systems that required calibration with blood glucose values obtained via glucometer or were less reliable). It is essential that future work evaluating diabetes technologies include assessments of child and parent experience to fully capture the benefits and challenges of using these devices.

Interventions

A number of clinical behavioral interventions for young children with T1D are new or in progress, with results forthcoming. With the Request for Applications by the National Institutes of Health (NIH) and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), promising studies are emerging, but they need to be replicated [7]. The majority of interventions have targeted caregivers of young children with T1D (see Table 1 for an overview of representative interventions). Existing interventions for parents of young children target skills for reducing hypoglycemia distress [69••], healthy eating and physical activity promotion [34], managing diabetes challenges [70], and optimizing CGM use [71••]. Through these interventions, several benefits for parents have been achieved including reduced hypoglycemia fear [69••], decreased stress [69••, 70] and diabetes burden [71••], and improved social support [72], quality of life [70, 72], and well-being [71••]. Young children also benefited from these interventions as evidenced by improvements in glycemic levels [32••, 34, 70]. Our work evaluating a stepped-care behavioral intervention aimed to support parents' psychosocial functioning found that parent coaching is feasible and improves parents' mood over the first year after a child's diagnosis. Additionally, interventions for other caregivers may also be warranted yet remain understudied. For example, one study utilized a video training program to improve primary school teachers' confidence in administering glucagon and found significant improvements in confidence and knowledge [73••]. There are also ongoing and unpublished interventions aimed at improving both parent and young child outcomes, including a positive parenting program [74], educational videos [75], and a web-based coping resource [76]. Additionally, Berget and colleagues are utilizing a sequential multiple assignment randomization trial (SMART) design to increase family adherence to CGM use and improve the quality of life of parents with young children with T1D [77].

Current Issues

Recently, studies have described the experience of managing diabetes in children during the COVID-19 pandemic [78–80]. Our team followed a cohort of parents of children ($n = 100$) who were diagnosed with T1D at a young age (1–6 years, pre-pandemic) who had completed a behavioral trial more than 6 months prior (enrolled between 2015–2019), and obtained data for 2 additional follow-up times points during the pandemic (Summer 2020, Winter 2021 [81]). During Summer, 2020, parents of children with T1D (M age = 6.74 years) who reported experiencing more pandemic-related life disruptions during the initial months of the pandemic also reported more negative diabetes-specific experiences as well as COVID-19-specific distress. Further, parents of young children with T1D who had higher social support pre-pandemic reported fewer depressive symptoms during Summer, 2020 [81].

Similar to other ongoing behavioral interventions [82], research focused on young children and T1D has adapted over the last few years to accommodate reliance on telehealth diabetes visits [83]. The necessity for remote delivery of interventions across this time period may prove advantageous for the future of intervention delivery, maximizing family convenience and reducing barriers that are commonly reported regarding participation in research [84, 85]. It is also possible that remote enrollment and intervention delivery may translate to increased diversity among future research samples.

Table 1 Clinical behavioral interventions for parents, caregivers, and young children with T1D published since 2014

Authors	Child age	*N*	Intervention	Selected results
Mackey et al., 2016 [72]	1–6	30 mothers	Feasibility, acceptability, and preliminary efficacy of a phone-based intervention to improve glycemic outcomes and parental and child well being	Feasible, intervention group demonstrated improved social support and quality of life over time
Gupta et al., 2017 [70]	3–5	2 cohorts with18 families each	Camp-based multi-component intervention to reduce A1c and improve psychosocial functioning in parents	Families in intervention group had a significant decrease in A1c before and after camp; mothers had a significant improvement in diabetes specific quality of life and reduction in stress
Patton et al., 2020 [69••]	1–6	42 parents	Telehealth video intervention to reduce hypoglycemia fear in parents	Parents in intervention group (vs control) had a significant reduction in hypoglycemia fear and stress
Tournilhac et al., 2020 [73••]	Primary school students	221 teachers	Efficacy of a video training program for teachers to improve confidence in administering glucagon during severe hypoglycemia	Teachers’ confidence to administer glucagon significantly increased after watching the training program
Mackey et al., 2021 [32••]	2–5	36 parents	Feasibility and acceptability of a healthy eating and physical activity behavioral intervention	High acceptability, increased number of children within target glycemic range (70–180 mg/dL); no significant change in A1c, diet or physical activity
SENCE Study Group, 2021 [71••]	2–7	143 children + caregivers	CGM + family behavioral intervention (vs standard CGM) to improve glycemic levels and parental quality of life	Intervention group improved parental well-being and significantly reduced hypoglycemic events; no differences in time in range between groups
In progress (outcome data not yet published)				
Lohan et al., 2016 [74]	2–10	N/A	Group-based parenting intervention	TBD, study seeks to evaluate the efficacy of *Positive Parenting for Healthy Living* program for parents of children with T1D
Hilliard et al., 2017 [48]	1–6	157 parents	Stepped-care behavioral intervention aimed to support parents psychosocial functioning and promote children’s glycemic outcomes	Parent coaching is feasible and can support parent mood
Wysocki et al., 2018 [76]	< 6	N/A	User centered design web-based coping intervention	TBD, study seeks evaluate the effects of website use on diabetes and psychosocial outcomes for both parent and child
Berget et al., 2019 [77]	2–6	N/A	Sequential multiple assignment randomization trial design: Four behavioral interventions: Two interventions focusing on optimizing adherence and two interventions focusing on achieving glucose targets	TBD, primary aim is to use CGM and behavioral supports for parents to improve glycemic and psychosocial outcomes
Marker et al., 2019 [75]	3–5	N/A	Web-based intervention that provides resources tailored to families of young children	TBD, study seeks to examine how access to T1D educational videos impacts parent and child outcomes (e.g., adherence, coping, glycemic levels)

Conclusions and Future Directions

Although ADA and ISPAD no longer include less conservative glycemic targets for young children as they did prior to 2015 [86, 87], there has been an increased recognition of the unique factors faced by children diagnosed with T1D at a young age, as well as the impact on their family members. As such, the research focused on young children with T1D has continued to grow over the last decade, and we expect further expansion of investigations targeting this young child age group to come. Behavioral interventions that show promise for both child and parent psychosocial functioning, as well as child glycemic outcomes, have been largely elusive to date. However, we remain optimistic that the behavioral strategies and related positive outcomes demonstrated thus far (i.e., improvements in parent distress, hypoglycemia fear, child well-being, and glycemic outcomes [34, 69••, 70, 71••]) could be incorporated into routine clinical care. Additionally, increasing social support appears to be a key mechanism to promote parent and child psychosocial functioning. Future research should include evaluation of these interventions into the clinical or real-world setting with representative samples of youth and parents reflecting diverse racial, ethnic, and socioeconomic groups, which will ultimately improve the well-being of young children with T1D and their family members.

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Declarations

Conflict of Interest The authors do not have existing conflict of interest.

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