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Young Children with Type 1 Diabetes: Challenges, Research, and Future Directions

Randi Streisand, PhD, CDE and

Center for Translational Science Children's National Medical Center 111 Michigan Ave NW Washington, DC 20010 (202) 476-2730 (phone); (202) 476-3966 (fax) rstreis@childrensnational.org

Maureen Monaghan, PhD

Center for Translational Science Children's National Medical Center 111 Michigan Ave NW Washington, DC 20010 (202) 476-4726 (phone); (202) 476-3966 (fax) mmonagha@childrensnational.org

Abstract

The incidence of type 1 diabetes (T1D) in young children (age <6 years) is rising. Diabetes management guidelines offered by the American Diabetes Association and health care teams understandably place a high burden of responsibility on caregivers to check young children's blood glucose levels, administer insulin, and monitor diet and physical activity with the ultimate goal of maintaining tight glycemic control. Unfortunately, this tight control is needed during a vulnerable developmental period when behavior is unpredictable, T1D can be physiologically difficult to control, parenting stress can be elevated, and caregivers are strained by normal child caretaking routines. Despite the potentially different management needs, specific education and clinical services for managing diabetes in young children are rarely offered, and behavioral research with this young child age group has been limited in scope and quantity. Research findings pertinent to young children with T1D are reviewed, and potential clinical implications, as well as areas for future research, are discussed.

Keywords

young children; type 1 diabetes; parenting

Introduction

Type 1 diabetes (T1D) is one of the most prevalent chronic illnesses diagnosed in childhood and occurs in 1:400-600 American children [1]. An increasing number of young children are

Corresponding Author: Randi Streisand, PhD, CDE.

Compliance with Ethics Guidelines

Conflict of Interest

Randi Streisand and Maureen Monaghan declare that they have no conflict of interest.

Human and Animal Rights and Informed Consent

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impacted by T1D [2, 3], with 15-20% of new diagnoses occurring in children under age 5 [4]. This is an alarming figure and the reason for the increased incidence in this youngest age group is unknown. Diabetes management in young children can be challenging for a variety of reasons, including physiological factors such as increased insulin sensitivity and a potentially shortened honeymoon period. Daily T1D management is further complicated by young children's cognitive, behavioral, and social-emotional development. In this review, we outline the unique challenges related to T1D management in young children and report descriptive research findings from studies including or focusing on this age group. We also review the few behavioral interventions that have included young children with T1D and present preliminary data from emerging research with a large sample of parents of young children with T1D. Finally, we offer considerations for specific care of young children with T1D as well as future clinical and research directions.

Characteristics of T1D Management in Young Children

Youth with T1D must adhere to a complex and time-consuming lifelong daily medical regimen to delay or prevent the onset of acute and chronic T1D-related complications such as seizure, coma, diabetic ketoacidosis, cardiovascular disease, retinopathy, nephropathy, and neuropathy [5-7]. Parents of young children with T1D are responsible for their child's daily T1D management, including frequent blood glucose (BG) monitoring, insulin administration, and diet/physical activity regulation [8, 9]. The American Diabetes Association (ADA) outlines specific BG level and glycemic control goals for children <age 6 [8, 7]. Goals include maintaining BG levels between 100-200 mg/dl and HbA1c levels below 8.5% (equivalent estimated average glucose [EAG] <197 mg/dl [13]), monitoring BG levels at least 4×/day, and engaging in healthy eating habits with adequate intake of vitamins and minerals. These relatively conservative glycemic goals recognize the developmental challenges of increased insulin sensitivity, unpredictable diet/physical activity patterns, and resulting glycemic variability in this population. The International Society for Pediatric and Adolescent Diabetes is less conservative and does not specify tailored treatment goals for young children, recommending that all youth with type 1 diabetes achieve an A1c <7.5%and maintain euglycemia as much as possible while avoiding hypoglycemia [10]. However, both the ADA and ISPAD-suggested treatment goals can be difficult to achieve and clinical behavioral T1D management programs do not typically offer tailored patient education/ counseling services specifically designed to meet the young child or his/her family's individual needs.

Challenges to T1D Management & Glycemic Control

Recent data from the T1D Exchange indicate that 36% of children less than 6 years of age fail to meet ADA goals for A1c (<8.5%) and 73% fail to meet the more stringent ISPAD goal of an A1c <7.5% [[11]. Physiological, developmental, and psychosocial issues contribute to the challenges of daily T1D care for young children and their parents. Table 1 provides examples of how developmental challenges in young children may play a role in management of T1D.

Physiologic Challenges

Following diagnosis, approximately 69% of young children experience a temporary restoration of beta cell function (i.e., honeymoon period) as a result of insulin therapy, during which less insulin is required. Yet, 90% of young children no longer fall into this category 12 months post-diagnosis [12]. Thus, parents must quickly adapt to a new T1D regimen and changing physiological needs. Young children also exhibit increased insulin sensitivity, susceptibility to hypoglycemia, and potentially long-term neuropsychological effects due to difficulties meeting treatment goals and longer disease duration. The burden of T1D management and resulting parental worry about acute and chronic complications likely contributes to daily BG management challenges and parent stress [13-15, 7].

Research on the neurocognitive consequences of early-onset T1D and related glycemic variability is emerging. Recently, the DirecNet research group published several papers comparing brain structure and neuropsychological functioning in a group of young children (ages 4-<10) with T1D to age-matched healthy controls. Using structural magnetic resonance imaging, Marzelli and colleagues found that young children with T1D with a history of significant hyperglycemia evidenced decreased gray matter volume as compared to healthy control participants in key brain regions associated with cognitive capacities [16]. The association between glycemic variability, particularly hyperglycemia, and cognitive function was more pronounced in young children with earlier onset and longer duration of diabetes, further highlighting the vulnerability of the developing brain in this age group [17]. In this same sample from the DirecNet study, Cato and colleagues reported trending associations among executive functioning, learning/memory, and hyperglycemia, suggesting that structural brain changes in youth with diabetes have a subtle, yet measurable, impact on cognition as soon as two years after the onset of T1D [18]. Additional research on the long-term cognitive impact of T1D and hyperglycemia in early childhood is needed.

The very young age at diagnosis during a critical period of rapid neurological growth contributes to significant concerns regarding hypoglycemia as well. For a variety of reasons, including lack of expressive language skills and cognitive immaturity, young children may be unable to reliably detect and/or report early symptoms of hypoglycemia [9]. Parents may struggle to discriminate between behavioral cues signifying a low or high BG level and normal developmental (mis)behavior such as temper tantrums [19], which can interfere with proper T1D management [20]. Further, young children's cognitive capacities make it difficult for them to grasp complex, higher-order concepts typically associated with formal, logical thought, including time and cause and effect. Given the concrete reasoning skills and limited problem-solving abilities of young children, adherence to the T1D treatment regimen may, in fact, seem like punishment [21]. The young child's limited cognitive ability to cope with daily regimen demands may also lead to aggression, resistance to BG checks or injections/site changes, or somatic complaints [19].

Nutrition

Dietary intake and mealtime behaviors play an integral role in overall T1D management. Postprandial glycemia is noted to be one of the most important predictors of HbA1c and is associated with the onset of complications [22]. Research has demonstrated that common

Streisand and Monaghan

childhood eating patterns, such as consuming a breakfast with a high glycemic index (i.e., cereal with milk), can have a substantial impact on glycemic control throughout the day and following night [23-25]. However, it can be difficult for children to eat appropriately balanced and nutritious meals at scheduled mealtimes under the best of circumstances, as transient food preferences and food refusal are typical even for healthy young children [26]. Insulin dosage, which is largely based on predicted food consumption, can be difficult to estimate in advance. Many parents therefore choose to administer insulin after a meal is consumed in order to avoid hypoglycemia if too little food is eaten, despite the fact that T1D control may be compromised by not administering the insulin pre-meal [27].

Eating behavior has been the focus of several descriptive studies of young children with T1D. Parents of children with T1D report greater negative child mealtime behaviors compared to parents of controls, including longer meal duration, poor appetite, and oppositional behavior [28]. Observational studies by Patton and colleagues found that problematic parent and child behaviors occurred, on average, for nearly half of videotaped family meals [29]. Further, Patton and colleagues videtapted 3 or more meals in 39 young children with T1D and found significant associations between glycemic control and child behaviors of 'play and away,' suggesting that disruptive behavior at meals may impact glycemic control [30]. In our own work with parents of young children with T1D, more frequent child feeding problems were similarly associated with a lower percentage of daily BG levels in range and poorer glycemic control [31]. Dietary quality of young children with T1D is also poorer than their healthy peers, as recent studies indicate that young children with T1D have diets lower in fruits/vegetables and higher in saturated fats, placing them at higher risk for cardiovascular disease [32]. Pickiness and dietary neophobia also impact dietary quality and variety (although not glycemic control directly) in older children with T1D [33].

Physical Activity

Physical activity and the need to balance energy expenditure and insulin dosing/food intake is another potential challenge when managing T1D in young children. Among healthy children, physical activity is known to decline beginning as young as ages 3-4 [34], which is especially risky for youth with T1D, for whom physical activity plays an important role in their later health [35]. Young children also have unpredictable physical activity patterns [36, 37] and parents may avoid activity for their younger children due to fears of hypoglycemia or may not appropriately alter their diabetes management in response to physical activity [35]. In one of the only published studies examining physical activity in young children with T1D, Sundberg and colleagues used accelerometers to measure daily physical activity in 24 children with T1D and 26 healthy children (all under 7 years of age). Young children with T1D were found to be less active overall, and engaged in fewer minutes of moderate-to-intense physical activity as compared to peers without T1D [38].

Our team recently completed a small pilot of physical activity, eating, and glycemic control in young children with T1D (n=10, M age=5.88 yrs, M HbA1c=7.29%, M T1D duration=2.69 yrs). Preliminary data suggest that young children experienced a number of BG excursions (<100 mg/dl or >200 mg/dl) that were captured by continuous glucose

monitoring yet missed by BG monitoring via glucometer. These excursions were more often high BG levels, as participants spent a daily average of 39.88% of their time (SD=17.89%) with a BG level above 200 mg/dl, and 14.37% of their time (SD=11.24%) with a BG level below 100 mg/dl. Daily minutes of physical activity was significantly correlated with percentage of time with BG levels below 100 mg/dl (r=.662, p=.04) but not with high BG levels (r=-.41, p=.24). When examining individual trends, it appeared that afternoon physical activity helped reduce high BG levels near bedtime for some individuals [25]. More research is clearly needed to determine the potential benefits of consistent physical activity in maintaining adequate glycemic control in young children with T1D.

Psychosocial Challenges

Management of T1D in young children has been described as 'unrelenting' [39]. Considerations related to diabetes management pervade nearly all of young children's daily activities, including play, meals, sleep, sibling interactions, peer relationships, and school/ daycare interactions [21, 40, 41]. Sullivan-Bolyai and colleagues coined the term "constant vigilance" to represent the continual attention that must be paid to daily T1D care, identification of resources to support T1D management, and navigation of developmental milestones [39]. Because of the all-encompassing nature of T1D, the psychosocial impact on parents is substantial and can derail the 'normal' parenting experience. Parents often experience psychosocial stressors due to the daily T1D responsibilities and resulting worry about their child's health [42, 39]. Less is known about the impact of T1D on the psychological health of young children; however, it is likely that both T1D regimen demands, and potentially poor parent psychological adjustment, together negatively impact quality of life in young children with T1D.

Initial Adjustment following Diagnosis

At diagnosis, parents must quickly become experts in T1D management while simultaneously teaching others about proper care and ensuring that their child maintains a similar developmental trajectory as before diagnosis [43]. Smaldone and Ritholz completed semi-structured interviews with 14 parents of children diagnosed with T1D in toddlerhood and found that the diagnosis period was frought with overwhelming feelings of fear, worry, and self-doubt. Parents also reported feelings of isolation, as it was difficult for family members and friends to understand diabetes care and participate in T1D care [41]. Research has indicated that elevated levels of distress are common during the initial months after diagnosis of T1D, including increased prevalence of post-traumatic stress, anxiety, and depressive symptoms [44-46]. Providing increased support for parents of young children at the time of diagnosis may be critical to facilitate this initial adjustment period and beyond, as maternal distress at diagnosis predicts maternal distress even years later [47]. Sociodemographic markers, such as lower income levels or single parent households, can portend which parents are at risk for elevated psychosocial concerns at diagnosis [48, 49].

General and Disease-Specific Parent Distress

The demands and stresses of the diabetes regimen may have long-lasting effects on parents' well-being and quality of life [50]. A recent systematic review of the psychological

experience of parents of children with T1D found that 19% of parents endorsed significant distress 1 to 4 years after diagnosis [51]. The younger the child with diabetes, the greater the likely impact on parental psychosocial functioning [50, 52].

Parents of young children with T1D are at increased risk for depression, anxiety, and disease-specific indicators of well-being such as pediatric parenting stress and hypoglycemia fear. In a sample of 67 mothers of young children (ages 1-8) diagnosed with type 1 diabetes >6 months, 21% of mothers reported clinically significant symptoms of anxiety and 24% reported clinically significant symptoms of depression [53]. Similarly, our earlier descriptive study of 73 parents of young children (ages 2-6) with T1D found that 21% of parents endorsed significant symptoms of anxiety [20].

Symptoms of anxiety and depression are often related to parent report of frequency of, and difficulty with, stressors related to caring for a child with a chronic illness, or "pediatric parenting stress [20, 54]." Assessment of pediatric parenting stress captures interrelationships among three central features: (1) child health, (2) parental roles, responsibility, and burden, and (3) psychological and behavioral response and adaptation to illness [55]. Several investigations have found greater levels of parenting stress in parents of young children with T1 diabetes as compared to parents of older children with diabetes and healthy controls [28, 19, 20].

As noted earlier, young children are more susceptible to glycemic variability, including hypoglycemia, and cognitive and verbal immaturity presents an additional challenge to hypoglycemia identification in young children. As a result, parents often express significant fear of hypoglycemia that impacts daily T1D management and parental quality of life. Patton and colleagues revised the Hypoglycemia Fear Survey [56] for parents of young children and found that parents endorsed significant worry about hypoglycemia that impacted daily behaviors. For example, in a sample of 24 parents of young children (ages 2-8) on continuous subcutaneous insulin infusion (CSII), many parents reported significant worry about their child having a low BG level while asleep (63%) or while away from a parent (46%); in addition, 38% of parents reported significant worry about their child having a seizure and 38% reported worry that no one would be able to help their child during a hypoglycemic event [57]. Episodes of severe hypoglycemia can shake a parent's confidence to effectively manage diabetes, leading to increased anxiety, difficult sleeping, and heightened vigilance [39]. Parents may also change daily T1D management behaviors in response to hypoglycemia fear, as elevated worry about hypoglycemia has been related to higher daily BG levels in young children [58].

Parent-reported symptoms of anxiety and depression, pediatric parenting stress, and hypoglycemia fear are highly correlated. Patton and colleagues examined relations among depressive symptoms, pediatric parenting stress, and hypoglycemia fear in parents of 39 young children (ages 2-7) with T1D. Results indicated that depressive symptoms were associated with 58% of the variance in parent-reported frequency of pediatric parenting stress. Further, depressive symptoms and hypoglycemia fear were associated with 68% of the variance in parent-reported difficulty with pediatric parenting stress, highlighting the interrelationships among general depressive symptoms and disease-specific indicators of

stress and worry related to T1D management [59]. Further, our own work has demonstrated that fathers who report high levels of pediatric parenting stress also report higher state anxiety, fear of hypoglycemia, and lower self-efficacy for diabetes care [60]. Parent stress and worry may increase during key developmental transitions for young children, such as starting school or going to summer camp [41].

Parent Sleep

Parents' own sleep patterns are often disrupted when caring for a young child with T1D [61, 39]. Our studies have demonstrated that a significant percentage of parents of young children with T1D report poor sleep quality, with 36% of parents perceiving their sleep quality as "fairly bad" or "very bad." Using baseline data from our ongoing randomized controlled trial (RCT), parents (n=134) reported an average of 6.19 hours of nightly sleep [62], far below the recommendations for adult sleep by the National Sleep Foundation [63]. Further, up to 42% of parents report routinely monitoring their child's blood glucose level after their child is asleep, which may significantly contribute to ongoing parent and child sleep disruption [64, 62]. Nighttime monitoring of BG levels has also been associated with increased anxiety and parenting stress, suggesting that daily T1D care demands may impact parental quality of life [65].

Impact of T1D on Children's Quality of Life/Emotional Functioning

Less research has systematically evaluated the impact of T1D on young children's quality of life. Studies with school-age children have demonstrated mixed results regarding whether youth with diabetes show significantly elevated stress and depression as compared to healthy controls [66, 67]. The DirecNet Study Group found that parents reported greater internalizing symptoms, including depression, anxiety, and somatization symptoms, in young children (ages 4-10) with T1D as compared to healthy controls [18]. A recent study evaluating routine behavioral and mental health screening in a pediatric diabetes clinic found that young children ages 4-7 were more likely to have parent-reported elevations on the Strengths and Difficulties Questionnaire (SDQ), suggesting that young children with T1D are at greater risk for psychological disorders such as anxiety or depression [68].

Greater parent difficulties also pose additional challenges for young children. In a large sample of 325 children ages 2-18, elevated parental fear of hypoglycemia was related to lower parent-reported child quality of life [69]. Greater reported pediatric parenting stress has been associated with more frequent child behavior problems [20] and mealtime misbehavior in young children with T1D [28]. Further, normative behavior problems, such as dawdling at meal times, refusing to eat food presented, and dawdling before bedtime, are perceived as more problematic for parents of young children with T1D as compared to normative samples [20].

On a positive note, research has consistently demonstrated that tools for diabetes management, such as insulin pumps or continuous glucose monitors, do not appear to negatively impact quality of life and may even improve quality of life in young children [70, 71]. Further, parents typically report high levels of satisfaction with such technologies for young children [72].

Other Caregivers

Not surprisingly, the burden of T1D care falls heaviest on mothers, who report performing 79% of insulin administrations and 70% of BG checks [73]. The vigilance, supervision, and complex knowledge required to monitor changes in children's BG levels make many parents hesitant to leave their child in the care of a teacher or babysitter; some parents have even described a sense of loss of their former support systems that were in place prior to the child's diagnosis as babysitters and grandparents express fear of the responsibility of caring for diabetes [19, 39, 41]. It is also not uncommon for a young child's diagnosis of T1D to negatively impact parents' employment and social activities. In examining qualitative responses from 134 parents of young children with T1D from our own unpublished work, we found several consistent themes, including parents stopping work completely, reducing hours, changes positions to increase employment flexibility, needing to continue working due to the financial strain of T1D, and T1D negatively affecting job performance or advancement.

Parents also report significant worry about their child attending school or daycare. In our same sample, 44% of parents reported that their child's diagnosis of T1D impacted their school enrollment decision and 12% of parents had removed their child from a school or daycare program due to T1D management difficulties. Parents of younger children were more concerned about a school's ability to appropriately manage T1D. Greater parental worry about hypoglycemia and worse child school/daycare functioning was associated with poorer parent-reported quality of life [74].

Interventions

Most T1D clinical behavioral interventions to date have limited trial participation to schoolaged children and adolescents [75]. A few small-scale clinical behavioral interventions for parents of young children with T1D exist that include parent social support via parent mentors [76], coping skills training for parents [77] and our own 5 session telephone-based intervention for parent training/stress management [78]. Through these interventions, several benefits for parents have been achieved including perceived support, decreased family burden, improved coping [76, 77], decreased parenting stress and increased social support [78], and improved quality of life in parents [77]. However, concomitant improvements in children's glycemic control remain elusive and under-studied.

Our team (R01DK0700118) is completing a multi-site RCT evaluating enhanced parental management of young children's T1D care vs. standard T1D education, the largest known behavioral trial targeting young children with T1D. In this trial, 134 parents (90% mothers, M age=36.80, 22% non-Caucasian) of young children ages 1-6 (49% female, M age=5.32, M HbA1c=8.1%, 30.8% with HbA1c 8.5%) were randomized to a parent support intervention or diabetes education comparison group. Intervention participants completed a phone-based 5-session intervention, including 4 individual phone calls with an interventionist, 1 group teleconference, and access to an online message board (89% of participants completed all 5 sessions). Intervention strategies targeted parental emotional functioning related to diabetes management, as well as support along several parenting behaviors (i.e., handling challenges related to eating, misbehavior, sleeping). Preliminary

findings suggest high intervention satisfaction, with significant improvements for intervention families in mealtime distress--one of the key areas targeted by our intervention. Furthermore, at 1-year follow up, 25% of intervention participants had HbA1c values that decreased by 0.5% or more from baseline, compared to only 16% of control families.

Future Directions and Clinical Implications

The clinical experience of families of young children with T1D coupled with the limited research focusing on this age group suggest that there are unique challenges to managing T1D in young children. A more in-depth understanding of the impact of early-onset type 1 diabetes on children as they age, as well as the impact on family members, is needed to better ascertain specific intervention targets. Research using advanced neuroimaging techniques has already identified subtle cognitive decrements in young children with type 1 diabetes; however, additional longitudinal evaluation of the long-term neurocognitive impact of diabetes and glycemic variability in young childhood is needed [79]. Additionally, there are still many gaps in knowledge regarding associations among and implications of nutrition, physical activity, glycemic control, and hypoglycemia in young children with T1D. Parents report elevated mealtime stress yet only one small pilot to date has focused on nutrition and behavioral aspects of feeding/eating [80]. Similarly, parents may benefit from guidance on how to encourage physical activity in their young children while at the same time properly managing diabetes. In addition, consideration of other caregivers, including in schools and day care settings, is deserving of future research. Encouraging parent-child problem solving and communication, promoting healthy parent-child interaction around diabetes-related tasks, and allowing young children opportunities to participate in their own care, as appropriate, may also be worthwhile intervention goals [81, 82].

In terms of clinical care, health care providers working with young children with T1D and their families should take into consideration the many challenges of managing diabetes in this age group. During routine clinics providers may learn a great deal by asking parents about their own level of stress, impact of diabetes on sleep, and parenting concerns. Young child-specific clinics may benefit both families as well as providers, and potentially allow parents to connect with others experiencing similar challenges. From providers, parents may need guidance about child development, and best practices for negotiating picking eating, or managing diabetes in a very active toddler/preschooler. Further, parents would likely benefit from clinical programs that support them in their employment and school/daycare decisions. With the changing health care system and discussion of mental health being incorporated into care with medical providers, perhaps it will become routine for families to meet with a psychologist or social worker as part of a young child's diabetes clinic appointment.

Conclusion

The incidence of T1D in young children is rising, and the developmental period of young childhood poses a number of unique challenges that may impact T1D management. Glycemic variability is common among young children with T1D and has significant and potentially long-term implications for health and well-being. Descriptive research has identified a number of potential targets to improve T1D management and adjustment in

young children and their caregivers but few behavioral or educational programs exist. Targeted interventions for young children with T1D and their caregivers are needed to reduce the risks for long-term T1D-related complications and improve more immediate T1D management and quality of life.

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Table 1

Developmental challenges of T1D management in young children

Areas of early childhood development Typical for through age 6	Impact on T1D management
Physical growth	
 Rapid period of physical and neurological development 	 Necessitates frequent monitoring and adjustments to insulin and nutrition needs during growth spurts
Activity level	
• Engage in frequent, inconsistent bursts of physical activity	 Requires increased monitoring of activity and related glycemic variability Parental worry about hypoglycemia may impact daily management May be difficult to get an active child to remain still for injections, site changes, or BG monitoring
Language Skills	
Difficulty verbalizing thoughts and feelings	• It may be hard for child to communicate symptoms of high or low BG levels, worries, or questions about T1D care
Cognitive development	
• Concrete thinking	• Young children may not understand why daily T1D management tasks are required, such as why insulin is needed, need for BG monitoring, or why they may not always eat the same types or amounts of food that their friends eat
Social Development	
• May be worried about being away from parents but may also become interested in spending time with others (e.g. play date at friend's house)	 Parents may need to teach others (teachers, friends' parents, family members) about T1D, including how to recognize signs of high or low BG levels and treatment. Parents may need to change their schedule to be available for phone calls, pick-up times, etc., as child starts day care, preschool, or kindergarten
Emotional and behavioral development	
•Often have specific fears •Temper outbursts are common •Sometimes want to do things "their" way or by themselves •Learn ways to manage their feelings as they grow and have new experiences	 Increased resistance to, or anger about, injections and BG checks Fear of doctors, the hospital, and needles Children want to make more of their own choices (e.g. eating, clothing, where to do BG or place pump site) It can be hard for parents to distinguish low or high BG levels from a "normal" tantrum or bad mood