

In Brief

This article identifies many of the special challenges encountered by anyone caring for and managing children and adolescents with diabetes. It uses a case study methodology to provide tools to clarify and explore developmental considerations and contributing factors for this population.

Unique Challenges for Pediatric Patients With Diabetes

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The needs of pediatric patients dictate guidelines for care that are different from those for adults. The American Diabetes Association recently published a statement on current standards of care pertaining to children and adolescents with type 1 diabetes.¹ In accordance with this, members of diabetes teams have become more aggressive in identifying goals and negotiating plans with families to meet standards and target hemoglobin A_{1c} (A1C) levels. Treatment plans are sometimes successful, but often they fall short because of multiple factors. These challenges require deeper exploration to identify sources of barriers to treatment and more effective strategies for motivation and behavior change.

Factors that contribute to pediatric challenges include normal growth and development, psychological characteristics, health status, family dynamics (including socioeconomic status and cultural considerations), and care outside of the home, such as in the school setting. These components increase the intricacy of caring for pediatric patients in general, and the addition of a chronic condition often further increases the complexity. The purpose of this article is to identify some of the special challenges encountered by anyone caring for and managing children and adolescents with diabetes and how these issues are influenced by contributing factors.

Factors That Contribute to Pediatric Challenges

Normal Growth and Development

Normal growth and development affects every aspect of diabetes care and forms a framework for managing care at different ages, as seen in Table 1.²⁻¹¹ The family's interpretation or expectation of developmental tasks and abilities of children and adolescents also contributes to pediatric challenges, as well as the health team's ability to promote anticipatory guidance in these areas.

Childhood is a time of rapid growth and organ maturation. For diabetes, this relates to continual changes of insulin doses and assessment of how insulin is used in the body. The goal of achieving normal puberty is also important. Insulin resistance occurs during puberty, with overall insulin response 25-30% lower in pubertal children than in prepubertal children.^{12,13}

Cognitive changes affect care as children's ability to understand, verbalize thoughts, and learn new information evolves. Hypoglycemia is a major concern in diabetes, particularly as it relates to potential adverse effects on the brain. Target glucose levels may be higher in young children to counterbalance hypoglycemia. Many studies show that hypoglycemia is particularly detrimental to the developing brain of young children.^{14,15} That is

why methods to prevent hypoglycemic events are crucial; such events have a widespread psychological effect on the family's ability to keep blood glucose levels in target.

Children assume increased responsibility with age. Anderson et al.¹⁶ have found that parents and children often do not communicate about how diabetes responsibilities are shared or

about expectations. Therefore, it is helpful for the diabetes team to identify the tasks of diabetes care and who takes responsibility for them, pinpoint tasks for which no one is

Table 1. Developmental Considerations for Children and Adolescents

	Babies and toddlers 0–3 years	Preschool 4–6 years	School 7–12 years	Teens/Adolescents 13–18 years
Physical	Physical Rapid growth Erratic eating and sleeping	Greater mastery of gross and fine motor skills	Pre-puberty Pre-adolescent growth spurt Menstruation Large variability in size of children	Puberty Hormonal changes Secondary sex characteristics
Cognitive	Differentiates self from others Learns to use language to represent objects and people	Thinking is egocentric Classifies objects by a single feature Magical thinking Simple choices	Begins to process abstract concepts such as numbers and relationships but needs concrete examples Can understand cause and effect	Can think in abstract terms Hypothetical and deductive reasoning Can think of multiple options, “what ifs” Living in here and now
Moral development	Judgments based on personal preference	Judgment of good/bad based on punishment/reward	Judgments based on maintenance of societal values Person's intention and being nice and fair is important	Judgments based on universal principles and internalized values
Emotional and sense of self	Begins to recognize that others' feelings are different from own Begins to have sense of self	Sex role differentiation Likes to help Wants to do things by self Deference to authority	Quest for social involvement/acceptance Important to do the “in” thing Sensitive to teasing	Separation and independence Preparation for adulthood Experimentation to “find self” Sexual curiosity/exploration Substance abuse (smoking, drinking, drugs) Driving
Social	Parallel play	Cooperative play	Same gender friendships Shared group activities	Opposite sex relationships Shared group/couples activities
Responsibility	Total care by parents/caretakers	Child begins to have some responsibility with adult assistance	Child does care with adult supervision	Teen does care independently with periodic adult oversight
School	At home/daycare Beginning to learn routines Adjusting to different caretakers	Entering school Separation from parents Learning routines, rules outside of home School readiness skills	Separating from parents for prolonged periods of time Bus transportation/field trips Identification of learning styles and disabilities	Most time away from parents/home Transition to junior/senior high school Multiple transitions Varying schedules Vocational/college prep
Extracurricular activities	Care by babysitters	School aftercare Playdates	Organized sports Clubs and hobbies Music/dance lessons Overnights Camps	School teams Clubs Performances Jobs Trips Dates
Incentives	Immediate and concrete	Immediate and can be symbolic (stickers, stars, etc.)	Token economies/toys Reward charts	Long-term consequences Driving privileges DVDs CDs

This table was compiled using the work of multiple theorists in child development, including J. Piaget, L. Kohlberg, and E.H. Erikson.^{2–11}

taking responsibility, and facilitate discussion of these issues. Transition of care from parent to child should be initiated gradually starting in middle school, allowing for continued success and supervision by parents. Autonomy can be fostered as children mature, understand more, become more manually dexterous, and gain the confidence necessary to implement more of their treatment program for themselves.

Because young people live for the moment and a great deal of energy is required to face long-term goals, short-term goals are often more attainable, and multiple successes build positive habits. Preparation for college can create concern and anxiety, so creating a plan of action with the parent and young adult can increase readiness for this important period of growth and development.¹⁷

Psychological Characteristics

Issues such as adjustment, depression, anxiety, and eating disorders influence diabetes control and need to be explored. Grey¹⁸ found that after an initial period of adjustment, children with diabetes have equivalent psychosocial status to children without diabetes. However, 2 years after diagnosis, children and teens with diabetes experience twice the amount of depression and adjustment problems as their peers. A family history of diabetes complications may negatively affect adjustment.

Psychological factors have been shown to increase risks of poor glycemic control. Leichter et al.¹⁹ identified pediatric examples including unresolved feelings over parental divorce, anger over relationship with stepfather, childhood molestation, child abuse, and parental conflict over diabetes care. Kovacs et al.²⁰ assessed school-age children over the first 6 years of their diagnosis and found a mild increase in depressive symptoms after the first year. Anxiety decreased for boys but increased for girls over time. The degree to which children were upset by the diabetes regimen related to anxiety and depression. Higher A1C levels in adolescents have been associated with depressive symptoms, suggesting the importance of early diagnosis and treatment.²¹

Clinicians ideally should consult with a mental health professional for screening patients and should develop a network of referral sources who are knowledgeable about diabetes.

Health Status

Other health issues often affect diabetes care, especially if they result in a second diagnosis. For example, the increased prevalence of celiac disease in type 1 diabetes can alter absorption of nutrients and insulin requirements, thereby affecting diabetes control.²² It also adds additional home management needs related to a gluten-free diet. Overt complications of diabetes are not prevalent in pediatrics, but patients should be screened for them. Antecedents to these problems are being identified in pediatrics, leading to earlier identification and treatment, especially for early kidney or eye problems. For type 2 diabetes, comorbid factors seen in adult obesity, such as dyslipidemia, glucose intolerance, hypertension, and sleep apnea, are also seen in adolescents.²³

Family Dynamics

A nurturing environment for people with diabetes includes caring, warmth, support, understanding, and healthy limit setting.²⁴ Culture defines our belief system about health and illness, as well as our personal responsibility in maintaining health and making treatment options.²⁵ Low socioeconomic status has been related to longer hospital stays, increased prevalence of diabetic ketoacidosis (DKA), and poorer metabolic control.²⁶ Societal changes, including divorce, one-parent families, and an increase in the number of work hours by parents, have decreased stability in the family, thereby identifying a need for diabetes camps, recreation, education, and support groups.

Parents report letting go of perfectionism and keeping a positive attitude as positive coping strategies.²⁷⁻²⁹ Strong positive connections with knowledgeable and skilled professionals are also helpful to promote clinic visits, which have been shown to decrease with single-parent households and to affect control.³⁰

Care Outside of the Home

Responsibility is often extended to a variety of caregivers because most children are supervised by multiple people, including family members, babysitters, and teachers. Children should receive the same level of diabetes management in school or with caregivers as they do when they are with parents. They should be medically safe at school, have the same access to educational opportunities as their

peers, and not be excluded from extracurricular events or field trips. Additionally, they should have immediate access to their supplies, be able to obtain a blood glucose reading, and be able to respond to the results as quickly and conveniently as possible. They should be allowed to test their blood in the classroom when capable to minimize missed classroom time.³¹ Parents and health team members often become advocates for children for issues such as performing diabetes care, health insurance, life insurance, recreational activities, and career opportunities.³²

Challenges in Pediatric Diabetes Management

One objective of diabetes care and education is to improve health and ensure the total well-being of the family. Diabetes is difficult to manage at any age, but it can be particularly challenging for young people. La Greca³³ states that considering all the challenges, it is no wonder that non-adherence is a problem with youths with chronic pediatric conditions. She promotes celebrating the many successes instead of focusing primarily on the setbacks.³³ The Diabetes Attitudes, Wishes, and Needs Study³⁴ identified that people with diabetes often feel alone and isolated as well as overwhelmed by the responsibility of diabetes management. These issues need to be addressed by integrating psychological and social issues and overcoming roadblocks to optimum diabetes management.³⁴ The diabetes care of children and adolescents requires the ability to learn and master specific treatment-related behaviors. Table 2 identifies these management issues and how they translate into challenges. By using the table as a tool, potential concerns can be identified before they become an issue, and plans can be developed to build on successes and decrease the effect of the challenge. The health care team can share this information with patients and families so they can be informed and active decision-makers.

Research to Practice

Case Study 1: Ana

Ana is a 2-year-old who was recently diagnosed with type 1 diabetes. She is a very spirited toddler, and she fights blood glucose testing by screaming, hiding, and clenching her fists. How can the educator help the family with

this challenge?

- Challenges of diabetes management: testing
- Factors contributing to the challenge: normal growth and development, family dynamics
- Developmental considerations: moral, emotional, incentives

Solution. At age 2, Ana's initial judgment about blood glucose testing is based on personal preference, and this does not include invasive procedures. At this age, it is not possible to convince Ana that she needs to test her blood glucose. The clear responsibility for making sure that blood glucose

testing is completed at necessary times belongs to the parents. There is a danger that the child's illness will alter the parental role.

With the assistance of Ana's father, her mother was able to model a matter-of-fact attitude and stick to the necessary routine. She provided imme-

Table 2. Age-Specific Challenges of Diabetes Management

Management Issues	Babies and Toddlers 0–3 years	Preschool 4–6 years	School 7–12 years	Teens/Adolescents 13–18 years
Medication regimen: fixed or basal-bolus insulin or oral agents	Choosing a regimen to fit eating patterns and lifestyle Getting child to accept injections	Requiring supervision in all settings Needing insulin coverage at preschool	Needing to include child in treatment decisions Planning regimen around normal activities Learning target blood glucose levels	Adapting for hectic lifestyle Doing self-treatment Treating to target Using patterns of blood glucose levels
Pumps	Picking the right catheter Finding the right catheter placement based on fat Using very small basal rates	Choosing a person to be responsible for pump Child wanting to push buttons	Learning technical skills without emotional maturity Wanting to "show off" Working toward independence	Transitioning to independence Increasing need for flexibility
Testing	Choosing sites for testing Checking overnight Selecting the right meter Having a small sample size Needing to include child in care	Progressing to do own checks Avoiding labeling blood glucose "good" or "bad"	Not wanting to test in public Being capable of doing tasks but not of making treatment decisions Needing adult supervision Avoiding too much responsibility too soon	School/work schedules interfering with testing Making up results Decreasing use of logbooks Finding new pattern management methods
Continuous glucose monitoring system	Reducing anxiety about overnight hypoglycemia	Evaluating basal bolus balance Checking overnight basal rates or long-acting insulin	Identifying effects of exercise Catching hidden low blood glucose levels	Fine-tuning basal-bolus Getting a 3-day picture
Hypo- and hyperglycemia	Unable to tell caregiver when high or low May not cooperate with treatment	Learning meaning of high/low blood glucose Needing help in identifying symptoms Fearing hypoglycemia	Beginning to identify patterns Understanding causes of high/low blood glucose Beginning to understand consequences of actions	Identifying cause and effect of high/low blood glucose Preventing high/low blood glucose Driving increases risks
Insulin administration and adjustment	Using very small doses Needing quarter-units Requiring diluted insulin Minimizing pain and fear	Having needle phobia	Requiring injections at school Starting to self-inject Progressing towards self-correcting	Increasing insulin resistance Needing increasing amounts of insulin Not wanting to carry supplies Changing insulin times to fit schedule
Health and sick-day management	Having more frequent vomiting and diarrhea Becoming dehydrated rapidly Needing immunizations	Having more outside exposure Increasing number of sick days Contracting childhood illnesses	Needing health screenings Having concerns with weight and body image Needing to learn obesity prevention	Puberty occurs with hormonal changes Increasing risk of eating disorders Learning complication prevention Preventing DKA Balancing high-risk behaviors
Nutrition	Breastfeeding makes measuring intake difficult Introducing solid foods Eating habits often erratic Using food as power struggle	Grazing eating patterns Using artificial sweeteners may be controversial Needing to involve child in meal plan	Incorporating school lunches and parties into meal plan Sharing and trading food Needing help with food choices in restaurants Increasing independent eating	Eating more fast food Increasing appetite and caloric requirements Erratic timing of meals/snacks Needing to coordinate school, work, and meals
Exercise/activity	Growing very rapidly Becoming mobile	Continuously in motion Energy level is high	Exercise inconsistent Increasing sedentary activities Adjusting to organized sports	Activities are higher intensity and longer duration Discrepancy between weekday and weekend activities

This table was compiled through interviews with the diabetes team at Childrens Hospital Los Angeles and completed using a consensus process.

diate and concrete incentives, such as a hug, telling Ana she did a good job, and letting her pick out a book to read. Within a very short period of time, Ana was willingly presenting her finger to her parents and allowing her blood glucose to be tested. Additionally, the diabetes team picked the diabetes supplies that would work best for this family, including a meter that was capable of alternate site testing, required a very small sample, and gave results in 5 seconds. The smallest-gauge lancet was also used.

Case Study 2: Terrel

Terrel is a 4-year-old diagnosed with type 1 diabetes 10 months ago and whose case is complicated by a recent diagnosis of celiac disease. He has been in a honeymoon period, his family has monitored his gluten-free carbohydrate intake very well, and he has had few management problems. He has now entered a private preschool that has a full-time nurse. He is experiencing regular episodes of hypoglycemia related to increased physical activity and less-consistent snack intake because of less supervision than when he is at home. How can the school nurse and the health care team correctly identify this challenge and use contributing factors to manage it?

- Challenges of diabetes management: testing, hypoglycemia, nutrition
- Factors contributing to the challenge: normal growth and development, care outside of home
- Developmental considerations: physical, moral development, emotional, responsibility, incentives

Solution. At age 4, Terrel likes to help, wants to do things by himself, and adapts well to routines. He is able to understand the meaning of low blood glucose and the importance of eating his carbohydrates. In the school setting, he needs to be supervised while at the same time learning to take some responsibility for his blood glucose levels. Incentives that work at this age include praise, stickers, and providing choices.

The diabetes educator met with the school nurse and Terrel's teacher. They developed a care plan that included sitting down with Terrel and explaining that they were going to help him not have low blood glucose at school. Every day before recess, he would get to choose one of two

gluten-free snacks provided by his mother. When he finished the snack, Terrel could pick a small prize from a treasure chest in the school nurse's office. Terrel liked being involved. Because he got to choose the snack, he was more inclined to eat it, and getting a prize when he finished eating was an extra incentive. Before long this routine became the norm, and the hypoglycemia disappeared.

Case Study 3: Rachel

Rachel is a 10-year-old who was diagnosed with diabetes at age 6. She is extremely bright and precocious, and she is in a family that has allowed her a lot of autonomy and responsibility for her diabetes. Rachel attends a public elementary school that has a school nurse 2 days per week. Her diabetes has been managed on an insulin pump for the past 3 months.

Rachel is very good with video games, so she was able to learn the technical aspects of the pump very quickly. Because Rachel's mother is unsure of herself with electronic devices, she has allowed Rachel to do the hands-on portion of pump care.

Recently, Rachel made a mistake while giving insulin at school and double-bolused, resulting in a severe low glucose event. Glucagon was given by the nurse who was on campus that day. This mistake produced a great deal of anxiety, and Rachel had difficulty returning to school after the incident.

Again, how can the diabetes team work with the school and the family to identify the factors contributing to this challenge and make a developmentally appropriate plan?

- Challenges of diabetes management: pumps, insulin administration
- Factors contributing to the challenge: normal growth and development, family dynamics, psychological factors, care outside of the home
- Developmental considerations: cognitive, moral, emotional, sense of self, social, responsibility, school

Solution. Although Rachel, at age 10, is able to master the technical aspects of the pump, she does not yet have the emotional maturity to be given total responsibility for it. Rachel's mother allowed her to take more responsibility than she was ready for. Rachel very much wants acceptance by her peers. The kids at school thought it was cool that she had the pump, and Rachel enjoyed the attention she got when

she gave a bolus. She was able to understand the consequences of her actions and was very frightened when she realized that she had made a mistake. She lost confidence in her ability and felt she had lost face with her friends.

The team brought Rachel and her mother in for an intense clinic visit. Developmental milestones were explained to them, and a contract was developed around responsibility for the pump. Rachel's mother agreed to do all hand-on pump programming when Rachel was at home until she was very comfortable with all aspects of the pump. After that, Rachel could again assist, but always with someone double-checking. It was agreed that at school Rachel would program the pump only with supervision by an adult and not as a social activity around her friends.

Because the nurse was only on campus 2 days a week, she arranged for a designated adult to double-check Rachel's entries. This person was also trained on glucagon administration for back-up if the nurse was not on campus on a day it was needed. The designated office person was very supportive and encouraging, and this reinforced Rachel's sense of self.

Rachel was excited about the suggestion of going to diabetes camp, where she would meet other children with diabetes using insulin pumps. Additional recommendations included upgrading Rachel to one of the new "smart pumps." These devices include a calculation algorithm and "active insulin" or "insulin on board" features that simplify insulin delivery with the pump and decrease the risk of error.

Case Study 4: Jose

Jose is a 16-year old with out-of-control type 1 diabetes. He lives with his single mother and two young half-brothers in a socioeconomically depressed area of a large urban city. He admits to having been involved in gang activity and to using alcohol and tobacco. His mother works at night, leaving Jose to manage his diabetes alone.

He was recently hospitalized for the third time in the past 12 months for DKA resulting from not taking his insulin. This time, he required intensive care monitoring because of a very low pH and depressed level of consciousness. When asked later why he stopped taking insulin, he said he was

angry with his mother and did it to get back at her.

What is the best plan using contributing and developmental factors for Jose?

- Challenges of diabetes management: testing, insulin administration, hyperglycemia, health and sick day management
- Factors contributing to the challenge: normal growth and development, family dynamics, psychological factors
- Developmental considerations: cognitive, moral, emotional, sense of self, responsibility

Solution. At almost 17, Jose is physically able to carry out all of the technical tasks of diabetes management. But he needs family support to cope with the emotional burden of a chronic illness. Although Jose understands the causes and effects of not taking his insulin, he is using this knowledge as a weapon against his mother. He is recklessly involved in risk-taking behaviors and putting himself in jeopardy.

During the recent hospitalization, his diabetes educator and social worker met with him and his mother. A report to the Department of Children and Family Services was made because of the severity of his condition and the number of recurring episodes of DKA. Both Jose and his mother recognized the seriousness of this admission.

On deeper exploration, Jose admitted he was angry at his mother because she wasn't home and depressed because he has no quality time with his mother and has not seen his father in several years. The mother verbalized her constant worry about Jose's condition and the family's financial stress requiring her to work nights.

Both Jose and his mother were willing to make small steps toward improving his control and preventing subsequent DKA. They were involved in developing a plan of care that included:

- Weekly contact by phone and monthly intense visits with the diabetes educator
- A referral for family counseling to have Jose's depression evaluated and to help Jose and his mother develop some coping strategies
- A referral to a mentor program through which Jose was matched with a young adult with diabetes

who is functioning well and willing to spend time with Jose to allow some male role-modeling to occur

- An agreement between son and mother to have dinner as a family one night a week and to plan one outing together per month.

Case Study 5: Loretta

Loretta is a 13-year-old African-American girl with a BMI of 32. She was referred to the diabetes clinic from her primary care pediatrician because of a random blood glucose level of 287 mg/dl, acanthosis nigricans, and 3+ glucose in the urine. On further work-up, she was found to be hypertensive and to have dyslipidemia.

Loretta lives with her mother and father and her maternal grandmother, who does the cooking. There is a strong family history of type 2 diabetes, and Loretta's paternal grandfather died of diabetes-related complications 2 years ago. All family members are heavy smokers, and Loretta has recently begun smoking.

Loretta was very angry about the diagnosis and stated that there was no way she would test her blood glucose at school. Additionally, she said it didn't matter what she did because she would end up dying anyway.

What is the plan and contributing factors for Loretta?

- Challenges of diabetes management: testing, medication administration, hyperglycemia, health and sick day management, exercise and activity
- Factors contributing to the challenge: normal growth and development, family dynamics, psychological factors, health status
- Developmental considerations: emotional, sense of self, social, responsibility, extracurricular activities, incentives

Solution. Loretta's reaction is common for a 13-year-old who wants to be accepted by her friends and live in the here and now. She is old enough to see cause and effect and can relate her diagnosis to the poor health of her relatives with diabetes, which creates her sense of learned helplessness and fatalism. Any solution is going to need to counteract this belief system, so frequent team visits coordinating small steps in the right direction will be necessary for Loretta.

She came into the outpatient education center for new-onset education with her mother and grandmother

and met with the diabetes educator, nutritionist, and social worker. The education session was kept short but concentrated on how lower glucose values positively affect health.

She was started on metformin. Her grandmother was also on metformin, and the team was able to set up a buddy system for taking the medication and blood glucose testing at home before breakfast, dinner, and bedtime. There was a compromise with Loretta at this point to not test her blood glucose at school while she was getting used to the routine.

The meeting with the nutritionist focused on how Loretta's grandmother could start making healthier food choices, especially related to the amount of sugar and fat in their family recipes. A referral to the hospital's weight management program was made for the summer session to give Loretta a few months to adjust to the diagnosis and new treatment routines. The entire family agreed to go to a smoking cessation clinic.

Conclusion

These case studies demonstrate how coordinating care for children can differ greatly from coordinating care for adults. They also illustrate the importance of considering the normative developmental issues of children and how diabetes management is affected by these factors.

Tables 1 and 2 can be used prescriptively to identify potential pediatric challenges and to derive solutions throughout childhood and adolescence. Although much information can be generated using this process, it is important to work collaboratively with patients and their families to prioritize education and treatment options. In so doing, positive behavior changes can be broken down into small manageable steps to promote more consistent and ongoing success.

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