

A Provider's Perspective on the Management of Diabetes From Preschool Through the Teen Years

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Providing care for children with diabetes has been my passion and dream fulfilled since 1979, and I continue to learn new things every day.

At the time I started in this field, there was no glucose monitoring or A1C testing to track how patients were doing. We were using the insulin pump at the research center where I worked to see if it was a feasible option, but we could not send patients home with it because there was no way to check glucose at home. That first pump was the size of a brick and weighed a couple of pounds. It needed to be plugged into the wall at night and had a flashing red light on the front (1).

Many things have changed since that time. Now we have smaller insulin pumps and continuous glucose monitoring (CGM) devices to help us care for patients in a way that is much safer. Fear of hypoglycemia has decreased immensely with the advent of alarms on CGM devices that can alert the children—and often their parents, school nurses, and other caregivers—if their glucose is too high or too low. This is a function of the SHARE mode on the devices, which connects to up to five phones.

My practice consists of a pediatric endocrinologist and myself, but I am the only one who cares for the 250 patients with diabetes. My background included working at a large medical center with a diabetes program managed by a team. Now, I am the team. I enjoy this most of the

time, but it can be overwhelming at times. The cost of maintaining a multidisciplinary team is prohibitive for a small center such as ours. And yet, all patients have access to 24-hour care, and all have my cell phone number (2).

Children with new-onset diabetes are usually diagnosed in their pediatrician's office, and then we receive "the call." Soon thereafter, they come to the office with their parents in tow, and the action begins. Many times, there is no room in my schedule for a 2-hour teaching session, but we manage to fit them in somehow so they can learn what they need to know to survive for a few days or a week until they can be seen again. Patients or their parents call daily for adjustments in the insulin doses, and any questions they may have are fully answered. They are always grateful to avoid an admission to the hospital.

Only rarely are such patients admitted to the hospital. This may happen if it is a weekend or if the patient is in diabetic ketoacidosis. Initiating newly diagnosed patients on an outpatient basis was not my philosophy when I was part of a large medical center with a team, but I have come to believe it is the best option for patients and their families. Children can go to school the following day and can follow their usual routine without being hospitalized. Parents can care for their other children and are not as stressed. This allows them to concentrate more on the education. The parents need to

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give an injection and perform a blood glucose test before they go home. They are given materials to continue their education at their own pace.

Toddlers and Preschoolers

Caring for patients in the toddler/preschooler age-group is difficult in some ways and easy in others. Because parents or caregivers of children in this age-group are totally in charge of their child's diabetes management, it is easier to maintain blood glucose levels in the normal range. Parents or caregivers count the carbohydrates in their child's meals and make sure the child has the right number of carbohydrates and the right dose of insulin to match those carbohydrates. They also regulate where the child is going and what he or she will be doing (3).

Normally, in my center, patients are started on an insulin pump as soon as their parents want one and their insurance agrees to pay for it. This varies based on insurance requirements, but more often than not, I am able to secure a pump rather early (within the first 3 months). This allows much more variability in eating and allows both the child and the parents or caregivers more flexibility in scheduling each day's activities. The child does not need to eat at certain times and stop what they are doing to have snacks and meals. This greatly decreases the family's stress level (4).

Toddlers and preschoolers are resistant to just about everything, so taking injections and testing blood glucose are challenging at first. Luckily, children in this age-group are also adaptable; within a few weeks, they often will help with the testing but still resist the shots. Many of the preschoolers in my practice are also put on a CGM device, which further reduces the stress level of their parents or caregivers (5).

The downside of caring for toddlers or preschoolers with diabetes is that, many times, they do not want to eat, or they want to eat more, after their insulin is given. Insulin pumps

allow for more food by simply providing another bolus. We also can give one-half of the dose before a meal, wait to see if the child will eat the full meal, and then give the rest of the dose, if necessary, after the meal. This can be helpful as long as the bolus to be given after the meal is not forgotten.

Managing diabetes for young children who are ready to start a preschool program can be particularly challenging because preschool staff and teachers often do not want to check blood glucose or administer insulin. Fortunately, these programs usually only last for a few hours of the day. Some parents have gotten the child's preschool teachers to check blood glucose or have put their child on a CGM device. If the child is on an insulin pump, a greater basal rate can be programmed into the pump to accommodate the carbohydrates consumed when food is given at lunch or snack during preschool. Some parents opt to send in a snack that has no carbohydrates and therefore will not raise the child's blood glucose level. Still others have found preschool programs that are run through the local public school system and have a nurse available for children with diabetes. This has been a great benefit for both the parents and the child. If a child is in daycare and the parents or caregivers are working, a daycare program must be found that will allow blood testing and insulin bolusing for the child. Finding such a program is a huge burden for parents. Using a CGM device can make the process easier. Still, getting the center to give insulin is the real challenge, and some just refuse. If the child is on injections, I use NPH insulin to cover lunch in this situation.

All caregivers are capable of performing blood glucose monitoring and giving insulin injections with proper instruction. They understand that their child needs this to survive. Most are also able to handle an insulin pump—even some that at first seemed most unlikely to. Much

time and effort and patience must be devoted to the caregivers who seem to be the most challenged. Having a provider available to answer questions at all times is essential. I have never had a parent or caregiver who was totally incapable of performing the tasks necessary to care for the child, but I have had many who need a great deal of support. As long as they know someone is there to help them and to answer their questions in a timely manner, they seem to do fairly well. Some patients and their parents or caregivers need to be seen weekly until they are capable of managing on their own. I continue to see some patients every other week to help ensure that they are successful and have an A1C that is at or near a goal of <7%.

School-Aged Children

School-aged children are usually fairly easy to manage because they are not growing rapidly and are now usually able to participate in their own care (6). When a school-aged child is diagnosed, he or she is started with NPH and lispro or aspart insulin to avoid needing an injection during the school day. In the beginning, it is easy to regulate their glucose with this combination. After about 6 months, this becomes more difficult, and we then suggest using an insulin pump (7).

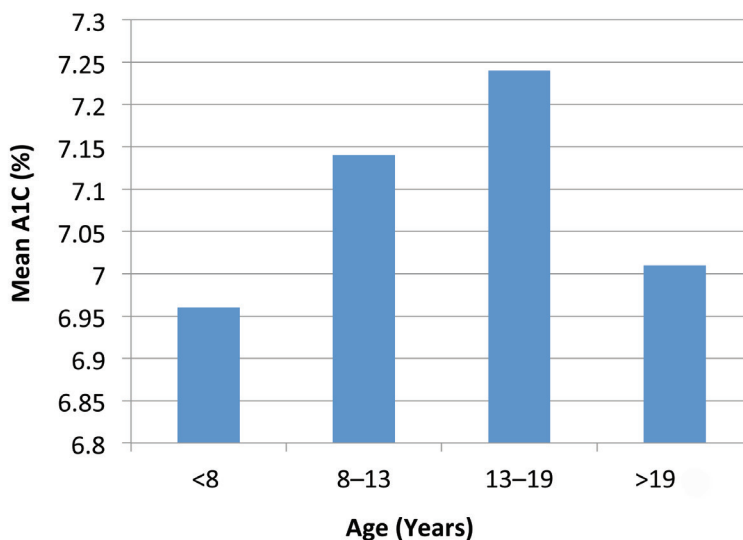
Many times, however, we start pump therapy earlier than this because it is easier when a child is in the "honeymoon phase" of diabetes; blood glucose levels are stable in this stage, which makes switching to a pump less complicated and doses easier to calculate. Many children are sick of taking shots after about 3 months; they are ready to try something that will give them better control without compromising their ability to eat at various times and to have more frequent snacks around sports and after-school activities without having elevated blood glucose by dinnertime. A pump can also help in managing glycemia around parties

and other irregularities in a child's routine.

Many parents opt to put the child on a CGM device that will allow them to see what the child's blood glucose level is when the child is away from them. Some school nurses have also opted to follow blood glucose from their office using this feature rather than requiring the child to come to the office for blood glucose checks. Some parents are glued to the CGM glucose sensor readings at first but then become accustomed to going about their usual routine. School nurses also are initially nervous and feel the need to constantly check their phone for readings, but they, too, become accustomed to it.

School-aged children are usually under the care of a school nurse and do fairly well during the day; in the evening, under their parents' watchful eyes, they also do well. Children in this age-group actually want to do well, and they try very hard to do all that is asked of them. They like being successful, and this makes it easy to care for them and help them achieve their blood glucose goals. Congratulating them on their achievements seems to be enough of a reward for them. Still, being available to their parents or caregivers is key because they are the ones who are responsible for adjusting doses and basal rates, using an insulin-to-carbohydrate ratio, and administering correction doses, and they need guidance with all of these tasks.

All the school-aged children need a written plan for school (8). We do this each year in July and August. I try to remember to start the process as early as May to better survive the start of school. Sometimes, however, parents lose their plan before school starts and need another one for the first week of school; this is one of the things I find most frustrating. These children will have diabetes for a lifetime, but this task must be done every single school year. When a child goes on a school trip, another



■ FIGURE 1. Mean A1C by patient age-group at the author's clinic.

set of orders is required. These tasks are one of the many things that make being in a solo practice more difficult; all of these orders must be done by me personally.

Teenagers

Teenagers can be difficult, both at diagnosis and during follow-up. It is particularly devastating to be diagnosed as a teen because so many other things are happening at this time. Newly diagnosed teens have the skills and abilities necessary to participate in their own care immediately (9). Consequently, parents tend to step back and let their teens do most of the care themselves. This may be a mistake for some teens who do not feel comfortable asking for help because they feel the need to take on this responsibility alone. Some teens just need to grieve for a while before completely taking on their diabetes care. The diagnosis comes as such a shock, and there are so many tasks that they need to master, that they can be overwhelmed (10,11).

On the other hand, teens are enjoyable to work with because they are involved in so many activities, and it is a joy to participate even in a small part in teaching them to be independent.

Sports are a big part of many a teenager's life. Helping keep their

blood glucose levels normal can make these teens better participants in their chosen sports. This is not an easy task because sports can really mess with blood glucose control. Many times, blood glucose will become elevated during the sports game or practice and then drop to a drastically low level later in the day. At other times, blood glucose is low during the sport and then very high after.

We need to work together to overcome these high and low blood glucose levels. Sometimes a snack is required before sports activity, sometimes a snack is needed at halftime, and sometimes it is needed at the end of the activity or even 2 hours later. This is often a trial-and-error process until we find the right treatment that works for a particular teen. Often, it depends in part on which sport is being played. Sports such as basketball, soccer, and hockey are different from football and baseball; sports that require constant high energy levels tend to lower blood glucose levels, whereas those requiring spurts of energy may elevate blood glucose. Measures to keep blood glucose in the normal range during sports will also depend on whether the teen is on an insulin pump or an injection regimen. We need to make adjustments until the right balance is achieved

and the child performs the best that he or she possibly can.

Many of my teenaged patients text me directly when they need help. This takes their parents out of the loop. Sometimes that is a good thing; sometimes it is not. For teens who feel comfortable contacting me directly, this system works best. It helps them feel in control and allows them some freedom to make their own decisions about their care.

Reaching A1C goals is essential to maintaining health and avoiding complications so that they are in position to partake in the “cure” when this becomes available. The mean A1C at our clinic for patients <8 years of age is 6.96%; for those 8–13 years of age, it is 7.14%; for those 13–19 years of age, it is 7.24; and for those who are >19 years of age (who we continue to see through college), it is 7.01% (Figure 1). It has been extremely rewarding for me to watch so many children grow and mature through the years and master the care of their diabetes. Many previous patients still keep in touch

and have matured into responsible, caring adults who are healthy and happy. This gives me the momentum to continue providing care to children with diabetes and watching a new generation progress with all the newer technologies now available for managing this disease. It is my hope that a cure will emerge in the near future and that I will live to see them all receive it, whatever it may be.

Duality of Interest

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

References

- Ahern JA, Arguello R. Development and evaluation of a pediatric diabetes program by a single provider. *Diabetes Educ* 2014;40:412–416
- Ahern JA. Insulin infusion pumps. *Nursing* 1981;11:107–108
- Valenzuela JM, Smith LB, Stafford JM, et al. Shared decision-making among caregivers and health care providers of youth with type 1 diabetes. *J Clin Psychol Med Settings* 2014;21:234–243
- Weinzimer SA, Ahern JH, Doyle EA, et al. Persistence of benefits of continuous subcutaneous insulin infusion in very young children with type 1 diabetes: a follow-up report. *Pediatrics* 2004;114:1601–1605
- Patton SR, Dolan LM, Smith LB, Thomas IH, Powers SW. Pediatric parenting stress and its relation to depressive symptoms and fear of hypoglycemia in parents of young children with type 1 diabetes mellitus. *J Clin Psychol Med Settings* 2011;18:345–352
- Scott LK. Developmental mastery of diabetes-related tasks in children. *Nurs Clin North Am* 2013;48:329–342
- Ahern JA, Boland EA, Doane R, et al. Insulin pump therapy in pediatrics: a safe alternative to safely lower HbA1c levels across all age groups. *Pediatr Diabetes* 2002;3:10–15
- American Association of Diabetes Educators. Management of children with diabetes in the school setting. *Diabetes Educ* 2014;40:116–121
- Wu YP, Hilliard ME, Rausch J, Dolan LM, Hood KK. Family involvement with the diabetes regimen in young people: the role of adolescent depressive symptoms. *Diabet Med* 2013;30:596–602
- Belendez M, de Wit M, Snoek FJ. Assessment of parent-adolescent partnership in diabetes care: a review of measures. *Diabetes Educ* 2010;36:205–215
- Grey M, Doyle E, Yu C, Sullivan-Bolyai S, Tamborlane WV. Person and family factors associated with quality of life in adolescents with diabetes. *Diabetes Care* 1998;21:909–914