

Open communication helps teens manage type 1 diabetes

May 24 2019, by Serena Gordon, Healthday Reporter



It's a simple concept, but new research reinforces the idea: Teens with



type 1 diabetes benefit when they feel their concerns have been heard.

Teens with type 1 <u>diabetes</u> may experience anger, frustration and anxiety if they haven't met their treatment goals. Their parents and <u>health care</u> <u>providers</u> may also feel frustrated and may blame the <u>teen</u>. But the new study suggests that interventions designed to improve diabetes-related care and communication could improve a teen's diabetes self-management.

"The biggest thing people don't understand about living with type 1 diabetes is that patients become physicians essentially, and doctors and staff become consultants," said the study's lead author, Dr. Harold Starkman. He's the director of pediatric endocrinology at the BD Diabetes Center at Atlantic Health System's Goryeb Children's Hospital in Morristown, N.J.

"Families and teens who have type 1 diabetes have the responsibility of caring for diabetes all the time. They have to figure out how much insulin they need, what to eat, count the carbohydrates in the food, consider the impact of diabetes," he explained.

Most teens are trying to do the best they can, but it's a lot of responsibility, he said. And, it's frustrating to ask for help when you're a teenager.

"Normally, teens need to separate from their parents and move on, but for teens with type 1 diabetes, diabetes is a tether," Starkman said.

Type 1 diabetes is an autoimmune disease that causes the immune system to mistakenly attack healthy insulin-producing cells in the pancreas. Insulin is a hormone that helps usher the sugar from foods into the body's cells to be used as fuel. This attack leaves people with type 1 diabetes with little to no insulin.



To survive, they must take insulin injections or receive insulin from an insulin pump multiple times a day, every day for the rest of their lives. They also must monitor their blood sugar levels to ensure they haven't given themselves too much or too little insulin, either of which can be dangerous.

Dr. Mary Pat Gallagher, director of the pediatric diabetes center at NYU Langone Health in New York City, agreed that diabetes can be tough for teens as they're trying to develop their independence.

"Diabetes raises the stakes on the usual adolescent journey," Gallagher said.

"Type 1 diabetes requires constant vigilance, and that's challenging for teens who have many other developmental tasks. Just as other adolescents do, teens with type 1 diabetes are trying to become separate from their families. They're also trying to identify with their peers and fit in with their peer group, and diabetes can make them feel different from their peer group," she explained.

At the same time, Gallagher said, parents may worry more because if their child doesn't do what they need to do, they could be putting their health in danger.

Teens may react to the pressure by trying to ignore their diabetes care by skipping insulin doses, or not checking their blood sugar levels.

Starkman said that "kids rebel by pretending they don't have diabetes." And that can backfire because it may leave teens feeling guilty and scared, he said.

For the study, the researchers interviewed nine teens with poorly controlled type 1 diabetes about their diabetes care. They also spoke



with the teens' parents and their health care providers.

The researchers found similar themes of anger, frustration, guilt and anxiety among teens, parents and providers.

The key to breaking these cycles is open communication, Starkman said. For example, a mother might become angry with a teen who didn't test his blood sugar. The teen just sees the anger, and might not realize she's angry because she's scared.

On the flip side, the teen may have missed his last blood sugar check, but maybe it was his fourth or fifth one of the day, and he'd also had to give himself two shots of insulin. And now he's frustrated and mad that mom didn't see everything he did remember to do.

"We have to work on getting away from being angry or being judgmental. Rather than telling kids what to do, ask questions: "It must be really difficult to do all of this. How can I help?" Or, if the teen has an issue—maybe they're going to prom and don't know what to do with their <u>insulin</u> pump. Say, "How can we solve this problem together? Maybe you could do shots during prom weekend? Or, wear your pump somewhere people won't see it?"" Starkman said.

He added that it's very difficult to have optimal diabetes management unless you have good communication.

For parents and providers, Gallagher recommended not focusing on diabetes right away. With her own patients, she said she asks them what's going on in their lives so she develops a relationship with them.

Gallagher said it's important to remain available to teens and to check-in frequently. But she added that you can let them lead the way. "Try to ask how you can be helpful to them. Do they need any supplies? Do they



want you to help look at their blood glucose patterns?" she suggested.

The researchers also recommended acknowledging a teen's efforts, and trying to focus less on just the blood sugar control numbers.

Starkman said it's extra important to keep <u>teens</u> engaged because they'll soon be transitioning to adult diabetes, and the researchers noted that nearly one-third don't seek care as adults until they have complications.

Findings from the study were published in the American Psychological Association's *Families, Systems, & Health* journal.

More information: Read more about how type 1 diabetes can impact mental health at <u>BeyondType1.org</u>.

Harold Starkman et al. Listening to adolescents with uncontrolled diabetes, their parents and medical team., *Families, Systems, & Health* (2019). DOI: 10.1037/fsh0000396

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Citation: Open communication helps teens manage type 1 diabetes (2019, May 24) retrieved 7 May 2024 from <u>https://medicalxpress.com/news/2019-05-teens-diabetes.html</u>

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