

Parents, professionals need better awareness of DKA and diabetes symptoms

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As a parent of two children with type 1 diabetes, I have spent a large portion of my life advocating for diabetes causes. I have written hundreds of articles dealing with everything from what to do with all of that Halloween candy to avoiding blood glucose checks when parked in a remote area. People with diabetes — and those who care for them — face many landmines on a daily basis.

Recently, an article about diabetic ketoacidosis (DKA) from *Pediatrics* caught my eye. The researchers concluded, “The frequency of DKA in youth with type 1 diabetes, although stable, remains high, indicating a persistent need for increased awareness of signs and symptoms of diabetes and better access to health care.”

This finding came at a time when there was much dialogue within the diabetes community about the death of two children during a single weekend from undiagnosed type 1 diabetes. The discussion broadened when it was revealed that the children had been back and forth to medical professionals with various influenza- or virus-like symptoms numerous times with no testing ordered to explore the possibility of elevated blood glucose. The course of events led me to wonder whether medical professionals need to be made aware that influenza or virus symptoms do not mask the onset of type 1 diabetes but, rather, are actual warning signs that warrant diagnostic testing.



Susan Weiner

Vague symptoms, missed diagnoses

When a patient’s complaint is of constant urination, fatigue and weight loss, it is almost certain that the child will be tested for type 1 diabetes. But what if a child presents with vomiting that is the result of DKA without other symptoms? Does this situation occur often enough for endocrinologists to warn parents, health officials and other medical professionals of a growing problem? Is it a growing problem?

A recent study examining how children receive a diagnosis of type 1 diabetes concluded that “future interventions should be targeted at parents in the appraisal interval and include the importance of timely presentation to a health care professional and the differences between type 1 and 2 diabetes. Primary care physicians should also take parental concerns seriously and do urine dipstick tests during the consultation for children with symptoms of type 1 diabetes.”

If there were a town hall meeting with medical professionals and elected officials, some would undoubtedly call for mandated testing for diabetes in children with these symptoms. However, although studies state that there is a rise in cases of DKA, the extent of the problem is not clear.

Informal survey results

I decided to hold my own online town hall meeting to see if, indeed, there was a real problem with DKA and a diabetes diagnosis being missed — nothing official, just to see if I could find any information that could dismiss or encourage my activities as an advocate. I would rather not waste time on a perceived problem that is not an actual problem. I created a survey with just a few questions, nothing scientific, thinking that if I could get 150 responses, perhaps someone would think the numbers were scientific enough to open a dialogue for further evaluation.



Tom Karlya

My 3-day survey received responses from 570 people (506 of whom sign-in with an email address), each of whom reported that their child had been diagnosed with type 1 diabetes while in DKA within the last 10 years in the United States. Of those, 96.5% stated their child was younger than 21 years; 79.3% had been hospitalized. Most children survived the hospital stay and moved on, but four experienced some sort of brain damage, and five died.

When asked if their child had seen a medical professional for influenza- or virus-like symptoms before being diagnosed, just more than half of the respondents said “yes.” The estimated medical bills of 320 respondents exceeded \$3 million; 125 people were unable to give an amount of their bill because it had been paid by Medicaid or the military. The number of workdays lost by caretakers of hospitalized children numbered 7,289, and 18 participants left their jobs altogether.

A major organization has begun to create a more comprehensive study with an institutional review board to see if more scientific results can be acquired.

Next steps

The problem of rising incidence of DKA exists and with it the number of patients with undiagnosed type 1 diabetes. Steps need to be implemented not only for better education of parents and patients, but also for medical professionals. The question I continue to grapple with is whether the steps to help eliminate missed diagnoses can be achieved through policy change or will require legislation. No one

wanted to be told that they had to wear a seat belt, but when mandated against fierce opposition, lives were saved. At the same time, policy changes in medical procedures have long been at the forefront of better care, not just in diabetes.

What I know is that one death just seems to be too many. I'm also a realist and know that any medical condition can cause harm. This growing problem is the fault of no one specifically, but working together, it should become all of our responsibility to, at the very least, lessen occurrences. When we achieve that, we will save a few lives at the same time. You are the medical professionals, and I seek your input to this discussion. I am just a diabetes dad.

References:

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For more information:

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