



White Paper

The Lived Experience of Diabetic Ketoacidosis: A Qualitative Study of Adults with Type 1 Diabetes and Caregivers of Children with Type 1 Diabetes

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Summary

Purpose

- Diabetic ketoacidosis (DKA) remains one of the most serious complications of type 1 diabetes (T1D), yet the lived experience of how people recognize, respond to, and recover from DKA is not characterized well.
- To explore this gap, T1D Exchange conducted one-on-one interviews with twelve participants—six adults with T1D and six caregivers of a child with T1D—each who had been hospitalized for DKA after diagnosis.

Findings

- Even highly educated, engaged people living with T1D are caught off guard by DKA. Many participants had lived with T1D for years or decades without a hyperglycemic emergency since diagnosis, and the symptoms of DKA were difficult to distinguish from illness.
- Access to real-time clinical guidance differs between adults and children: caregivers relied on structured on-call healthcare support for managing their child's ketones, whereas adults with T1D monitored ketones and decided when to seek emergency care on their own.
- The toll of DKA lasts long after physical recovery. Fatigue, frustration, and guilt were common in the immediate aftermath, while fear and panic lingered for months. Many participants remained on high alert to prevent DKA from recurring.
- Current tools for ketone monitoring leave an unmet need. Participants raised concerns about the accuracy and sensitivity of urine ketone strips, and many had low familiarity with blood ketone meters. Both methods capture only a single point in time, pointing to the potential of continuous ketone monitoring to enable earlier detection and treatment of ketones.

Background

For people with type 1 diabetes (T1D), diabetic ketoacidosis (DKA) remains one of the most serious complications and affects thousands of individuals each year, even in the era of continuous glucose monitoring (CGM) and automated insulin delivery.¹ Clinically, DKA is characterized by three features: first, insulin deficiency leading to ketone-body production; second, metabolic acidosis; and third, in most but not all cases, hyperglycemia.² Emerging evidence highlights that glucose and ketones can follow independent trajectories in people with diabetes, meaning ketones may rise dangerously high even when blood glucose is within the normal range.³ For many people, particularly youth, DKA is the presenting feature at the time T1D is diagnosed.⁴ In people with established diabetes, DKA is often precipitated by illness or infection, missed insulin doses, or insulin pump malfunction (including infusion set failures).⁵

Promptly detecting and treating ketones is critical to preventing DKA, which carries risks of both mortality and morbidity. Clinical guidelines recommend ketone monitoring during illness, insulin omission, or persistent hyperglycemia.⁶ People with diabetes are advised to drink more fluid and take additional insulin if ketones are detected, and to seek medical care if they develop symptoms of DKA. In the hospital, clinicians treat DKA with intravenous insulin and intravenous fluid for hydration and electrolyte replacement, while also identifying and treating the precipitating cause.⁷

The burden of DKA falls on both people with diabetes and the healthcare system. In the United States, hospitalization for DKA costs between \$21,000 and \$36,000 per admission, totaling an estimated \$5.1 billion per year.^{6,8} For people with diabetes, the consequences of DKA extend beyond hospitalization, carrying risks of serious neurological, renal, and cardiovascular harm.^{9,10}

Objective

Existing research has focused largely on clinical outcomes of DKA; far less attention has been given to how people recognize, respond to, and recover from this acute diabetes complication. We developed this white paper to explore the lived experience of DKA in adults with T1D and caregivers of a child with T1D who had been hospitalized for DKA at least once post-diagnosis. Using qualitative interviews, we investigated participants' characterization of the onset, symptoms, and treatment of DKA; their reflections on knowledge of DKA that they lacked prior to this experience; their descriptions of the toll DKA took on their lives and the steps they took to prevent recurrence; and their perspectives on and engagement in ketone monitoring.

Methods

We conducted a qualitative study with semi-structured one-on-one interviews to explore the lived experience of DKA. The study was approved by the WCG Institutional Review Board.

Eligibility

Eligible participants were adults (≥ 18 years old) living with T1D and caregivers of a child (< 18

years old) living with T1D. In both groups, the person with T1D had to use insulin therapy via insulin pump or injections, have lived with T1D for at least one year, and have been hospitalized for DKA at least once after their T1D diagnosis. Eligibility was based on self-report only; medical records were not reviewed to confirm diagnosis of DKA. Participants were recruited from the T1D Exchange Registry, a longitudinal study of people with T1D in the United States.

Participants

Twelve participants (six adults with T1D and six caregivers of a child with T1D) completed an interview after providing informed consent. As shown in Table 1, the six adults with T1D had a median age of 34 years and T1D duration of 20 years; the six children (as reported by their caregiver) had a median age of 9 years and T1D duration of 5 years. The most recent DKA event occurred a median of 4.5 years before the interview for adults with T1D and 2.5 years before the interview for children. In addition to the DKA event after diagnosis, which was the focus of the interview, most (5 of 6 adults and 4 of 6 children) had also experienced DKA when they were diagnosed with T1D.

Table 1. Characteristics of interview participants

Characteristic	Group	
	Caregivers / children with T1D (n=6)	Adults with T1D (n=6)
Characteristics of caregiver		
Sex, <i>female</i>	5 (83%)	—
Education, <i>bachelor's degree or higher</i>	4 (67%)	—
Age, <i>years</i>	40 [37, 43]	—
Characteristics of person with T1D		
Sex, <i>female</i>	3 (50%)	4 (67%)
Education, <i>bachelor's degree or higher</i>	—	5 (83%)
Age, <i>years</i>	9 [6, 11]	34 [28, 42]
Age at T1D diagnosis, <i>years</i>	3 [2, 4.75]	17 [12, 20.5]
Duration of T1D, <i>years</i>	5 [4, 8]	20 [16, 29]
Prior DKA at T1D diagnosis	4 (67%)	5 (83%)
Time since DKA event occurred, <i>years</i>	2.5 [2, 4.5]	4.5 [2, 7]
Current treatment regimen		
Insulin pump with CGM and AID	6 (100%)	4 (67%)
Insulin pump without CGM	0 (0%)	1 (17%)
MDI and CGM	0 (0%)	1 (17%)

Data reported as n (%) or median [interquartile range]. T1D, type 1 diabetes; DKA, diabetic ketoacidosis; CGM, continuous glucose monitor; AID, automated insulin delivery; MDI, multiple daily injections.

Most interview participants were female and held a bachelor's degree or higher. All children and most adults used an insulin pump and CGM with automated insulin delivery. Participants' demographic characteristics and high engagement with technology mirror the characteristics of the T1D Exchange Registry and should be considered when interpreting findings.

Procedures

Semi-structured interviews were conducted by a diabetes researcher via video conference and lasted up to one hour. Participants were first asked how and when they were diagnosed with T1D, then asked to describe their experience with DKA in chronological order, from the context in which it occurred through seeking medical care. They were asked about their emotions during and after hospitalization; their perceptions of whether and when DKA could recur; their perceived knowledge of ketones and DKA, including anything they learned during or after the hospitalization; and their familiarity and experience with monitoring ketones via urine or blood, including which method they preferred and why.

After completing the interview, participants received a gift card as compensation for their time.

Interviews were recorded and transcribed verbatim. Transcripts were reviewed to identify recurring themes and representative quotes. Emerging findings were shared with colleagues for feedback and validation.

Results

Findings are organized into six sections, beginning with how participants characterized the DKA event and knowledge they lacked before it occurred; followed by their reflections on the toll of DKA and how they try to prevent it from recurring; and concluding with their engagement in ketone monitoring and perspectives on monitoring urine versus blood ketones.

Characterizing the DKA Event

Perceived Precipitators

Most participants described their DKA event as being triggered by an illness or infection. As explained by one participant:

“I got the flu, influenza B, and norovirus at the same time... And apparently, that combination kicked me into DKA.”

—Adult with T1D

Two participants, both adults with T1D, experienced an infusion set failure overnight:

“I was changing my [insulin pump infusion] set, and it was at night, which I know you're not supposed to do, but... I thought it was in, and I checked my blood [glucose], and in four hours, it was very, very high, and I thought, I'm not getting any insulin. I put it in wrong.”

—Adult with T1D

Onset and Recognition of Symptoms

Nausea and vomiting were the most common symptoms participants reported. One caregiver described how her son's vomiting became more frequent over time:

“He had gotten the stomach bug, and he threw up a few times... But at some point, really quickly, he started throwing up a lot.”

—Caregiver of child with T1D

An adult with T1D recalled severe vomiting that rendered her unable to retain fluid thus unable to administer bolus insulin:

“We were trying everything to get some sugar in me so I could still take insulin and try and get my ketones regulated. Like I was literally just like swishing sugar water in my mouth on my gums to just try and get something, some level of carbs in my body so I could push carbs and insulin and water and try and take care of it. But nothing was helping.”

—Adult with T1D

Beyond nausea and vomiting, participants described a constellation of symptoms. One participant described feeling tightness of the chest and difficulty breathing:

“It's nauseous without eating... it's like there is a lead weight on your body. And even though it was not nearly as difficult to breathe as it had been 20 years before, it was still a tightness of the chest.”

—Adult with T1D

Another participant described itchiness, thirst, and fatigue:

“Skin gets really itchy. You just feel like bugs are crawling all over you. You're incredibly thirsty. You just want to sleep.”

—Adult with T1D

One caregiver recognized the smell of ketones on her daughter's breath:

“I remember I could smell the ketones on her breath... and I still, to this day, can always smell them. It's just such a distinct smell.”

—Caregiver of child with T1D

For some participants, their recognition of symptoms—and with it, the decision to monitor ketones or seek care—was delayed. One adult with T1D woke up with severe nausea and fatigue after unknowingly experiencing an infusion set failure overnight. Her blood glucose was high, but below the threshold she associated with DKA, and she repeatedly fell asleep from fatigue rather than troubleshoot the symptoms or suspect DKA:

“In the night, I remember I woke up once to the pump beeping, and I admittedly just silenced it... And then I don't remember it beeping again. I woke up on Sunday and I felt horrible... My blood sugar wasn't super high, it was maybe, like, 230, so, it wasn't like alarm bells right away to the DKA... [and] it was just like a tiredness that I had never felt... I wasn't actually passing out, but I felt like I was kind of going in and out of consciousness... I was kind of, like, ‘Oh, something weird is going on’ and then I would just pass out and wake up, like, an hour later. And that cycle kind of went on for hours. I would wake up, throw up, be like, ‘This is weird’ and then I'd fall asleep.”

—Adult with T1D

One caregiver did not initially attribute her son's symptoms to DKA because of inaccurate CGM data. Her son was vomiting but his CGM readings were within target range, so she was not concerned about ketones. After his vomiting worsened, she contacted their healthcare team, who advised them to go to the emergency department; there, a fingerstick revealed blood glucose roughly 300 mg/dL higher than the CGM had shown:

"It felt like mostly the stomach bug, like a really bad stomach bug... He threw up a few times... I was expecting the blood sugars to go up, but they stayed pretty level, so we were managing it through the day. I'm like, 'Drink your water,' all the things... And this whole time, [his CGM sensor] is reading 90, 95. So I was... I was not super concerned because of his numbers with his ketones... We get to the ER. They do a finger stick, and he was almost 400."

—Caregiver of child with T1D

Treatment and Resolution

All participants were eventually hospitalized but differed in how they sought emergency care. Most caregivers, after suspecting DKA, contacted their child's healthcare provider by phone and were directed to go to the emergency department. One caregiver scheduled a same-day sick visit for her daughter at the pediatrician's office, where they were directed to go to the emergency department:

"We went to the doctor. They took one look at her, and were like, 'We're not equipped to deal with this. Go to the hospital.'"

—Caregiver of child with T1D

Adults with T1D, on the other hand, called an ambulance or went directly to the hospital without seeking clinical support. One participant recognized she needed help after a urine ketone strip turned the darkest color, so she asked her friends to take her to the hospital:

"I had been vomiting.... And [my CGM reading] wasn't really coming down, but it also wasn't going up much, which was kind of surprising... so I checked the finger stick, and it was a little bit higher than the sensor had been reading, maybe like 250, 260. And then I had the urine ketone strip, and I peed on it, and it immediately turned the darkest color possible... No one was home. I was like, I know that I need help. And luckily, my three roommates from college all lived within, like, a five-mile radius. And I remember I just texted them and was-- and I don't even know if I gave details—but I think I was like, "I need help. Come over"... And they came up and helped me get dressed and then brought me to the ER."

—Adult with T1D

Most were admitted to the hospital for between one and four nights:

"I stayed in the hospital for two days. They gave me fluids because I was dehydrated... I was able to start drinking again and eating a little bit. And I still felt awful. But I was able to be okay enough to go home."

—Adult with T1D

Some discussed how the healthcare provider identified the underlying cause of DKA, like one participant who experienced an infusion set failure:

“I was in the ICU for two nights... They had me take the pump off and put me on an insulin drip, and when I pulled off the site, there was a whole pool of insulin underneath it.”

—Adult with T1D

A caregiver, whose daughter had lost CGM access after a lapse in health insurance, was given samples of CGM sensors before being discharged:

“And they made sure that we had sensors when we left and told us like, ‘Hey, just come up and tell us you need a sample, and we’ll give you samples of sensors.’”

—Caregiver of child with T1D

Gaps in Knowledge

Participants shared misconceptions they held about ketones and DKA before their hospitalization—beliefs that, in several cases, had been shaped by education received at the time of T1D diagnosis.

DKA Can Occur Post-Diagnosis Despite Actively Managing Diabetes

Several participants had understood DKA primarily as something that happens at T1D diagnosis rather than as an ongoing risk, especially those who considered themselves highly engaged in T1D management and having an established sick-day plan:

“We’ve learned how to manage it. We do as good of a job being a pancreas as we can. And so, you have that back thought that your child can go into DKA, but it’s so far in the back of your mind that it’s not there. And so, then when he did get DKA, three years later, it was like, oh, wow, he really can get DKA after [diagnosis], and it doesn’t matter how well you manage it. It doesn’t matter all the things you do... It’s still a possibility, and it’s still a risk.”

—Caregiver of child with T1D

Ketones Can Develop Without Severe Hyperglycemia

Many believed that ketones only develop when blood glucose exceeds a high threshold, typically 250 or 300 mg/dL sustained over time—and some believed that hyperglycemia itself causes ketone production. Participants recalled later learning that ketones can develop with blood glucose lower than 250 mg/dL:

“I was so shocked when they told me I had DKA because I thought that was the only way you could get it was if your sugar is crazy high.”

—Adult with T1D

Ketones Can Develop Rapidly

Some participants were caught off guard by how quickly ketones developed during their illness, increasing from absent or trace to large within hours.

"We were probably checking his ketones every hour or so. So early on, ketones are completely normal. No ketones.... And then probably about two hours later, we go back and check the ketones. There's large ketones. So it went from 0 to 60 in two hours. I was just surprised by the speed at how quickly things went from okay to very bad within a matter of hours."

—Caregiver of child with T1D

The Onset of DKA Occurs in Distinct Phases

One caregiver recounted an occasion when she took her daughter to the emergency department after detecting ketones; there, she learned that ketone production and metabolic acidosis are distinct stages, and that the presence of ketones does not automatically mean that full DKA has developed:

"She did develop ketones, and we went to our local emergency room and it was interesting because they said she was okay. So, she was diabetic, had ketones, but wasn't in acidosis yet. That was the first time I had heard the breakdown of you could have some, but not all of it."

—Caregiver of child with T1D

The Toll of DKA

Participants described a toll from DKA that evolved over time. In the immediate aftermath, they felt fatigue and frustration; in the following weeks and months, distress, fear, and panic. Some described lasting, unresolved trauma from the event.

Immediate Aftermath: Fatigue, Frustration, and Feelings of Failure

Participants reported emotional, mental, and physical fatigue. One participant attributed the fatigue to the cumulative effect of hyperglycemia and stress in the days leading up to the event:

"With the sustained high blood sugar, I think that there's a lot of fatigue physically, but also emotionally and mentally. Your [CGM] is going off every five minutes, it feels like, regardless of how many times you click off it. You're giving yourself so much stinking insulin, and it's a stress of, oh my gosh, it hasn't come down yet."

—Adult with T1D

Another adult with T1D took several days off work to recover from DKA, which left her feeling exhausted and depleted:

"I felt exhausted... kind of that feeling when you're recovering from an illness and your symptoms are better, but your body just feels depleted, and you need to rest and re-energize, and yeah. I just kind of felt depleted and I just wanted to lay on the couch. I think I actually took a couple extra days off of work."

—Adult with T1D

Participants felt frustrated, sometimes with themselves:

"I was also frustrated with myself because I do take really good care of myself."

—Adult with T1D

Others felt guilty and described the DKA event as evidence of failing themselves or their child:

"It was kind of like my worst nightmare. I told you about how much importance I put on just taking care of it for her. So, I really just felt like— I kind of felt like we had let her down."

—Caregiver of child with T1D

Lasting Distress and Fear

Several adults described DKA as fear-inducing. Some were scared by the physical symptoms, such as the sensation of being unable to breathe:

"I think anybody who's had it never wants to have it again. It's just terrible. Diabetes is terrible, and DKA is worse. The feeling is scary... being unable to breathe, it's just scary."

—Adult with T1D

Another was unsettled by the severe cognitive effects of DKA that impaired her ability to troubleshoot and treat her symptoms:

"I was really shaken up about how different I was acting. I'm normally very type A and so on top of it. And I just was surprised at how altered I got in my thinking because on a normal day, I would have been like, 'Oh. Let me check for ketones. I'm vomiting. This is really bad' but it just wasn't clicking, which was scary to me of how much it affected my normal brain process."

—Adult with T1D

Participants were frightened by what could have happened, as shared by one participant whose friends responded to her urgent need for help:

"It really scared me. I was very grateful that my friends came, no questions asked because I feel I would have just passed out in the hallway."

—Adult with T1D

For one, the fearful experience was a stark reminder of the serious risks of T1D, a disease that had become second nature to manage:

"[It was] just another reminder, I guess, of like, 'This is a lifelong thing. There's going to be other situations in the future that are scary.' I just think it was like a shock to the system because it had kind of become like second nature at that point."

—Adult with T1D

Echoing this sentiment, another adult with T1D characterized DKA as an eye-opening realization that seemingly mild illnesses could lead to severe or deadly outcomes:

"When you get sick like that, it's kind of eye opening. You know, a normal person can just combat the flu and be sick for a few days, but, like, I get debilitating sick. So, it's scary because as I get older, you know, stuff like that can — you kind of realize that that could kill you."

—Adult with T1D

Persisting Panic

In the weeks and months following their child's DKA, caregivers reported heightened anxiety

characterized by compulsive ketone monitoring:

“The first couple of months after her DKA... we were just so on edge about the whole situation that we were a little bit more jumpy about like, ‘Oh, let's check her ketones.’”

—Caregiver of child with T1D

For another caregiver, this vigilance was driven by fear that a recurrence of DKA could be even more severe:

“We went through a pack of 60 blood ketone strips within two weeks. So, it was just being terrified that he was going to go into DKA, and that this time was going to be the time where he would go into a coma and be in ICU.”

—Caregiver of child with T1D

Even years after DKA, an adult with T1D experiences anxiety whenever she feels nauseous, which was a primary symptom of her DKA:

“I get anxiety with nausea, for sure. And I think it's related somewhat to that. I mean, no one likes throwing up. But if I get any sort of nausea... I get really anxious about it, and I think that that's probably related.”

—Adult with T1D

Enduring Trauma

Some described DKA as traumatic, with its impact persisting long after physical recovery. One caregiver traced the trauma to her daughter's T1D diagnosis, when she feared her daughter would not survive the drive to the hospital:

“Because of her initial diagnosis and DKA, how scary it was and driving her to the hospital, and the doctor was basically like, ‘You need to talk to her and keep her alert,’ and you feel like your child's going to die in the back seat. So that just has never left me.”

—Caregiver of child with T1D

Another reflected on the enduring weight of knowing what DKA can become, having heard other families' experiences with severe outcomes:

“There's something so daunting around DKA. This last time that he was DKA...it was traumatic, and anything involving your child and something happening to them is traumatic... I mean, we have heard of horror stories of these children not being diagnosed with type 1 until they're in a coma... so it's always a fear.”

—Caregiver of child with T1D

One adult with T1D recalled the traumatic experience of DKA when she was diagnosed with T1D several years earlier:

"I was scared of the DKA because it wasn't a good experience the first time I was in it. And I think I was in it for way longer that time. So, I didn't want to get stuck in DKA and wind up with a month-long recovery time for my body to start feeling decent again. Just being in the hospital kind of traumatized me."

—Adult with T1D

Ongoing Behavioral Change to Prevent DKA

Participants shared their feelings and perceptions of the risk of recurrent DKA. Most felt that if DKA recurred, it would most likely be caused by illness or infusion set failure. Participants described how they try to prevent DKA, detect and treat ketones, and prepare mentally and logistically for a possible recurrence.

Timing and Placing Infusion Sets

One participant changed where she placed her infusion sets, avoiding sites where infusion set failures seem to occur:

"I would say 1 in every 25 [infusion] set changes, I get a blockage... it's usually if I put [the infusion set] on my stomach... so I either try to avoid putting it on my stomach, or I've found out that if I lay down and then put it directly on my stomach, the angle's a little bit different."

—Adult with T1D

She also avoids changing her infusion set at bedtime, so that a potential set failure would not go unnoticed overnight, as it had before:

"I try to not change my pump before bed because that's kind of what happened before. And I know that if I sleep through it, then it'll be hours [without insulin]."

—Adult with T1D

Owning and Using Ketone Monitoring Tools

The hospitalization prompted some to purchase ketone monitoring tools:

"I had always had in the back of my mind, of all the supplies and things we need for diabetes, [blood ketone meters] should probably be one that I should add. So, I think I bought it while we were still in the hospital. I was like, 'We're going to have one of these now, I see why they're important'"

—Caregiver of child with T1D

Participants monitored their ketones more often than they did before the DKA event, especially when hyperglycemic:

"I probably check for ketones more now than I did before that, if my blood sugar's high."

—Adult with T1D

Participants kept supplies on hand at home and when traveling:

"When we travel, we'll go with both [blood ketone meters and urine ketone test strips]."

—Caregiver of child with T1D

Modifying Social and Vocational Plans

One adult with T1D took steps to reduce his chances of acquiring illness, like washing his hands frequently and avoiding large social gatherings:

"It's not a thing I worry about daily, but it's something that's in the back of my mind, like, hey, maybe [I will] not go to this crowded place in the middle of January where everyone's coughing on each other, getting sick."

—Adult with T1D

A caregiver tended to keep his son home from school with mild illness, giving him time to recover and allowing them to monitor ketones at home:

"This [season] tends to be a period when he does get sick in some way, whether it's flu, cold, whatever it might be... [If] he's not 100%, he's going through something, we'll keep him home from school."

—Caregiver of child with T1D

One caregiver works remotely when his son is sick, should the illness progress and require a trip to the emergency department:

"I do have some flexibility to work from home, so days that he's not feeling well, I'm going to work from home... I want to be around in case I'm needed, in case we have to run to the hospital."

—Caregiver of child with T1D

Seeking Emergency Care

After the DKA event, some participants sought emergency care more often for suspected DKA, like one adult with T1D who later had food poisoning:

"In fact, a couple of years later, I actually had food poisoning and was throwing up... My blood sugar was a little high. I had small to moderate ketones. And I went to the emergency room... They did the whole workup, and they were like, 'You're not DKA.' But I was much more on top of it."

—Adult with T1D

A caregiver noted having high alertness when her daughter was ill, ready to seek emergency care quickly if ketones could not be managed at home:

"I get panicky almost when she has high ketones. I know what to do and I can zone in. But my thoughts go to like, 'Okay, we got to prepare to go to the hospital. We got to do X, Y, Z. This is going to happen again,' type of thing."

—Caregiver of child with T1D

Maintaining Heightened Awareness

Participants felt a heightened awareness of the risk of DKA, describing it as a worst-case scenario but not a source of daily worry:

“It really becomes top of mind in those situations when his blood sugars get very, very high, whether that's because he needs a pump change or he's ill... I don't spend too much of my day necessarily worrying about it, but I always have it as-- it's the worst-case scenario.”

—Caregiver of child with T1D

Another participant reported higher awareness of DKA overall, with occasional bouts of anxiety:

“I think it's more so that I'm more aware of things and on top of it than actively worrying about it. But then there are definitely some times where I'm, like, a little anxious about it.”

—Adult with T1D

Participants felt anxious about factors outside of their control. For example, one adult with T1D felt confident that she could treat ketones in most cases, but was unsure about what to do if she experienced another episode of persistent vomiting:

“I worry about, like, another episode of that happening where, like, what if I can't keep anything down again? And I don't have a good answer to that— if I can't keep food or water down— for how to manage that.”

—Adult with T1D

Worry was especially pronounced among those living alone, who expressed concern about being unable to recognize symptoms or seek help:

“Well, I worry about it because of this new pump... I worry if I don't put it in correctly... And it's more that I live alone, so if I fall asleep and go into a coma or something, then who's going to even know?”

—Adult with T1D

Engagement in Ketone Monitoring

Participants' engagement in ketone monitoring varied—and were categorized as symptomatic monitoring, asymptomatic monitoring, or no monitoring—reflecting differences in awareness, access, and perceived risk.

Symptomatic Monitoring

Most participants monitored ketones reactively in response to illness, prolonged hyperglycemia, or unexplained hyperglycemia:

"It's because I have been sick or it's been like a couple days and I won't get my blood sugar below like 200 and then I start to freak out, like, if my blood sugar is has not gone under 200 within 48 hours."

—Adult with T1D

Others monitored ketones when blood glucose exceeded a specified threshold:

"Even when he's not sick, but he's in the 400s, I'm immediately like, 'Whoa. What is the ketones? Let me make sure the ketones are okay.'"

—Caregiver of child with T1D

An adult with T1D monitors her ketones when she has hyperglycemia from suspected infusion set failure, as the sensation feels different to her than postprandial hyperglycemia:

"I can kind of tell feeling-wise, when my blood sugar's high from food or whatever versus a high from not having insulin. They feel different to me. And so definitely, if I feel the weird one where I'm like, 'This isn't a normal food high,' I always check."

—Adult with T1D

Asymptomatic Monitoring

Two participants monitored ketones routinely when asymptomatic. One participant monitored ketones out of concern about euglycemic DKA while taking a GLP-1 medication:

"Now that I'm taking a GLP-1... euglycemic DKA scares me a lot. And so, I probably test now once a month."

—Adult with T1D

The other has incorporated ketone monitoring into his child's morning routine since the child's T1D diagnosis, a habit sustained by the quiet reassurance of a negative result:

"The way the prescription was always written was 'Test ketones once a day, every morning.' We never deviated from that... it just became part of the morning routine... 99% of the time, it's trace or negative... so it's almost a little affirmation or small victory."

—Caregiver of child with T1D

No Monitoring

Two participants did not monitor ketones. One cited high cost and low perceived utility:

"I don't, because it's so rare that I ever have ketones and the strips are really expensive, so I'm not going to buy a new box of 50 which will sit in the bathroom for five years or ten years."

—Adult with T1D

Another had never owned ketone monitoring tools or been advised to use them:

"Ketones are not really something I watch or ever test for. I've never had a healthcare provider give me a script for the ketone strips or anything like that, or even suggest that I have them or test ever."

—Adult with T1D

Perspectives on Urine versus Blood Ketone Monitoring

Participants compared urine ketone strips and blood ketone meters, including whether they were familiar with each, and if so, how and when they became aware. Their preferences for one over the other were driven by trust in the tool’s ability to detect ketones with accuracy and precision; confidence in interpreting and acting on the test result; convenience of collecting a urine versus blood sample; and affordability of supplies. Patterns are summarized in **Table 2** and discussed in subsequent sections with illustrating quotations.

Table 2. Participant perspectives on ketone monitoring methods

Dimension	Ketone Monitoring Method	
	Urine Ketones	Blood Ketones
Familiarity	High awareness and familiarity; introduced by healthcare provider soon after T1D diagnosis.	Low awareness and familiarity; discovered independently after longer T1D duration.
Accuracy	Low accuracy and precision of ketone detection.	High accuracy and precision of ketone detection.
Clarity	Ambiguous results, especially with mid-range color.	Clear and actionable results.
Convenience	Similar ease to blood for adults; preferred by some for fitting into daily routine and being less invasive.	More convenient for young children and when a urine sample is hard to obtain (e.g., dehydration); more invasive for some people.
Affordability	More affordable.	Less affordable.

Familiarity

All participants were familiar with urine ketone strips, and most had learned about them from healthcare providers at or soon after their T1D diagnosis:

“We used the urine ketone strips out of the hospital because that was what was given to us.”
—Caregiver of child with T1D

Participants were less familiar with blood ketone meters:

“[We use] urine test strips only. I didn't even know that there were blood ketone meters. I've never used one, never seen one.”
—Caregiver of child with T1D

Blood ketone meters were usually discovered independently or through peer networks:

“They didn't tell us about [blood ketone meters] in our training. So, through online groups that I follow, people had mentioned that.”
—Caregiver of child with T1D

One participant was informed of blood ketone meters by their healthcare provider, but only after expressing challenges with urine ketone strips:

"They had told us to test it through urine. But he still wasn't potty-trained... They were like, 'Oh. Well, you can try and squeeze urine out of this pull-up.' And I'm like, 'There's got to be a different way to do this.' And that's when they were like, 'Well, you could do a blood ketone.'"

—Caregiver of child with T1D

Accuracy

Participants lacked trust that urine ketone strips accurately measure ketones:

"The urine strips being what they are, I do worry sometimes about-- they can't tell you super accurately how many ketones you've got"

—Adult with T1D

One participant understood that urine ketone strips measure ketones that accumulated in urine over the preceding hours, not the current moment:

"I understand the urine ketone strips are delayed. So, when you're looking at whether or not ketones are present, the reading is really accurate for like a couple hours ago...where the blood ketone is current in your system."

—Caregiver of child with T1D

On the other hand, participants trusted the accuracy of blood ketone meters:

"I feel like [the blood ketone meter] can tell me to a higher degree of accuracy how bad the ketones that I've got are, if I've got ketones and give me an answer that leaves me feeling more confident in."

—Adult with T1D

Clarity

Participants described feeling confused when deciphering the color result of a urine ketone test strip, particularly in the mid-range of the spectrum, and not knowing whether to be concerned.

"Looking at the color [on the urine test strip], it's like, is this taupe, or is this mauve?... There's a certain color where it reaches where you're like, 'I can't tell if this is okay or not okay.'"

—Caregiver of child with T1D

Numerical results from a blood ketone meter were viewed as clear and actionable. One caregiver liked being able to collect multiple numeric readings over time to assess whether the presence of ketones diminished.

"With [blood ketone meters], it's easy to see where the levels are going. If she's coming down, her ketones are going away, then I feel like we're on the right track."

—Caregiver of child with T1D

However, one adult with T1D liked viewing a color result. Citing the severe fatigue and confusion she felt during DKA, she believes interpreting a number would have been too complicated in that cognitive state:

“Especially with thinking back of how altered I was, I do think that matching colors is probably easier in that state of mind than reading a number.”

—Adult with T1D

Convenience

Adults with T1D found urine and fingerstick samples equally easy to collect. One felt that urine ketone monitoring fit into her routine better than an extra step of fingerstick:

“It kind of flows into the routine a little bit more. I just keep them in the bathroom... I mean, I prick my finger enough. If I'm going to pee anyway versus like an extra finger prick, I'd rather just pee on the strip.”

—Adult with T1D

Caregivers of young children preferred the blood ketone meter, comparing the simplicity of a fingerstick with the inconvenience of collecting a urine sample:

“The meter is a lot easier because you're not having to deal with having him urine into a cup and then test the urine or trying to do a free stream test.”

—Caregiver of child with T1D

A caregiver of an older child weighed the pros and cons of urine collection, noting that urine collection was less invasive for her son, who has a fear of needles, but that dehydration and illness sometimes made a blood ketone meter necessary:

“We still use mostly [urine ketone test strips]. That's less invasive for him. And it serves as a good quick check... But if he says he can't go to the bathroom and there's, in my opinion, a need that we really need to check it... we would do the blood ketone”

—Caregiver of child with T1D

Another caregiver of an older child discussed how her daughter often forgets to use the urine ketone strips when directed, which prompted her to use a blood ketone meter instead:

“After her DKA, I ordered a blood meter for her just for some ease and simplicity because I cannot count the number of times that we'll be like, “Hey, next time you pee, we got to check for ketones.” And then she comes out of the bathroom, and it's like, “Did you check for ketones?” “Oh no, I forgot.” Like, “All right. Well, now you can't forget. Now stick your finger.”

—Caregiver of child with T1D

Affordability

The costs of ketone monitoring supplies varied. One participant considered herself fortunate because her health insurance covered 100% of the cost of all ketone monitoring supplies:

“With our insurance, anything that's considered durable medical equipment, we get at zero cost. So, her blood glucose test strips and the ketone test strips both fall under that. So that's just a set order. Every three months, they just come to my house.”

—Caregiver of child with T1D

Another participant's insurance did not cover blood ketone monitoring supplies; thus, he used

urine ketone test strips because of their lower out-of-pocket cost:

“Blood [ketone] strips are really expensive. And in my experience, I haven't had great luck with insurance understanding why blood might be better than the urine ones when the urine ones are so much cheaper. So, I've often used the urine ones.”

—Adult with T1D

The affordability of these costs also varied. One caregiver considered the blood ketone monitoring supplies manageable relative to other healthcare expenses:

“I was just like, “All right. I'm just going to buy [the blood ketone meter] now [out-of-pocket]. There's definitely other things that we feel limited by our insurance...but a \$40 meter is a little bit more manageable.”

—Caregiver of child with T1D

Conclusions

Through in-depth interviews, we examined the experiences of people with T1D who developed DKA after being diagnosed with T1D, including the context leading to DKA, its symptoms and treatment, and the toll it took on their lives.

Participants were highly engaged in diabetes management and described being caught off guard by DKA. Because many had lived with T1D for years or decades without an acute hyperglycemic emergency since diagnosis, experiencing DKA was an eye-opening reminder of the seriousness of T1D and its potential risks. Onset of DKA was often attributed to a specific trigger—usually illness or insulin pump malfunction—and its symptoms were sometimes difficult to recognize, either because the symptoms mimicked those of co-occurring illness or because the symptoms impaired their ability to detect and treat ketones before DKA developed. Access to clinical support differed between adults and children, with adults seeking emergency care independently and caregivers relying on guidance from their child's healthcare provider.

Experiencing DKA was frightening and sometimes traumatic, with its emotional weight outlasting physical recovery. For some who had previously experienced DKA at T1D diagnosis, the later event compounded their feelings of trauma. Caregivers felt anxious for weeks or months after their child's hospitalization, frequently monitoring ketones out of fear that a recurrence was imminent. Adults who lived alone worried they might not recognize symptoms or be able to get help, particularly overnight. Acute fear and panic subsided with time, but heightened awareness of DKA remained, driving behavior changes to minimize the risk of recurrence.

Even in this highly educated sample, meaningful gaps in knowledge about DKA emerged. A notable misconception was that hyperglycemia is a prerequisite for hyperketonemia, and that hyperglycemia causes ketones to develop. Some participants also understood DKA as an all-or-nothing event; learning that it develops along a spectrum, with a distinction between ketosis and acidosis, was new and clarifying. And even among participants who considered themselves knowledgeable and equipped in sick-day management, the speed at which ketones developed

during acute illness was unexpected. Ketone monitoring was often not initiated until symptoms were already severe, when the urine ketone strips were reading at the darkest color.

Engagement in ketone monitoring was predominantly prompted by symptoms of illness or prolonged hyperglycemia, with only two participants monitoring ketones routinely when asymptomatic. All were familiar with urine ketone strips, and participants appreciated their affordability and accessibility, but raised concerns about their accuracy and sensitivity in detecting ketones; moreover, participants lacked confidence in how to interpret results—particularly in distinguishing trace from moderate ketone levels—and how to determine the color threshold that warranted action. Blood ketone meters were less familiar to participants but preferred for their greater precision and accuracy. Both tools, however, share fundamental limitations: they capture only a single point in time, offer no visibility into how quickly ketones are rising or falling, and require the person with diabetes or the caregiver to initiate the test.

Owning ketone monitoring tools and knowing how to use them does not guarantee timely detection of ketones, as using these tools still requires correct timing, presence of mind, and sound judgment, all of which can be compromised by acute illness and the cognitive effects of DKA itself. Ketones can develop rapidly and independently of glucose, yet current tools for detecting ketones capture only a single point in time and remain unfamiliar or underused. These findings point to a clear unmet need. Continuous ketone monitoring holds meaningful potential to enable earlier detection and timely intervention and reduce the anxiety that persists long after the acute event resolves.

References

1. McCoy RG, Herrin J, Galindo RJ, et al. Rates of hypoglycemic and hyperglycemic emergencies among US adults with diabetes, 2011–2020. *Diabetes Care*. 2023;46(2):e69–e71. doi:10.2337/dc22-1673
2. Dhatariya KK, Glaser NS, Codner E, Umpierrez GE. Diabetic ketoacidosis. *Nat Rev Dis Primers*. 2020;6(1):40. doi:10.1038/s41572-020-0165-1
3. Bergenstal RM, Viridi N, Quadri F, Alva S. Monitoring ketonemia in people with diabetes: Preliminary findings from real-world studies. *Diabetes Technol Ther*. 2025;27(S4):S25–S31. doi:10.1177/15209156251390833
4. Jensen ET, Stafford JM, Saydah S, et al. Increase in prevalence of diabetic ketoacidosis at diagnosis among youth with type 1 diabetes: The SEARCH for Diabetes in Youth Study. *Diabetes Care*. 2021;44(7):1573–1578. doi:10.2337/dc20-0389
5. Giessmann LC, Kann PH. Risk and relevance of insulin pump therapy in the aetiology of ketoacidosis in people with type 1 diabetes. *Exp Clin Endocrinol Diabetes*. 2020;128(11):745–751. doi:10.1055/a-0654-5134
6. Umpierrez GE, Davis GM, ElSayed NA, et al. Hyperglycemic crises in adults with diabetes: A consensus report. *Diabetes Care*. 2024;47(8):1257–1275. doi:10.2337/dci24-0032
7. Yuang K, Espinoza AL, McCoy RG. Glycemic management in adults with diabetes during illness. *Clin Diabetes*. 2025;43(5):735–745. doi:10.2337/cd25-0056
8. Desai D, Mehta D, Mathias P, Menon G, Schubart UK. Health care utilization and burden of diabetic ketoacidosis in the US over the past decade: A nationwide analysis. *Diabetes Care*. 2018;41(8):1631–1638. doi:10.2337/dc17-1379
9. Ghetti S, Kuppermann N, Rewers A, et al. Cognitive function following diabetic ketoacidosis in children with new-onset or previously diagnosed type 1 diabetes. *Diabetes Care*. 2020;43(11):2768–2775. doi:10.2337/dc20-0187
10. Budhram DR, Bapat P, Bakhsh A, et al. Prognostic implications of diabetic ketoacidosis in adults on long-term mortality and diabetes-related complications. *Can J Diabetes*. 2024;48(7):462–470.e3. doi:10.1016/j.jcjd.2024.07.002

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