Understanding Perspectives of People with Type 1 Diabetes on Hyperketonemia, Diabetic Ketoacidosis (DKA), and Ketone Monitoring: A Qualitative Study in Adults

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Background

- Diabetic ketoacidosis (DKA) is a life-threatening complication of diabetes characterized by hyperglycemia, hyperketonemia, and acidosis
- Around two-thirds of episodes of DKA occur in people living with type 1 diabetes (T1D), with DKA being the most common acute complication of T1D [1–3]
- Ketone monitoring is important for the early detection of hyperketonemia and prevention of DKA[4]
- Previous research has identified barriers to ketone monitoring, and that engagement with monitoring, especially among adults, is low[4,5]
- We used a qualitative interview approach to investigate the perspectives of adults living with T1D on ketone monitoring, as part of a large mixed-methods study including both qualitative and quantitative analyses

Objective

- To explore awareness, experiences, and barriers to ketone monitoring among adults with T1D

Methods

Study design

- This was a non-interventional, qualitative interview study
- Individual 60-minute, in-depth interviews were conducted with people living with T1D using web-based conferencing
- Participants received an honorarium following the interviews

Study population and recruitment

- Participants were recruited in collaboration with the patient advocacy organization T1D Exchange
- The study population consisted of adults (≥ 18 years or age of majorit) with a self-reported diagnosis of T1D
- For inclusion, people with T1D were required to be currently receiving insulin therapy, English language proficient, and resident in the USA, to have knowledge about ketones, to have access to technology in order to participate, and to provide informed consent

Table 1. Interview topics

Topic Domains	Discussion points
Current approaches to prevention management of ketosis, hyperketonemia, and DKA	• How participants currently monitor and manage ketone levels, from early awareness and routine monitoring (ketosis), to taking immediate action and decision-making for when to contact a healthcare provider (hyperketonemia), to emergency prevention measures (DKA) • Daily management practices, decision-making processes, use of tools or technologies, confidence in recognizing early signs, and the role of healthcare guidance
Impacts of ketosis, hyperketonemia, DKA, and ketone monitoring burden	• The personal impact of hyperketonemia, DKA, and the burden of ketone monitoring • Emotional, psychological, clinical, financial, technological, and lifestyle-related effects – both immediate and long-term
Adoption and use of ketone monitoring and management	• Key factors that may influence the adoption and ongoing use of ketone monitoring and management tools

DKA, diabetic ketoacidosis; T1D, type 1 diabetess.

Interviews

- Interviews were facilitated by experienced graduate-level interviewers
- A semi-structured discussion guide was used to ensure interviews explored participants' experiences, knowledge, and perceptions related to hyperketonemia, DKA, and ketone monitoring
- Interview topics are summarized in **Table 1**

Analysis

- All study data were deidentified to ensure participants' confidentiality
- Audio recordings were transcribed and imported into qualitative data analysis software (NVivo; Lumivero, Burlington, MA, USA)
- Standardized transcripts were coded in an iterative manner and analyzed thematically, using combined deductive and inductive approaches6,7

Results

Study population

- In total, 36 interviews were conducted with people with T1D
- Participant characteristics are shown in **Table 2**
  - Participants had a mean age of 46 years, and 69% were female
  - Most participants were White or Caucasian
  - Participants were spread across multiple US regions, majority had private health insurance (72%), and 75% had received education on ketone monitoring

Table 2. Participant Characteristics

Characteristic	Adults living with T1D (N = 36)
Age, years, mean (SD)	45.8 (19.7)
Sex, n (%)	
Female	25 (69.4)
Male	11 (30.6)
Race, n (%)	
White or Caucasian	34 (94.4)
Black of African American	2 (5.6)
Ethnicity, n (%)	
Hispanic, Latino, or Spanish origin	1 (2.8)
Not Hispanic or Latino	35 (97.2)
Census region, n (%)	
Midwest	7 (19.4)
Northeast	12 (33.3)
South	7 (19.4)
West	10 (27.8)
Insurance type, n (%)[a]	
Medicare	8 (22.2)
Medicaid	3 (8.3)
Private health plan	26 (72.2)
Insulin delivery modality, n (%)	
Insulin pump (tubed or pod)	27 (75.0)
Insulin injections (pen or syringe)	6 (16.7)
Insulin patch/pod	2 (5.6)
Inhaled insulin	1 (2.8)
Education on ketone monitoring, n (%)	
Yes	27 (75.0)
No	5 (13.9)
I don't know/not sure	4 (11.1)

[a]Participants could select more than one option. SD, standard deviation; T1D, type 1 diabetes.

Table 3. Results of thematic analysis

Domain	Theme	Representative quotes
Perspectives on ketone monitoring and management	• **Lower prioritization in daily care**: While considered important, most do not prioritize ketone checks in daily management unless they have a history of DKA • **Glucose as a proxy for ketones**: Typically rely on high glucose readings as a trigger for ketone testing and may not clearly distinguish between glucose and ketone monitoring • **Urine strips as the primary tool**: When ketone testing is performed, urine strips remain the most commonly used and accessible method • **Key prompts for testing**: Situations such as prior DKA episodes, feeling unwell, illness, or use of certain medications (e.g., steroids) drive ketone checks • **Positive provider support**: Favorable experiences with healthcare professionals offering guidance and troubleshooting for ketone monitoring and management when needed	*"It really is only something that I pull in when I am consciously doing something that I know would affect my sugar levels. On a day-to-day basis, I try to just maintain my sugars with my CGM, and I don't use ketones to manage that"* 62-year-old female, diagnosed at 8 *"I think testing it when I was sick has been helpful. I wouldn't have known that I had really high ketones. I think just by drinking a lot of fluids I was able to bring it down and not end up in DKA…."* 30-year-old male, diagnosed at 27
Awareness of ketone monitoring	• **General awareness of ketones**: Most understand the importance of ketone monitoring, with education typically provided at diagnosis and reinforced over time • **Increased awareness among those at a high risk of DKA**: Those with a history of DKA are more likely to actively monitor ketones and prioritize testing compared to others	*"I think it's important. I would like it to be more convenient, I guess"* 22-year-old male, diagnosed at 16 *"I mean, it's life-threatening and scary [DKA]. I mean, I don't ever want that to happen to me, but I would say that I don't actively—right at this moment in my life – monitor ketones"* 57-year-old female, diagnosed at 21
Barriers to ketone monitoring and management	• **Added burden to self-management**: Ketone testing is perceived as inconvenient, creating extra steps in an already complex diabetes care routine • **Challenges with urine strips**: Strips can expire and interpreting color guides is often difficult, reducing reliability and ease of use • **Delayed feedback**: Ketone test results are not real-time, limiting their usefulness for immediate decision-making and management	*"The other thing is, honestly, if I'm out in public, it's no biggie to test your sugar or look at my palm, but you're going to go into a public bathroom and check your ketones. That just seems weird, right"* 57-year-old female, diagnosed at 21 *"The aggravating part of urine test strips is they only lasted like a month or something if you opened up the container"* 75-year-old male, diagnosed at 6

CGM, continuous glucose monitoring; DKA, diabetic ketoacidosis; T1D, type 1 diabetes.

Discussion

- People living with T1D recognize the importance of ketone management
- However, reliance on urine ketone strips – with testing often triggered only by elevated glucose or acute illness – reflects both usability challenges and gaps in real-time actionable feedback
- In the context of already complex diabetes self-management, ketone monitoring is perceived as an added burden, limiting assessment of ketones as prescribed, despite the recognized clinical value
- A strength of the interview study design is the use of qualitative data collection techniques, which enables the capturing of perspectives across a broad spectrum of people living with T1D
- Limitations include the potential for recruitment bias driven by access to and ability to use the technology necessary for participation. In addition:
  - There is a possibility of self-selection bias, given that people participating in the study may be more enthusiastic about discussing the study subject than those who chose not to participate
  - The information collected is self-reported and may be subject to reporting/recall bias

Conclusion

- While adults with T1D understand the importance of ketone monitoring for DKA prevention, real-world use is infrequent and largely reactive rather than proactive
- Together, these findings underscore the need for integrated, easy-to-use monitoring solutions and targeted education to enable earlier identification of hyperketonemia and support timely intervention to reduce DKA risk

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