


Awareness and knowledge of diabetic ketoacidosis in people with type 1 diabetes: a cross-sectional, multicenter survey

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ABSTRACT

Introduction To evaluate awareness and knowledge of diabetic ketoacidosis (DKA), a common and potentially life-threatening complication in people living with type 1 diabetes (T1D).

Research design and methods A survey was developed to assess individuals' current knowledge, management, and unmet needs regarding DKA. The study was conducted in six Swiss and three German endocrine outpatient clinics specialized in the treatment of diabetes.

Results A total of 333 participants completed the questionnaire (45.7% female, mean age of 47 years, average duration of T1D at 22 years). Surprisingly, 32% of individuals were not familiar with the term 'diabetic ketoacidosis'. Participants rated their own knowledge of DKA significantly lower than their physicians ($p < 0.0001$). 46% of participants were unable to name a symptom of DKA, and 45% were unaware of its potential causes. 64% of participants did not test for ketones at all. A significant majority (67%) of individuals expressed the need for more information about DKA.

Conclusions In patients treated in specialized centers, knowledge of DKA was found to be inadequate, with a lack of understanding regarding symptoms and causes. Healthcare professionals tended to overestimate individuals' knowledge. Future efforts should focus on addressing these knowledge gaps and incorporating protective factors into the treatment of T1D.

INTRODUCTION

Diabetic ketoacidosis (DKA) is a potentially life-threatening, acute complication in people living with type 1 diabetes mellitus (T1D)¹ and the leading cause of death among people under 58 years with T1D.² Known risk factors for DKA include poor adherence to diabetes management,³ technical failures in insulin pump users, socio-economic disadvantage based on education level, income and insurance status, younger age (13–25 years), female gender, high HbA1c, and psychiatric comorbidities (eg, eating disorders and depression).^{4–7} Because

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Diabetic ketoacidosis (DKA) is a potentially life-threatening complication in people living with type 1 diabetes, but little is known about patients' awareness and knowledge of DKA.

WHAT THIS STUDY ADDS

⇒ Many individuals were unfamiliar with the term 'diabetic ketoacidosis' and almost half of participants could not name a single symptom or potential cause of DKA.

⇒ Healthcare professionals overestimate patients' knowledge of DKA.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Critical evaluation by healthcare professionals of patients' knowledge is needed and effective ways to help individuals better understand the causes, symptoms and treatment of DKA are required

sodium-glucose cotransporter-2 (SGLT2) inhibitors also increase the risk of DKA, their use in people living with T1D is not authorized by the European Medicines Agency anymore.⁸ Recent data indicate that event rates for DKA have been increasing significantly over the past years, especially during COVID-19 pandemic.^{9–11} Early diagnosis is essential to prevent further deterioration, particularly in elderly individuals and those with severe underlying diseases.¹² In addition to early diagnosis, adequate patient education is required to notice signs of DKA in order to initiate diagnostic and/or therapeutic measures in time. Especially individuals who already had a previous episode of DKA are at increased risk of having another episode.² Recent data during the COVID-19 pandemic have also shown that the risk of hospital readmission with DKA, within 1 year of a DKA

episode requiring intensive care, is approximately 29% and is associated with high risk of long-term mortality and high hospital costs,¹³ highlighting the need for further research on the distinct causes and suggesting a knowledge gap regarding DKA. However, data on patient knowledge of DKA are scarce^{14 15} and may not accurately reflect the full picture, as they do not fully capture both the individual's actual knowledge and the perceived knowledge of the treating healthcare professionals. The aim of our study was to investigate individuals' attitudes, awareness and knowledge of DKA in a multicenter, international approach involving the treating physicians.

MATERIALS AND METHODS

Study design

Data were collected between 1 January 2021 and 30 June 2021 at six sites in Switzerland (Metabolic Center Cantonal Hospital Olten, Metabolic Center St Gallen, University Hospital Basel, Gesundheitszentrum Fricktal Rheinfelden, MedCenter Volta Basel and Cantonal Hospital Basel-Land Site Bruderholz) and three sites in Germany (University Medical Center Hamburg-Eppendorf, Diabetes Centre DZHW Hamburg, Diabetespraxis Buxtehude), in clinics that exclusively treat adolescents from the age of 16 and adult patients. All participating centers are well-known centers for treatment of T1D in their region and are dealing regularly with the disease. Further, all centers have diabetes nurses available and provide classes for knowledge transfer of T1D. Participation was limited to people with an established diagnosis of T1D according to current standards, was completely voluntary and anonymous and took about 10–15 min.

Survey questionnaire

The survey questionnaire was developed at the Metabolic Center Olten, Switzerland, and covered basic questions about DKA, the patient's demographic and medical history. The questionnaire was discussed and further developed together with a registered diabetes nurse with more than 10 years of experience and two people living with T1D. The final questionnaire was given to the study participants in paper form following their outpatient consultation by their healthcare professionals and after informing them about the scope of the survey and its entirely independent and voluntary nature of participation. Participants were allowed to return the questionnaires by mail or in a separate box in the respective study centers allowing their anonymity. Baseline parameters (age, sex, education, duration of diabetes, HbA1c), content on personal experience and theoretical knowledge of DKA were collected. To assess individuals' knowledge of DKA, they were first given free-text answers about possible causes and typical symptoms of DKA. They could then select from a range of symptoms, some of which were not typical of DKA. In addition, the attending physician gave a subjective assessment of the individual's general

knowledge of diabetes ranging from '1 - no knowledge' to '10 - excellent knowledge' with a numerical value without further comment. An English translation of the final questionnaire is available in online supplemental file 1. A brief summary video is available in online supplemental file 2.

Furthermore, representatives of each study site were asked about the type of institution, the number of physicians employed in the respective department, the average number of patients in general, specifically people living with T1D seen per quarter on average, estimation of general knowledge about DKA, treatment of individuals with T1D with SGLT2 inhibitors and the existence of a specific DKA program.

Statistical analysis

Study data were collected and managed using REDCap electronic data capture tools hosted at the University Hospital Basel, Basel, Switzerland,^{16 17} and analyzed using GraphPad Prism V.9 for MacOS V.9.4.1. Continuous data are presented as arithmetic mean with 95% CI or median and IQR and were analyzed for normal distribution by comparing arithmetic mean, median, skewness and kurtosis as well as using D'Agostino and Pearson tests. For the level of significance, an alpha error of 0.05 or less was considered statistically significant. The Wilcoxon matched-pairs signed-rank test was used for two-group comparisons of non-parametric paired data, the Mann-Whitney U test for non-parametric unpaired data and Student's t-test for parametric data. Spearman r was calculated for correlation analyses.

Missing data were not imputed and classified as missing at random.

Ethics and transparency

The study does not fall under the Swiss Human Research Act as only anonymized data were collected and the questionnaire was entirely voluntary. Participants were individually briefed by their physicians regarding the questionnaire's purpose. Their participation in any portion of this survey was considered implicit consent for the study.

RESULTS

Baseline characteristics

Baseline characteristics are shown in [table 1](#). A total of 333 individuals participated in the study. There were slightly more men (54%) than women (46%) among the 324 who declared their sex. A total of 69% (n=216) reported that they were married or in a partnership and 33% (n=105) were either single, divorced or widowed. The majority of individuals (n=264, 84%) reported living with a partner, family, friends or in a shared apartment, while only 17% (n=52) reported living alone. A total of 171 patients (69%) reported working part-time or full time and 21 patients (7%) were students or in training. Approximately 80% of individuals had received diabetes counseling within the past 6 months.

Table 1 Baseline characteristics of all 333 respondents

| Characteristic | Mean (SD; range) | n (%) | Missing values (%) |
|----------------------------------------------------------|-----------------------|------------|--------------------|
| Age | 47.6 (16.6; 18–86) | | 10 (3.0) |
| Sex | | | 9 (2.7) |
| Female | | 148 (45.7) | |
| Male | | 176 (54.3) | |
| Body weight (kg) | 78 (17.6; 44–190) | | 20 (6.0) |
| Body mass index (kg/m ²) | 26.2 (4.7; 16.4–48.4) | | 23 (6.9) |
| Duration of type 1 diabetes (years) | 22 (15.9; 0.1–85) | | 5 (1.5) |
| Type of treatment | | | 8 (2.4) |
| Multiple daily insulin injections | | 216 (66.5) | |
| Insulin pump therapy | | 109 (33.5) | |
| Latest level of glycosylated hemoglobin A1c (HbA1c) in % | 7.6 (1.3; 4.8–14.7) | | 16 (4.8) |
| Last diabetes counseling | | | 14 (4.2) |
| <6 months ago | | 260 (81.5) | |
| 7–12 months ago | | 18 (5.6) | |
| 13–24 months ago | | 15 (4.7) | |
| >2 years ago | | 26 (8.2) | |
| Relationship status | | | 18 (4.5) |
| Single | | 76 (24.1) | |
| Relationship | | 52 (16.6) | |
| Married | | 158 (50.2) | |
| Divorced | | 23 (7.3) | |
| Widowed | | 6 (1.9) | |
| Household | | | 17 (5.1) |
| Single | | 52 (16.5) | |
| Partner | | 122 (38.5) | |
| Family | | 134 (42.4) | |
| Friends | | 1 (0.3) | |
| Shared apartment | | 7 (2.2) | |
| Highest education | | | 21 (6.3) |
| Primary school | | 9 (2.9) | |
| Secondary school/high school | | 52 (16.6) | |
| Apprenticeship | | 164 (52.6) | |
| University | | 87 (27.9) | |
| Employment | | | 26 (7.8) |
| Apprenticeship/study | | 21 (6.8) | |
| Full time | | 155 (50.5) | |
| Part-time | | 57 (18.6) | |
| Unemployed | | 12 (3.9) | |
| Retired | | 62 (20.2) | |
| Have you ever had diabetic ketoacidosis yourself? | | | 22 (6.6) |
| Yes, once | | 54 (17.4) | |
| Yes, several times | | 56 (18.0) | |
| No | | 98 (31.5) | |
| I don't know | | 103 (33.1) | |

Continued

Table 1 Continued

| Characteristic | Mean (SD; range) | n (%) | Missing values (%) |
|-------------------------------------------------------------------------------------------------|------------------|------------|--------------------|
| Do you feel that diabetic ketoacidosis is a dangerous complication of type 1 diabetes mellitus? | | | 18 (5.4) |
| Yes | | 214 (67.9) | |
| No | | 28 (8.9) | |
| I don't know | | 73 (23.2) | |
| Can diabetic ketoacidosis be prevented? | | | 20 (6.0) |
| Yes | | 237 (75.7) | |
| No | | 7 (2.2) | |
| I don't know | | 69 (22) | |
| Do you feel confident in treating a possible ketoacidosis? | | | 34 (10.2) |
| Yes | | 120 (40.1) | |
| No | | 64 (21.4) | |
| I don't know | | 115 (38.5) | |

Means with SD, range, absolute number with percentage and number of missing values are given.

A total of 232 participants were from Switzerland (Cantonal Hospital Olten (n=104, 31.2%), University Hospital Basel (n=11, 3.3%), MedCenter Volta Basel (n=6, 1.8%), GZF Rheinfelden (n=37, 11.1%), Stoffwechszentrum St Gallen (n=49, 14.7%), Cantonal Hospital Basel Land, Site Bruderholz (n=25, 7.5%)) and 101 participants (30.3%) from three German centers. Approximate mean response rate based on the average number of people living with T1D seen at each center was 48% and varied from 11% to 98%.

Patients' awareness and self-evaluation of prevalence of DKA

A total of 220 (68%) of the respondents stated that they have heard about DKA and 103 (32%) did not hear or were not familiar with the term.

A total of 54 participants (17%) reported at least one and 56 patients (18%) several DKA episodes, whereas 98 individuals (32%) stated that they never had an episode. One hundred and three participants (33%) were unsure about DKA episodes. Approximately 40% of participants felt confident in managing DKA (see [table 1](#)). The majority of participants (n=214, 68%) reported that DKA is a dangerous complication, 28 participants (9%) did not agree and 73 participants (23%) were unsure about it. Asked about whether DKA can be prevented, 237 (76%) participants agreed, 7 (2%) individuals disagreed, and 69 (22%) were unsure about it.

Patients' knowledge about DKA

When participants had to rate their knowledge about DKA on a scale from 0 (no idea at all) to 10 (excellent), median knowledge was 5 (IQR 1–7, mean 4.33, SD 3.1).

In the questionnaire, all individuals were asked to provide free-text answers concerning possible causes and symptoms of DKA. Of the participants, 185 individuals (55%) answered the causes question, while 181 participants (54%) answered the symptoms question.

All individuals who answered the causes of DKA also completed the symptoms field.

Of the free-text answers given, 33 (18%) were not rated as correct or rated as inadequate causes of DKA (eg, 'hypoglycaemia', 'no idea', 'too much insulin', 'acetonemic' or 'fruity urine/odour') and 15 (8%) answers were not rated as correct for possible symptoms of DKA.

The most common multiple-choice causes of DKA were missed insulin injection (61%) and illness (54%) (see [figure 1A](#)). A total of 85 (25%) participants stated 'too low' or 'forgotten insulin administration' as causes of DKA, whereas 62 (19%) participants attributed 'high glucose values' and 5 (2%) participants specifically stated 'pregnancy', 'stress' and 'diseases' as causes of DKA.

With regard to free-text symptoms of DKA most frequently 'nausea', 'vomiting' or 'abdominal pain' were mentioned by 59 (18%) participants; 'Thirst', 'need to urinate' or 'dry mouth' by 44 (13%) participants; and symptoms such as 'fruity' or 'acetonemic odour/urine' by 33 (10%) participants. A total of 30 (9%) participants mentioned further symptoms of DKA such as 'tiredness', 'sweating', 'visual disturbances' or 'coma'. Participants were then offered multiple-choice answers including atypical symptoms of DKA. Answers can be found in [figure 1B](#). Symptoms not typical for DKA that were offered included aggression, muscular pain, olfactorial disorder, increased appetite and hearing disorder.

There was a significant but low positive correlation between diabetes duration and knowledge of DKA (Spearman $r=0.187$; 95% CI 0.0714 to 0.298; $p=0.001$).

Ketone body testing

A total of 185 (64%) individuals did not test for ketones at all, 124 (56%) participants tested less than every 6 months and 78 participants (38%) only if glucose was high or testing was needed. The last testing was longer

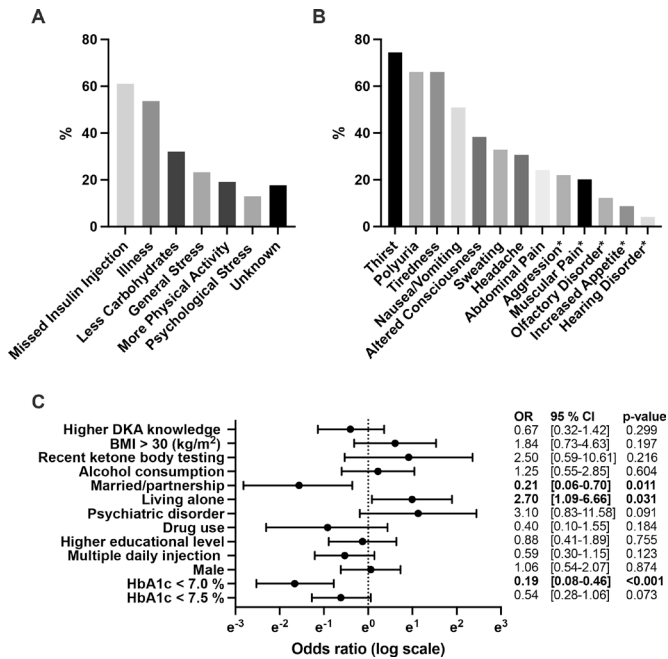


Figure 1 (A) Picked answer options for potential causes of diabetic ketoacidosis (DKA) by participants. (B) Most frequently picked DKA symptoms out of multiple answers to choose from. (C) ORs for individuals reporting no DKA compared with those with several experienced DKA episodes. ORs with 95% CI are depicted. *Indicates atypical symptoms. BMI, body mass index.

than 1 year ago or never happened in a total of 165 participants (63%). A total of 148 individuals (60%) reported that their ketone test strips were either expired or they did not know (see table 2).

HbA1c levels and incidence of DKA

Participants who reported having had one or more episodes of DKA (n=104) had significantly higher HbA1c levels compared with those who reported not having DKA (n=96) (mean HbA1c: 7.8% (SD 1.3) vs 7.3% (SD 1.0), p=0.009). Individuals who were unsure about previous DKA episodes (n=98) had significantly higher HbA1c levels compared with those who reported not having DKA episodes (n=96) (mean HbA1c: 7.7% (SD 1.4) vs 7.3% (SD 1.0), p=0.029).

Use of SGLT2 inhibitors in patients with T1D

A total of 14 individuals (4.2%) reported the use of SGLT2 inhibitors (ertugliflozin (n=1, 0.3%), empagliflozin (n=3, 0.9%), dapagliflozin (n=8, 2.5%), canagliflozin (n=2, 0.6%).

Substance use

When questioned about alcohol consumption, the survey findings indicated that 31 participants (14.5%) reported complete abstinence from alcohol, 77 participants (36%) claimed infrequent drinking, and 10 participants (4.7%) mentioned consuming alcohol daily.

Regarding substance use in general, 186 participants (87.7%) reported no substance use, while 16 participants (7.5%) disclosed past substance use. Additionally, 10 participants (4.7%) admitted to current substance use. Among the substances reported, the most frequently

Table 2 Ketone body testing

| Question | n (%) | Missing values (%) |
|---------------------------------------------------|------------|--------------------|
| Do you test for ketone bodies? | | 23 (6.9) |
| Yes | 74 (23.9) | |
| No | 197 (63.5) | |
| I don't know | 39 (12.6) | |
| Frequency of testing for ketone bodies | 111 (33.3) | |
| Several times a week | 1 (0.5) | |
| 1×/week | 1 (0.5) | |
| 1×/month | 6 (2.7) | |
| 1×/every 6 months | 16 (7.2) | |
| Less frequent | 124 (55.9) | |
| Only if glucose is high/if needed | 78 (38.1) | |
| Last testing for ketone bodies | 72 (21.6) | |
| <1 month | 21 (8.0) | |
| <3 months | 23 (8.8) | |
| <6 months | 21 (8.0) | |
| <12 months | 31 (11.9) | |
| Longer than a year ago/never | 165 (63.2) | |
| Type of ketone body test | 84 (25.2) | |
| Urine | 99 (39.8) | |
| Blood | 62 (24.9) | |
| Both (urine and blood) | 17 (6.8) | |
| I don't know | 71 (28.5) | |
| Glucose threshold for ketone body testing | 47 (14.1) | |
| <10 mmol/L (180 mg/dL) | 7 (2.4) | |
| 10–15 mmol/L (180–270 mg/dL) | 9 (3.1) | |
| 15–20 mmol/L (270–360 mg/dL) | 48 (16.8) | |
| >20 mmol/L (360 mg/dL) | 38 (13.3) | |
| I do not test | 185 (64.7) | |
| Are your ketone test strips good (ie, unexpired)? | 87 (26.1) | |
| Yes | 98 (39.8) | |
| No | 59 (24.0) | |
| I don't know | 89 (36.2) | |

Absolute numbers, percentages and missing values are given for common test for ketone bodies, including frequency of testing, last time point, type of ketone body test, glucose threshold and whether ketone body test strips are not expired.

used was cannabis (n=24), followed by cocaine (n=2) and lysergic acid diethylamide (LSD, n=2).

Associated factors for DKA

Improved glycemic control (HbA1c <7.0% compared with 8% and higher) showed a protective effect against DKA (OR 0.19, 95% CI 0.08 to 0.46, $p<0.001$). Additionally, being in a partnership or being married, as opposed to being divorced or widowed, was also found to be a protective factor (OR 0.21, 95% CI 0.06 to 0.70, $p=0.011$). Conversely, living alone, as opposed to other forms of cohabitation, increased the likelihood of experiencing multiple episodes of DKA (OR 2.7, 95% CI 1.09 to 6.66, $p=0.031$) (see [figure 1C](#)).

Healthcare professionals' assumption of patients' knowledge

Estimates of the individual's personal knowledge on DKA were reported by healthcare professionals only from the Swiss centers on a scale from 0 (no knowledge at all) to 10 (perfect knowledge and management of DKA). Median knowledge on DKA was rated as 6 (IQR 4–7). The patients' personal knowledge on DKA was rated significantly lower by themselves (mean 4.33, SD 3.11 vs 5.60, SD 2.34; $p<0.0001$) compared with their healthcare professionals' assumption. However, the two ratings correlated significantly ($r=0.268$, 95% CI (0.1253; 0.3992), $p=0.0002$).

Individual needs regarding DKA

In response to inquiries about their needs related to DKA, 201 participants (66.6%) expressed a desire for additional information regarding the condition. Conversely, 42 individuals (13.9%) were uncertain about their informational requirements, while 59 participants (19.5%) reported feeling adequately informed (see [table 3](#)).

The majority of individuals preferred information leaflets (n=166, 56.5%) and counseling by a diabetes nurse (n=51, 17.3%), followed by personal counseling through their treating physician, online training/webinars or other means (see [table 3](#)).

Of all participating study sites, two reported having a dedicated DKA program for counseling of people living with T1D.

DISCUSSION

Despite significant advances in monitoring technologies as well as insulin therapeutics, rates of both outpatient and hospital-acquired DKA have increased significantly over the past years.⁹

Key factors in the prevention of DKA are early detection and adequate patient education.¹⁸ Our results show that people living with T1D do not seem to be adequately informed about DKA despite being treated in specialized centers. A total of 32% had never heard of or were unfamiliar with it. Although the majority of participants (68%) stated that DKA is a dangerous condition, 46% of individuals could not name a single symptom of DKA,

Table 3 Patient-perceived needs for further information regarding DKA, as well as the type of information material preferred by participants, and automated prescription of ketone measuring strips once a year

| Question | n (%) | Missing values (%) |
|-----------------------------------------------------------------------------------------------------------|------------|--------------------|
| Would you like more information about diabetic ketoacidosis? | | 31 (9.3) |
| Yes | 201 (66.6) | |
| No | 59 (19.5) | |
| I don't know | 42 (13.9) | |
| What would help you learn more about diabetic ketoacidosis? | | 39 (11.7) |
| Information leaflets (eg, brochures) | 166 (56.5) | |
| Diabetes counseling | 51 (17.3) | |
| Physician counseling | 112 (38.1) | |
| Online training (eg, webinar) | 63 (21.4) | |
| Other | 11 (3.7) | |
| Should the test strips be prescribed by the attending physician as standard with the annual prescription? | | 41 (12.3) |
| Yes | 165 (56.5) | |
| No | 46 (15.8) | |
| I don't know | 81 (27.7) | |
| Given are absolute numbers, missing values and percentage. DKA, diabetic ketoacidosis. | | |

and 45% could not spontaneously recall possible causes of DKA.

In our cohort, the majority of participants (69%) reported either part-time or full-time employment, and a significant portion (83.5%) did not live alone. Our analysis revealed that being in a partnership or being married, in comparison to being divorced or widowed, acted as a protective factor against DKA (OR 0.21, 95% CI 0.06 to 0.70). Conversely, living alone, rather than other forms of cohabitation, substantially increased the likelihood of experiencing multiple episodes of DKA (OR 2.7, 95% CI 1.09 to 6.66). It has been reported that being married is associated with lower HbA1c levels,¹⁹ which may explain in part also a lowered risk of DKA, but data on marital status or cohabitation on DKA risk are lacking and our findings need further investigation.

The average HbA1c in our cohort was 7.6%, which is slightly above the recommended target of <7% set by the American Diabetes Association and the European Association for the Study of Diabetes.²⁰ However, it is still lower than what would be expected for non-adherence and consistent with HbA1c levels of other specialized diabetes centers.^{21 22} Interestingly, our findings indicate that patients who reported experiencing one or more

episodes of DKA, as well as those who were uncertain about their DKA history, had significantly higher HbA1c levels compared with patients who reported no DKA episodes. Additionally, our results show that achieving improved glycemic control (HbA1c <7.0% compared with 8% and higher) appears to have a protective effect against DKA (OR 0.19, 95% CI 0.08 to 0.46). These associations are consistent with the findings of Weinstock *et al*, who observed a correlation between DKA occurrences and HbA1c levels, particularly noting that DKA is more prevalent at HbA1c levels of $\geq 10.0\%$ (≥ 86 mmol/mol).⁶

A minority of 4.2% of individuals reported the use of SGLT2 inhibitors, with dapagliflozin being the most common (n=8, 2.5%). The use of SGLT2 inhibitors in T1D was still authorized at the time of patient enrollment and remains an ongoing topic of discussion due to their impressive cardiorenal benefits.²³ In a meta-analysis of randomized controlled trials, Huang *et al* showed that the use of dapagliflozin as an adjunct to insulin therapy in people living with T1D provided significant benefits in terms of HbA1c, weight loss, average daily blood glucose and average daily blood glucose variability, and did not increase the risk of infection, DKA or discontinuation due to adverse events compared with placebo.²⁴ On the other hand, the risk of developing euglycemic DKA remains a significant limiting factor. Time will tell whether SGLT2 inhibitors will find their way into T1D treatment guidelines. However, if so, a strong improvement of patients' knowledge about DKA has to be demanded to make the use as safe as possible.

Regarding the management of DKA, increased home ketone monitoring may lead to self-management of ketoacidosis prior to hospital admission and thus improve individual outcomes.²⁵ However, in our cohort, 60% of participants reported that their ketone test strips were either expired or they did not know.

A total of 67% of individuals wanted more information about the condition of DKA, particularly through general information and discussion with their doctor. Healthcare professionals play an important role in the prevention of DKA. In our study, patient-reported knowledge of DKA did not match the perceived knowledge of their healthcare professionals, who rated patients' knowledge significantly higher than the patients themselves. These findings suggest a communication gap in the physician–patient relationship. The Joint British Diabetes Societies for Inpatient Care as well as other societies strongly recommend education about DKA in people living with diabetes and several programs and practical recommendations do exist^{25 26} even for individuals treated with SGLT2 inhibitors.²⁷ In particular, they recommend counseling about precipitating factors and early warning symptoms, including the rules about sick days.^{25 28} They also emphasize the involvement of healthcare professionals by including an assessment of the individual's understanding of DKA. Participation in a structured diabetes (self-)education program leads to a substantial risk reduction of DKA and is cost-effective,

as shown by numerous studies.^{7 29–32} However, our results suggest that DKA seems to play a minor role or used means in adults are less effective in the management of T1D among physicians and diabetes nurses, or that the tools used in adults are less effective. There is a need for appropriate patient education.

To our knowledge, this is one of the largest studies to assess knowledge of DKA with more than 300 participants in two countries and different institutions. The fact that the questionnaire was developed in collaboration with a professional diabetes instructor and two individuals with T1D and that the response rate was high are further strengths of the study.

The study also has some notable limitations. First, the study was conducted only in Germany and Switzerland, which limits the generalizability of the results, especially with regard to other healthcare systems. Second, the simple survey design, using a non-validated instrument, as well as the observational nature of the study, inherently limits the study. The anonymous survey design was chosen to prevent participants from feeling judged since assessing knowledge may be a sensitive matter, and thereby bearing the risk for a lower participation rate. Answers reflect individuals' knowledge and perceptions rather than documenting their actual medical history, rate of DKA episodes and HbA1c history. Although current HbA1c value assessed in the questionnaire may not represent the general quality of diabetes therapy adherence and the questions regarding DKA episodes do not specify the exact duration since the last occurrence, participants' reports indicate significant knowledge gaps and unmet needs that are important for future DKA prevention strategies. Since participation in the study was entirely voluntary, it is possible that a selection bias may exist, with a higher likelihood of motivated, skilled and compliant individuals participating. Given our study findings, this could potentially reflect even greater knowledge gaps within the broader population of individuals with T1D.

In addition, participation varied widely between centers in Switzerland, with few participants from the University Hospital Basel. As patients treated at the University Hospital tend to be more complex cases and are treated more often by physicians in training, this may not reflect the average situation of people living with T1D anyway.

CONCLUSION

This study represents the first multicenter survey examining individuals' perceived knowledge gaps and unmet needs concerning DKA, including insights from treating physicians. The findings highlight a lack of participants' knowledge about DKA and its management as well as a communication gap regarding DKA within the physician–patient relationship with a widespread desire for education. To optimize future prevention strategies for DKA, it appears crucial to prioritize two key areas. First, addressing the existing knowledge gaps surrounding

DKA by incorporating the topic in the individual consultation is essential. Second, it is important to consider and include protective factors in the treatment of T1D to reduce the prevalence of DKA and improve patient outcomes.

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Supplements

Questionnaire Diabetic Ketoacidosis

Dear Participant

Thank you for taking the time to answer this questionnaire. Participation is voluntary and your data is completely anonymous. The aim of the survey is to assess the knowledge about diabetic ketoacidosis (DKA) in patients with type 1 diabetes mellitus and subsequently to enable more targeted training. Answering the questionnaire takes about 10-15 minutes. Please do not use any aids and answer the questionnaire as well as you can.

1. How many years have you had type 1 diabetes mellitus?

2. What type of insulin therapy do you use?

Basal/Bolus-Insulin Insulin pump

3. Are you taking any of the following medications (SGLT2 inhibitors) in addition to insulin?

no Steglatro/Segluromet Jardiance/Jardiance Met
 Forxiga/Xigduo Invokana/Vokanamet

4. What is your current HbA1c? If you do not know exactly, an approximate figure is sufficient.

_____ I don't know.

5. When was your last diabetes counselling?

< 6 months 7 – 12 months 13 – 24 months > 2 years

6. Have you ever heard of diabetic ketoacidosis?

yes no I don't know.

7. How well do you rate your knowledge of the recognition and treatment of diabetic ketoacidosis on a scale from 0 (no idea at all) to 10 (excellent)?

8. Which typical causes of diabetic ketoacidosis do you know?

Free text

9. Which symptoms of diabetic ketoacidosis do you know?

Free text

10. Which of the following symptoms do you think belong to diabetic ketoacidosis (multiple answers possible)?

- | | | |
|--------------------------------------------------|---------------------------------------------|-------------------------------------|
| <input type="checkbox"/> sweating | <input type="checkbox"/> abdominal pain | <input type="checkbox"/> headaches |
| <input type="checkbox"/> increased urination | <input type="checkbox"/> nausea/vomiting | <input type="checkbox"/> tiredness |
| <input type="checkbox"/> decreased consciousness | <input type="checkbox"/> hearing disorders | <input type="checkbox"/> thirst |
| <input type="checkbox"/> muscle pain | <input type="checkbox"/> increased appetite | <input type="checkbox"/> aggression |
| <input type="checkbox"/> odour disorders | | |

11. Have you ever had diabetic ketoacidosis yourself?

- yes, once yes, several times no I don't know

12. What causes do you see that could lead to the ketoacidosis?

- | | |
|------------------------------------------------------|------------------------------------------------------|
| <input type="checkbox"/> basal insulin forgotten | <input type="checkbox"/> illness/infection |
| <input type="checkbox"/> psychological stress | <input type="checkbox"/> reduced carbohydrate intake |
| <input type="checkbox"/> increased physical activity | <input type="checkbox"/> stress |
| <input type="checkbox"/> I don't know | |

13. Do you feel that diabetic ketoacidosis is a dangerous complication of type 1 diabetes mellitus?

- yes no I don't know

14. Can diabetic ketoacidosis be prevented?

- yes no I don't know

15. Do you test for ketone bodies?

- yes no I don't know

16. How often do you test for ketone bodies?

- several times a week 1 x per week 1 x per months
 at least 1 x per half year less frequently
 if necessary/unexplainably high blood glucose levels

17. When did you last test for ketone bodies?

- < 1 month < 3 months < 6 months
 < 12 months >12 months/never

18. Under which conditions do you test frequently (multiple answers possible)?

- | | |
|------------------------------------------------------|------------------------------------------------------|
| <input type="checkbox"/> illness/infection | <input type="checkbox"/> operations |
| <input type="checkbox"/> increased physical activity | <input type="checkbox"/> lowered carbohydrate intake |
| <input type="checkbox"/> lowering insulin dose | <input type="checkbox"/> symptoms of ketoacidosis |
| <input type="checkbox"/> alcohol consumption | <input type="checkbox"/> I do not test. |

19. At what blood glucose level do you test for ketone bodies?

- | | | | |
|-----------------------------------------|---------------------------------------|---------------------------------------|------------------------------------|
| <input type="checkbox"/> < 10 mmol | <input type="checkbox"/> 11 – 15 mmol | <input type="checkbox"/> 16 – 20 mmol | <input type="checkbox"/> > 20 mmol |
| <input type="checkbox"/> I do not test. | | | |

20. What type of test do you have at home?

- | | | | |
|-------------------------------------|-------------------------------------|-------------------------------|----------------------------------------|
| <input type="checkbox"/> urine test | <input type="checkbox"/> blood test | <input type="checkbox"/> both | <input type="checkbox"/> I don't know. |
|-------------------------------------|-------------------------------------|-------------------------------|----------------------------------------|

21. Are you sure that your test strips are still good (i.e. not expired)?

- | | | |
|------------------------------|-----------------------------|----------------------------------------|
| <input type="checkbox"/> yes | <input type="checkbox"/> no | <input type="checkbox"/> I don't know. |
|------------------------------|-----------------------------|----------------------------------------|

22. Should the test strips be prescribed by the attending physician as standard with the annual prescription?

- | | | |
|------------------------------|-----------------------------|----------------------------------------|
| <input type="checkbox"/> yes | <input type="checkbox"/> no | <input type="checkbox"/> I don't know. |
|------------------------------|-----------------------------|----------------------------------------|

23. Do you feel confident in treating a possible ketoacidosis?

- | | | |
|------------------------------|-----------------------------|----------------------------------------|
| <input type="checkbox"/> yes | <input type="checkbox"/> no | <input type="checkbox"/> I don't know. |
|------------------------------|-----------------------------|----------------------------------------|

24. Would you like more information about diabetic ketoacidosis?

- | | | |
|------------------------------|-----------------------------|----------------------------------------|
| <input type="checkbox"/> yes | <input type="checkbox"/> no | <input type="checkbox"/> I don't know. |
|------------------------------|-----------------------------|----------------------------------------|

25. What would help you learn more about diabetic ketoacidosis?

- | | |
|-------------------------------------------------------------------------|-------------------------------------------------------|
| <input type="checkbox"/> information material | <input type="checkbox"/> renewed diabetes counselling |
| <input type="checkbox"/> online training/webinar | |
| <input type="checkbox"/> personal counselling by the treating doctor(s) | |
| <input type="checkbox"/> other (<i>free text</i>): | |

26. Please state your sex.

- | | | |
|-------------------------------|---------------------------------|-----------------------------------------|
| <input type="checkbox"/> male | <input type="checkbox"/> female | <input type="checkbox"/> not specified. |
|-------------------------------|---------------------------------|-----------------------------------------|

27. Your age (in years).

28. Please state your marital status.

- single in partnership married
 divorced widowed

29. In what way do you live at home?

- alone with partner family
 with friends shared flat

30. Are you employed?

- in training/study yes, full-time yes, part-time
 no, looking for work no, retired

31. Please select your highest completed education.

- primary school secondary school grammar school
 vocational apprenticeship university degree

32. Please state your height in metres.

33. Please state your weight in kilograms.

34. Do you have a known psychiatric illness?

- no yes

35. Do you drink alcohol (e.g. glass of red wine/bottle of beer)?

- never very rarely 1 x per week
 2-3 x per week daily

36. Do you use other drugs?

- never in the past yes

If yes, which? _____

37. Do you have any comments or feedback for us?

Free text:

Thank you for your valuable cooperation! Please hand in the questionnaire or return it by post.