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# 'You have to use everything and come to some equilibrium': a qualitative study on hypoglycemia self-management in users of continuous glucose monitor with diverse hypoglycemia experiences

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#### **ABSTRACT**

Introduction Although continuous glucose monitoring systems (CGMs) can help reduce hypoglycemia, about one-quarter of people with type 1 diabetes (T1D) who use CGMs still either spend at least 1% of the time with dangerously low blood glucose or develop severe hypoglycemia. This study explored experiences around hypoglycemia self-management in people who are living with T1D and using CGMs to identify factors contributing to hypoglycemia development.

Research design and methods Purposive sampling and semistructured interviews with 28 respondents with T1D and using CGMs were conducted to explore experiences around hypoglycemic episodes and hypoglycemia self-management during CGM use. Open coding and thematic analysis were employed to identify emergent themes related to hypoglycemia experiences.

Results About one-third of respondents each respectively spent 0%, 0.1%-0.9% and ≥1% of time in level 2 hypoglycemia; 39% had impaired awareness of hypoglycemia and 32% had severe hypoglycemia in the past 6 months. Four themes were generated: (1) prioritizing symptoms over CGM data (subthemes: hypoglycemia symptoms for confirming hypoglycemia and prompting management actions; minimal management actions without hypoglycemia symptoms); (2) distraction from the demands of daily life; (3) concerns about hypoglycemia management choices (subthemes: fear of rebound hyperglycemia; other health consequences related to sugary food consumption; aversions to treatment foods and treatment food consumption); and (4) social influences on management choices (subthemes: positively perceived social support and inclusion; unwanted attention to oneself or concerns about inconveniencing others; social stigma and criticism related to hypoglycemia and CGM use).

**Conclusions** Despite using CGMs, people with T1D can face a complex biopsychosocial process of managing hypoglycemia. Interventions for addressing psychosocial and behavioral barriers are needed to improve hypoglycemia self-management in those who continue to face challenges in minimizing hypoglycemia while using CGMs.

#### **KEY MESSAGES**

- ⇒ What is already known: Clinically significant hypoglycemia continues to occur in one-quarter of people with type 1 diabetes (T1D) who use advanced diabetes technologies. Little is known about care gaps that contribute to hypoglycemia development.
- ⇒ What this study adds: A qualitative study with semistructured interviews and thematic analysis was conducted. Themes were identified regarding the complex biopsychosocial process of, and facilitators and barriers to, hypoglycemia self-management in T1D advanced diabetes technology users.
- ⇒ How this study might affect research, practice or policy: Findings could inform interventions addressing psychosocial and behavioral barriers to reduce hypoglycemia in people with T1D who continue to develop dangerous hypoglycemia despite using advanced diabetes technologies.

#### **INTRODUCTION**

Hypoglycemia is associated with acute complications, including cognitive and physical impairments and cardiac arrhythmias, along with long-term health risks such as cardiovascular events and increased mortality. Realtime continuous glucose monitoring systems (CGMs) can provide readily available glucose information and hypoglycemia alarms for hypoglycemia prevention and management.<sup>2</sup> Automated insulin delivery systems can offer CGM users additional support, including algorithm-based calculations of predicted future glucose values and automatically adjusted insulin doses to reduce hypoglycemia.<sup>3</sup> However, clinically significant hypoglycemia, such as level 2 hypoglycemia (ie, blood glucose levels <54 mg/dL or <3 mmol/L) or severe hypoglycemia (where cognitive or physical dysfunctions develop and assistance for administering treatment is



required<sup>4</sup>), continues to affect about 15%–35% of people with type 1 diabetes (T1D) despite use of these advanced technologies.<sup>5–10</sup>

Qualitative studies have expanded knowledge of patients' perspectives on using CGMs, 11-13 outlined barriers to hypoglycemia self-management in non-CGM users, 14 15 and improved understanding of the roles of complex cognitive-behavioral 16 17 and psychosocial<sup>18</sup> factors in hypoglycemia management. However, limited research has described the hypoglycemia selfmanagement process among advanced diabetes technology users. A persistent question is 'What happens when someone using advanced diabetes technologies develops hypoglycemia and undertakes hypoglycemia self-management?' Related information could deepen comprehension of hypoglycemia experiences and management in this population by identifying factors contributing to clinically significant hypoglycemia despite using advanced diabetes technologies. In this qualitative interview study, we solicited experiences of hypoglycemia self-management from a cohort of adults with T1D and diverse hypoglycemia experiences including having minimal hypoglycemia or developing severe hypoglycemic episodes while using CGMs. We also explored barriers to hypoglycemia self-management in this population.

### METHODS Study design

We conducted a cross-sectional, qualitative study with a descriptive approach to explore experiences of managing hypoglycemia in T1D adults who were using CGMs. All respondents provided informed consent.

#### **Setting and respondents**

The study was conducted between 2021 and 2022 at a tertiary medical center. The potential candidate population was previously phenotyped,<sup>9</sup> with representative samples demonstrating the mean CGM hypoglycemia profile comparable to large clinical trials. <sup>19–21</sup> Eligibility criteria were a diagnosis of T1D, age ≥18 years, and use of real-time CGMs ≥6 months<sup>19 22</sup> for ≥70% of the time.<sup>23</sup> People with uncontrolled psychological conditions or chronic cognitive impairment were excluded. Purposive sampling, <sup>34</sup> a sampling method in qualitative research to identify 'information rich' cases that have relevant experiences central to the research question, was used for the scope of this study. While the purpose of qualitative research using purposive sampling is not to generalize to the population, this sampling method supports to develop in-depth understanding of the lived experience of a phenomenon. We used maximum variation sampling, a type of purposive sampling,<sup>24</sup> to recruit people across minimal to large periods of time spent in level 2 hypoglycemia to identify common or disparate hypoglycemia experiences. Specifically, CGM data were obtained during screening to identify candidates with

minimal (ie, 0%), some (ie, 0.1%–0.9%) and higher than recommended (ie,  $\geq 1\%^4$ ) time in level 2 hypoglycemia. History of severe hypoglycemia despite using CGMs and hypoglycemia awareness status (determined with the Gold questionnaire<sup>25</sup>) were evaluated during screening to ensure inclusion of respondents with diverse hypoglycemia experiences. Sex, race and ethnicity were also reviewed during sampling to ensure that data were collected from a population with demographic diversity.

#### **Data collection**

We developed a semistructured interview guide to explore hypoglycemia experiences with CGM use, covering respondents' thoughts, feelings, and behavior during hypoglycemia; hypoglycemia experiences in different social settings; hypoglycemia risk perceptions and outcome expectations; and worldview around hypoglycemia (online supplemental table 1). As part of the interview, the interviewer displayed the respondent's glucose-level time graphs from CGM reports downloaded within a week prior to the interviews to help respondents map out events that occurred during hypoglycemia.<sup>26</sup> Pilot interviews were held to refine the interview guide with two eligible volunteers who had T1D and who were using CGMs; these data were excluded from analysis. MD (PhD, mixed methodologist, woman) and YKL (MD, clinical diabetes researcher/endocrinologist, man) conducted one-on-one interviews. The conversations took place through Health Insurance Portability and Accountability Act (HIPAA)-compliant Zoom video/telephone calls due to the COVID-19 pandemic. At the start of each interview, both interviewers introduced themselves as diabetes researchers; YKL did not actively disclose his clinician role to avoid confounding respondents' reporting of their diabetes experiences. All recorded audio (spanning 37:25-96:40 min) was professionally transcribed.

#### **Data analysis**

Inductive thematic analysis<sup>27</sup> was conducted with MAXQDA by four members of the research team, including YKL, MD, AA (undergraduate research assistant, woman), and SC (research program manager, woman), all of whom are trained in qualitative analysis. We initially coded six transcripts together to develop a list of central ideas (ie, codes) in the data and ensure a shared understanding of the early coding scheme. Each transcript was subsequently assigned to at least two team members, who individually applied the existing codes to segments of text using MAXQDA software. Consistent with an inductive approach, additional codes were generated and applied as needed based on new information in subsequent transcripts. The team members next met to review which codes applied to which segments, address divergencies, and collaboratively determine a final application of codes. In team meetings, we discussed data saturation and reviewed potential themes and supporting quotes. Themes were developed by linking related codes

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and synthesizing respondent experiences within the combined codes. The wording of themes and subthemes was then finalized. Discrepant data (ie, respondent experiences that varied from the theme) were included in the final descriptions to highlight differences in respondents' perspectives.

#### **RESULTS**

#### Sample characteristics and identified themes

Interviews were completed with 28 respondents, at which point no new themes were emerging. The respondents (54% women) had mean±SD age of 46±17 years. About one-third of respondents each respectively spent 0%, 0.1%–0.9% and  $\ge 1\%$  of time in level 2 hypoglycemia; 39% had impaired awareness of hypoglycemia and 32% had severe hypoglycemia in the past 6 months (table 1). Respondents included a balanced number of women and men with diverse ages, racial backgrounds, socioeconomic status, and hypoglycemia experiences. Upon beginning to use advanced diabetes technologies, respondents received diabetes education from an Association of Diabetes Care & Education Specialistsaccredited diabetes self-management education and support program.<sup>28</sup> No respondent had an established relationship with the interviewer prior to the interview. One respondent completed a follow-up interview, as additional questions were generated during analysis. Four primary themes were identified, each with up to three subthemes.

#### **Prioritizing symptoms over CGM data**

When receiving CGM hypoglycemia data, respondents relied on the presence or absence of hypoglycemia symptoms to determine whether they trusted the CGM information before managing hypoglycemia.

#### Hypoglycemia symptoms for confirming hypoglycemia and prompting management actions

Many respondents described the need for both hypoglycemia symptoms and CGM hypoglycemia information to confirm the development of hypoglycemia prior to hypoglycemia self-management:

If I know I'm feeling terrible and I know it's because of a low, that's the thing that's most likely to prompt [me managing the low]. I have good confidence in my CGM, but I definitely have more confidence in the feelings of my body. (40F, 2% of time with glucose <54 mg/dL, no severe hypoglycemia, normal hypoglycemia awareness)

Some respondents described how symptoms enabled them to predict the severity of a hypoglycemic episode and to identify an episode when they could not access their CGM data. Hypoglycemia symptoms alone could also produce an urge to immediately manage hypoglycemia:

Because I think there's that urge that your body has, like, 'You're dying. You need to fix yourself.' (41M, 0.1% of time with glucose <54 mg/dL, no severe hypoglycemia, normal hypoglycemia awareness)

 Table 1
 Patient demographic and diabetes characteristics

(N=28 unless noted otherwise)		
Characteristics	n (%) or mean±SD (range)	
Sex		
Woman	15 (54)	
Man	13 (46)	
Age, years	46±17 (20-75)	
Racial background		
Non-Hispanic Caucasian	23 (82)	
African American	3 (11)	
Other	2 (7)	
Education level		
High school graduate	1 (4)	
Some college	2 (7)	
Associate degree	4 (14)	
Bachelor's degree	11 (39)	
Master's degree	5 (18)	
Doctoral degree	2 (7)	
Do not wish to provide	3 (11)	
Household income		
<\$25 000	1 (4)	
\$50 000–\$75 000	4 (14)	
\$75 000–\$100 000	5 (18)	
\$100 000–\$200 000	10 (36)	
>\$200 000	3 (11)	
Do not wish to provide	4 (14)	
Do not know	1 (4)	
Duration of diabetes, years	24±13 (3-50)	
Hypoglycemia awareness score	2.9±1.9 (1-7)	
Impaired awareness of hypoglycemia	11 (39)	
HbA1c level, %	6.9±0.9 (5.2–9.3)	
HbA1c level, mmol/mol	51.9±9.8 (33.3-78.1)	
CGM type		
Dexcom	24 (86)	
Medtronic	4 (14)	
CGM use duration		
7–12 months	1 (4)	
1–2 years	10 (36)	
3–6 years	9 (32)	
>6 years	8 (29)	
Insulin pump use	25 (89)	
With autosuspension feature	1 (4)	
With automated insulin delivery feature	15 (54)	
Insulin pump use duration, years (n=25)		

Continued

Table 1 Continued	
Characteristics	n (%) or mean±SD (range)
1–2	3 (12)
3–6	5 (20)
>6	17 (68)
Active CGM use time, %	93±6 (80-100)
Time with glucose levels <70 mg/dL (3.9 mmol/L), %	3.4±3.4 (0-12.6)
Time with glucose levels <54 mg/dL (3.0 mmol/L), %	0.8±1.2 (0-4.9)
Spending 0% of time with glucose levels <54 mg/dL	9 (32)
Spending 0.1%–0.9% of time with glucose levels <54 mg/dL	10 (36)
Spending ≥1% of time with glucose levels <54 mg/dL	9 (32)
Six-month history of severe hypoglycemia	9 (32)
Number of severe hypoglycemic episodes (n=9)	4.3±4.3 (1–15)
.CGM, continuous glucose monitoring system; HbA1c, hemoglobin A1c.	

#### Minimal management actions without hypoglycemia symptoms

Respondents who had no or only minimal symptoms could easily postpone or even completely dismiss hypoglycemia management. Although respondents occasionally checked for self-monitoring blood glucose (SMBG) levels with glucometers, they often waited and only managed hypoglycemia once symptoms developed:

[The CGM] alarmed six times and I was working outside. I didn't feel like my blood sugar was low. And my problem is waiting. I shouldn't wait to treat that. But I continued to work. And then it continues to alarm, and then I kind of feel tired. So I head to the house [to manage my low]. (73M, 0.6% of time with glucose <54 mg/dL, had severe hypoglycemia and impaired hypoglycemia awareness)

Some respondents described that their severe hypoglycemic episodes resulted from delaying or dismissing hypoglycemia self-management based on a lack of symptoms.

#### Distraction from the demands of daily life

Striking a balance between living one's life and managing hypoglycemia remained challenging despite using advanced diabetes technologies. Respondents had to navigate different settings and activities, including at work or school and during sleep or family time. Many respondents cited obstacles to achieving an equilibrium in competing situations, especially when working on professional or time-sensitive tasks. Some respondents reported choosing to 'power through' current activities while acknowledging the risk of developing severe hypoglycemia. One respondent explained:

I don't want to waste my time on my exam, so I will consciously ignore the low when having an exam. Or if I'm running errands or something, then I might wait before correcting it or just unplug my pump and hope it goes back up. (21F, 1.2% of time with glucose <54 mg/dL, no severe hypoglycemia)

Some respondents reported prioritizing personal tasks over managing hypoglycemia. One respondent, who had recurrent severe hypoglycemia and did not take corrective action in response to CGM hypoglycemia alarms, attributed these severe episodes to his temperament and expectations:

That part's more of a DNA thing because my mom has kind of like a go-getter attitude, and even with the low sugar, I have that attitude still, where I'm like, 'Oh, I can get it done. I can get it done.' And then by the time I get it done, I might get a little bit dizzy or whatever and confused. (47M, 0.9% of time with glucose <54 mg/dL, had severe hypoglycemia)

Other respondents described feeling frustrated or guilty when favoring hypoglycemia management over other responsibilities or when their hypoglycemia management affected others. One respondent reported dilemmas in fulfilling family responsibilities versus managing hypoglycemia:

But [the bad low] does happen, enough that my kids know... 'You want me to play? I can't play. I can't play right now. I can't go get you that thing.' I'm normally a very busy, kind of bustling around person, and when I'm having a really dramatic low, I can't do that stuff. (40F, 2% of time with glucose <54 mg/dL, no severe hypoglycemia)

#### **Concerns about hypoglycemia management choices**

Challenges in choosing and eating hypoglycemia treatment foods, either due to concerns about health-related consequences or aversions to certain foods, could lead to delays in or dismissal of management actions.

#### Fear of rebound hyperglycemia

Although CGMs allowed respondents to view changes in glucose levels in real time, the technology did not completely prevent respondents from experiencing or worrying about hyperglycemia. Anxieties about rebound hyperglycemia, including the development of post-treatment hyperglycemia, hypoglycemia—hyperglycemia cycles, and future hyperglycemia complications, were common. Some respondents reported delaying or dismissing hypoglycemia management or prevention whenever possible to avoid hyperglycemia:

When I have a low, if I can allow the insulin pump to automatically correct it, I'll do that. (34F, 0.3% of time with glucose <54 mg/dL, had severe hypoglycemia)

#### Other health consequences related to sugary food consumption

Several respondents mentioned attempting to adopt healthier lifestyles for better health outcomes (eg, weight management, dental health). Consuming sugar to

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manage hypoglycemia thus seemed counterproductive. Some described using less effective management foods to minimize sugary food consumption:

No pop, because what sugar does, when you have sugar, it eats away at the muscles... And what protein does, is it builds the muscles. So instead of having [some] sugar, I have the protein muscle drinks, and those are healthier for me as a [person with diabetes]. (26M, 0% of time with glucose <54 mg/dL, had severe hypoglycemia)

#### Aversions to treatment foods and treatment food consumption

Some respondents reported struggling with their relationships with treatment foods, including feeling tired of eating these foods, needing to eat despite a low appetite or at irregular times, and disruptions to future meals due to additional food consumption. One respondent stated that he simply refused to use certain foods to manage hypoglycemia:

But I don't like honey. That's the worst thing you can give me, and I think most [people with diabetes], because they used to give me honey, honey, honey, honey, honey. I hate honey. You give me honey, and I'm going to spit it out of my mouth. (70M, 0% of time with glucose <54 mg/ dL, no severe hypoglycemia)

Several respondents discussed preferring to adhere to a daily routine, even if doing so might prolong hypoglycemia:

When I wake up with a low in the morning, I probably just wait for breakfast. It can be 30 or 60 minutes or longer after waking up. I get real particular in the morning, what I'm eating. I just don't like to start off with something like drinking juice or something. It'd make me feel weird. (20F, 2.8% of time with glucose <54 mg/dL, no severe hypoglycemia)

#### Social influences on management choices

Respondents described a variety of social environments where they managed hypoglycemia from supportive and friendly to critical and disinhibitory. CGMs could play roles in either improving social support or raising barriers to hypoglycemia self-management.

#### Positively perceived social support and inclusion

Many respondents reported that CGMs could be helpful in eliciting support from others during hypoglycemia, including engaging family members or friends in hypoglycemia self-management. By keeping others informed about real-time glucose information, some respondents felt secure, comfortable, and included. These social supports could also act as hypoglycemia checks and facilitators to hypoglycemia self-management:

Now whenever I eat marshmallows [to treat lows], I have two little grabby children who are like, 'We want marshmallows. Give us marshmallows, Mom.' My daughter routinely asks me, 'Is your blood sugar low?' just because she wants treats. She'll even bring me the bag of marshmallows, 'Mom, is your blood sugar low?' 'No, honey, it's not. I'll let you know.' (36F, 0.1% of time with glucose <54 mg/dL, no severe hypoglycemia)

## Unwanted attention to oneself or concerns about inconveniencing

At times, respondents considered other people's attention to CGM hypoglycemia alarms or offers to support hypoglycemia management as undesirable or potentially disruptive despite often good intentions. One respondent, who worked in a healthcare setting, cited instances when her CGM hypoglycemia alarms went off:

People kind of whip into a panic around you when things happen too. And then it makes it so much more a scene. I just get embarrassed because I don't want to be causing a scene. The [colleagues] at the time were aware of my stuff, and they like to baby you and stuff. 'Do you have your juice?' ... And so they knew the sound [of CGM alarms]. And then they would be like, 'Was your sugar okay?' in front of the doctors or patients. (46F, 0.4% of time with glucose <54 mg/dL, had severe hypoglycemia)

Some respondents also thought their hypoglycemia would inconvenience others or lead to distractions. To minimize this unwanted social attention, some respondents delayed hypoglycemia management whereas others became more proactive in preventing or managing low sugar levels. One respondent reported:

I used to have a lot [more] hypoglycemia. Being with my wife now, I also don't want to put her through such an [emergency] experience. So that has led to raising [my blood glucose targets to avoid hypoglycemia]. If I were to live alone, I would probably go lower again. (57M, 2% of time with glucose <54 mg/dL, had severe hypoglycemia)

Respondents who proactively prevented or managed hypoglycemia seemed to have more social support on-site to better navigate their situation:

Having [a] low at work, it's not fun. I've had a low at work where I was getting ready to present at a meeting, and I had to whisper to my colleague next to me and say, 'Can you go and get me some orange juice from the café?' And there are certain people that know [I live with diabetes], so they know exactly what to do. So it's nice. (60F, 0% of time with glucose <54 mg/dL, no severe hypoglycemia)

#### Social stigma and criticism related to hypoglycemia and CGM use

Several respondents reported poor experiences managing hypoglycemia when with other people. Some subsequently avoided managing hypoglycemia around others to minimize criticism or social stigma. For example, one respondent stated:

Any time you're mentioning a low or high blood sugar, they think, like, 'She doesn't take care of herself.' So there's always some type of judgment that you feel from other people... So a lot of times [when the CGM goes off], I do tend to hide it. Like, 'Oh, yeah. Nothing's wrong.' Just kind of eat something in secret. Try to act normal. Yeah. Just don't tell anybody. (33F, 3% of time with glucose <54 mg/dL, no severe hypoglycemia)

One respondent also noted feeling excluded by peers when disclosing hypoglycemia and his CGM. These reactions caused him to dismiss hypoglycemia management:

A lot of times when I talk about [my diabetes], people try to put me down. I want people to think that I'm normal, for lack of better words... So sometimes when I delay treatment for a low blood sugar, I'm insecure and scared to tell people that [I live with diabetes], or afraid to tell them what the [CGM] patch is on my arm. (26M, 0% of time with glucose <54 mg/dL, had severe hypoglycemia)

#### DISCUSSION

Our qualitative study with respondents with diverse hypoglycemia experiences highlights that hypoglycemia management with advanced diabetes technologies requires more than simply consuming treatment foods and achieving recovery from hypoglycemia after receiving CGM hypoglycemia data. Rather, one's response involves complex decisions, including confirming CGM hypoglycemia information, balancing daily life and hypoglycemia management, and navigating potential complications from hypoglycemia management and aversions to treatment foods and their consumption. This already taxing process can occur either in a socially supportive or socially challenging (and even disinhibitory) environment.

Our findings largely fall under the previously reported 'living and coping with CGM'<sup>11</sup> 18 29 and 'psychological issues and support'<sup>11</sup> 18 frameworks of CGM user experiences. Multiple barriers to hypoglycemia self-management identified within our study population aligned with those previously documented in non-CGM users. <sup>14</sup> 15 29 Our observations offer further evidence of how these barriers can lead to the delay or dismissal of hypoglycemia self-management and the development of clinically significant hypoglycemia in CGM users. Importantly, instead of failing to acknowledge potential hypoglycemic episodes or the risk of hypoglycemia, clinically significant hypoglycemia developments in CGM users were often due to inappropriate responses related to psychological or social barriers.

For instance, minimizing hypoglycemia concerns<sup>17 30</sup> has been identified in SMBG populations with problematic hypoglycemia who receive only discrete blood glucose information. Some of our respondents' neglect to prioritize hypoglycemia management suggests that CGMs, despite presenting hypoglycemia information with trend graphs, trend arrows, and hypoglycemia alarms, do not fully overcome hypoglycemia concern minimization. One may speculate that professional, family, or personal tasks, but not hypoglycemia management, are related to a person's core beliefs and self-image<sup>31</sup> and are hence given priority. Similarly, fear of hyperglycemia, 15 32 concerns related to health consequences from treatment food consumption, 1415 and aversions to certain treatment foods<sup>29</sup> are attitude-related issues rather than knowledge deficits. As CGMs do not manage hypoglycemia but only provide glucose information, diabetes education

on effective responses to ongoing or impending hypoglycemia remains critical. In addition, psychoeducation programs focused on adjusting hypoglycemia-related psychology,<sup>33</sup> coupled with training in coping skills to improve hypoglycemia management in social settings,<sup>18</sup> could serve as interventions to reduce these management barriers.

This study also identified facilitators to hypoglycemia self-management among advanced technology users. Our results suggest that, even when continuous glucose information is available, hypoglycemia symptoms continue to influence hypoglycemia self-management by confirming CGM hypoglycemia information or by acting as strong management prompts in and of themselves. This finding partially elucidated an earlier observed association between impaired hypoglycemia awareness and hypoglycemia development in CGM users.<sup>5 34</sup> Although hypoglycemia symptoms may enhance patients' trust in CGM hypoglycemia information, research has shown that people favor subjective symptoms over objective glucose results (including SMBG information). 16 35 This inclination indicates that one's reliance on hypoglycemia symptoms transcends mere concerns about CGM glucose accuracy. <sup>11</sup> 12 36 Training to improve hypoglycemia symptom detection <sup>37</sup> 38 may therefore be a key way to increase patients' use of CGM glucose information.

Social factors can function as supports, 11 12 facilitators, or barriers<sup>39</sup> to hypoglycemia self-management as demonstrated in this and other studies. Our findings bolster the literature on how CGM technologies amplify these effects, leading to either greater engagement with social support for hypoglycemia self-management or to the delay or dismissal of hypoglycemia management to reduce embarrassment or criticism. Future research is needed to (1) identify salient characteristics, including personality traits, related to favorable or avoidant reactions to social attention around hypoglycemia self-management; (2) expand understanding of the psychology of managing hypoglycemia in public (in both people with T1D and their families, friends, and others); and (3) acquire knowledge about social stigma around hypoglycemia and hypoglycemia self-management<sup>40</sup> to delineate the complex interactions between patients, hypoglycemia, and CGM event witnesses. This information is essential for creating multilevel interventions to address social barriers<sup>40</sup> to, and stress<sup>41 42</sup> resulting from, public hypoglycemia self-management.

Although we discerned multiple barriers consistent with the extant literature, other impediments (eg, lacking self-efficacy in hypoglycemia management<sup>15</sup>) were not identified in our study. Different from prior research, <sup>14</sup> respondents were also aware that 15 g of carbohydrate could adequately treat most hypoglycemic episodes. These differences were likely tied to respondents' prior participation in structured diabetes education programs. For a presumably similar reason, we did not discern gross knowledge gaps in respondents' definitions of hypoglycemia or in their symptomatology and

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CGM information interpretation. Alarm fatigue is a wellestablished phenomenon<sup>11</sup>; however, we did not observe simple ignorance of CGM hypoglycemia information. Underlying psychological or behavioral reasons instead tended to result in failure to address hypoglycemia, as described earlier.

Our themes were organized based on a theorized process of CGM users' hypoglycemia self-management experiences. These themes could be differentially associated with CGM. Themes 1 and 4 (using symptoms to confirm CGM hypoglycemia information; social experiences around managing hypoglycemia with CGMs) were more directly related to CGMs. Themes 2 and 3 (balancing daily life and hypoglycemia management; navigating decisions about treatment foods/consumption and potential complications including hyperglycemia) may not be as closely related to CGM technology; CGM users may nonetheless need to navigate these decision-making processes more frequently and might become more aware of hyperglycemia given continuous glucose information. 12 18

#### **Strengths and limitations**

To our knowledge, this study is one of the first to specifically examine CGM users' experiences with hypoglycemia management. To complement the current understanding of CGM and hypoglycemia management experiences, we have described in greater depth which and how barriers delay or stop advanced diabetes technology users from managing hypoglycemia. Additionally, we have specified facilitators to hypoglycemia self-management to promote intervention development. Our respondents were recruited from a well-phenotyped population, possessing diverse hypoglycemia characteristics as well as other demographic and socioeconomic attributes. Because we recruited respondents from a tertiary medical center which uses the standard of care for diabetes management, our findings may not be fully representative of the entire T1D CGM-using population. Also, as the study data were collected from a diverse respondent cohort including those who continue to develop severe hypoglycemia despite using CGMs, findings may not be generalizable to all people using these advanced technologies. Results from the studied cohort, however, advocate for interventions beyond current management recommendations targeting on those who continue to suffer from hypoglycemia despite using CGMs to minimize hypoglycemia in advanced diabetes technology users.

Biases from the interviewers and analysts likely existed; however, our multidisciplinary team (including a diabetes healthcare provider member, a member living with T1D and using CGM, and two members who were originally not familiar with diabetes) collaboratively conducted the analysis. Also, our findings were mostly congruent with prior reported CGM and hypoglycemia management experiences while providing new insights into the research question.

In conclusion, a complex biopsychosocial process of managing hypoglycemia exists in T1D adults who use CGMs, which may explain the persistence of impaired hypoglycemia awareness and incomplete protection against level 2 and severe hypoglycemia among advanced diabetes technology users. 9 Psychosocial and behavioral factors should be considered when healthcare providers support hypoglycemia management in this population. Hypoglycemia awareness training, psychoeducation, and multilevel interventions could help address behavioral and social barriers while enhancing facilitators to hypoglycemia selfmanagement in advanced diabetes technology users.

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#### **REFERENCES**

- 1 Amiel SA, Aschner P, Childs B. Hypoglycaemia, cardiovascular disease, and mortality in diabetes: epidemiology, pathogenesis, and management. Lancet Diabetes Endocrinol 2019;7:385-96.
- ElSayed NA, Aleppo G, Aroda VR, et al. Diabetes technology: standards of care in Diabetes - 2023. Diabetes Care 2023;46:S111-27.

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- 3 Forlenza GP, Lal RA. Current status and emerging options for automated insulin delivery systems. *Diabetes Technol Ther* 2022;24:362–71.
- 4 Agiostratidou G, Anhalt H, Ball D, et al. Standardizing clinically meaningful outcome measures beyond Hba1C for type 1 diabetes: A consensus report of the American Association of clinical Endocrinologists, the American Association of diabetes educators, the American diabetes Association, the endocrine society, JDRF International, the Leona M. and Harry B. Helmsley charitable trust, the pediatric endocrine society, and the T1D exchange. Diabetes Care 2017;40:1622–30.
- 5 Lin YK, Chan O, Fisher SJ. RE: impaired awareness of hypoglycemia continues to be a risk factor for severe Hypoglycemia despite the use of continuous glucose monitoring system in type 1 diabetes. Endocr Pract 2019:25:1080-1.
- 6 Seyed Ahmadi S, Westman K, Pivodic A, et al. The association between Hba<sub>1C</sub> and time in hypoglycemia during CGM and selfmonitoring of blood glucose in people with type 1 diabetes and multiple daily insulin injections: a randomized clinical trial (GOLD-4). Diabetes Care 2020;43:2017–24.
- 7 Ólafsdóttir AF, Bolinder J, Heise T, et al. The majority of people with type 1 diabetes and multiple daily insulin injections benefit from using continuous glucose monitoring: an analysis based on the GOLD randomized trial (GOLD-5). *Diabetes Obes Metab* 2021:23:619–30.
- 8 Akturk HK, Dowd R, Shankar K, et al. Real-world evidence and glycemic improvement using dexcom G6 features. *Diabetes Technol Ther* 2021;23:S21–6.
- 9 Lin YK, Richardson CR, Dobrin I, et al. Beliefs around hypoglycemia and their impacts on hypoglycemia outcomes in individuals with type 1 diabetes and high risks for hypoglycemia despite using advanced diabetes technologies. *Diabetes Care* 2022;45:520–8.
- 10 Pettus J, Liu J, Titievsky L, et al. 92-OR: persistence of impaired awareness of Hypoglycemia, severe Hypoglycemic events, and suboptimal Glycemic control despite advanced diabetes Technologies. *Diabetes* 2022;71.
- 11 Pickup JÖ, Ford Holloway M, Samsi K. Real-time continuous glucose monitoring in type 1 diabetes: a qualitative framework analysis of patient narratives. *Diabetes Care* 2015;38:544–50.
- 12 Vloemans AF, van Beers CAJ, de Wit M, et al. Keeping safe. continuous glucose monitoring (CGM) in persons with type 1 diabetes and impaired awareness of hypoglycaemia: a qualitative study. Diabet Med 2017;34:1470–6.
- 13 Lawton J, Blackburn M, Allen J, et al. Patients' and Caregivers' experiences of using continuous glucose monitoring to support diabetes self-management: qualitative study. BMC Endocr Disord 2018:18:12
- 14 Lawton J, Rankin D, Cooke DD, et al. Self-treating hypoglycaemia: a longitudinal qualitative investigation of the experiences and views of people with type 1 diabetes. *Diabet Med* 2013;30:209–15.
- 15 Speight J, Barendse SM, Singh H, et al. Cognitive, behavioural and psychological barriers to the prevention of severe Hypoglycaemia: a qualitative study of adults with type 1 diabetes. SAGE Open Med 2014:2
- 16 Gonder-Frederick L, Cox D, Kovatchev B, et al. A biopsychobehavioral model of risk of severe hypoglycemia. *Diabetes Care* 1997:20:661–9.
- 17 Rogers HA, de Zoysa N, Amiel SA. Patient experience of hypoglycaemia unawareness in type 1 diabetes: are patients appropriately concerned? *Diabet Med* 2012;29:321–7.
- 18 Ritholz MD, Atakov-Castillo A, Beste M, et al. Psychosocial factors associated with use of continuous glucose monitoring. Diabet Med 2010;27:1060–5.
- Lind M, Polonsky W, Hirsch IB, et al. Continuous glucose monitoring vs conventional therapy for glycemic control in adults with type 1 diabetes treated with multiple daily insulin injections: the GOLD randomized clinical trial. *JAMA* 2017;317:379–87.
   Heinemann L, Freckmann G, Ehrmann D, et al. Real-time continuous
- 20 Heinemann L, Freckmann G, Ehrmann D, et al. Real-time continuous glucose monitoring in adults with type 1 diabetes and impaired hypoglycaemia awareness or severe hypoglycaemia treated with multiple daily insulin injections (hypode): a multicentre, randomised controlled trial. Lancet 2018;391:1367–77.

- 21 Brown SA, Kovatchev BP, Raghinaru D, et al. Six-month randomized, multicenter trial of closed-loop control in type 1 diabetes. N Engl J Med 2019;381:1707–17.
- van Beers CAJ, DeVries JH, Kleijer SJ, et al. Continuous glucose monitoring for patients with type 1 diabetes and impaired awareness of Hypoglycaemia (IN CONTROL): a randomised, open-label, crossover trial. Lancet Diabetes Endocrinol 2016;4:893–902.
- 23 Danne T, Nimri R, Battelino T, et al. International consensus on use of continuous glucose monitoring. *Diabetes Care* 2017;40:1631–40.
- 24 Palinkas LA, Horwitz SM, Green CA, et al. Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. Adm Policy Ment Health 2015;42:533–44.
- 25 Gold AE, MacLeod KM, Frier BM. Frequency of severe hypoglycemia in patients with type I diabetes with impaired awareness of hypoglycemia. *Diabetes Care* 1994;17:697–703.
- 26 Kolar K, Ahmad F, Chan L, et al. Timeline mapping in qualitative interviews: A study of resilience with marginalized groups. International Journal of Qualitative Methods 2015;14:13–32.
- 27 Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology* 2006;3:77–101.
- 28 Davis J, Fischl AH, Beck J, et al. National standards for diabetes self-management education and support. Sci Diabetes Self Manag Care 2022;48:44–59.
- 29 Martyn-Nemeth P, Duffecy J, Fritschi C, et al. Challenges imposed by Hypoglycemia in adults with type 1 diabetes. Clin Nurs Res 2019;28:947–67.
- 30 Cook AJ, DuBose SN, Foster N, et al. Cognitions associated with hypoglycemia awareness status and severe hypoglycemia experience in adults with type 1 diabetes. *Diabetes Care* 2019;42:1854–64.
- 31 Beck JS. Cognitive therapy. In: The Corsini Encyclopedia of Psychology: 1-3.
- 32 Polonsky WH, Fortmann AL, Price D, et al. Hyperglycemia aversiveness: investigating an overlooked problem among adults with type 1 diabetes. J Diabetes Complications 2021;35.
- 33 Amiel SA, Potts L, Goldsmith K, et al. A parallel randomised controlled trial of the Hypoglycaemia awareness restoration programme for adults with type 1 diabetes and problematic Hypoglycaemia despite Optimised self-care (Harpdoc). Nat Commun 2022;13:2229.
- 34 Lin YK, Groat D, Chan O, et al. Associations between the time in hypoglycemia and hypoglycemia awareness status in type 1 diabetes patients using continuous glucose monitoring systems. *Diabetes Technol Ther* 2020;22:787–93.
- 35 Gonder-Frederick LA, Cox DJ. Behavioral responses to perceived hypoglycemic symptoms. *Diabetes Educ* 1986;12:105–9.
- 36 Messer LH, Cook PF, Tanenbaum ML, et al. CGM benefits and burdens: two brief measures of continuous glucose monitoring. J Diabetes Sci Technol 2019;13:1135–41.
- 37 Cox DJ, Gonder-Frederick L, Ritterband L, et al. Blood glucose awareness training: what is it, where is it, and where is it going. *Diabetes Spectr* 2006;19:43–9.
- 38 Rondags S, de Wit M, Twisk JW, et al. Effectiveness of hypoaware, a brief partly web-based psychoeducational intervention for adults with type 1 and insulin-treated type 2 diabetes and problematic hypoglycemia: a cluster randomized controlled trial. *Diabetes Care* 2016;39:2190–6.
- 39 Speight J, Barendse SM, Singh H, et al. Characterizing problematic Hypoglycaemia: Iterative design and preliminary Psychometric validation of the Hypoglycaemia awareness questionnaire (Hypoa-Q). *Diabet Med* 2016;33:376–85.
- 40 Chatwin H, Broadley M, Hendrieckx C, et al. Unmet support needs relating to Hypoglycaemia among adults with type 1 diabetes: results of a multi-country web-based qualitative study. *Diabet Med* 2022:39
- 41 Stuckey HL, Desai U, King SB, et al. The experience of a severe Hypoglycaemic event from the perspective of people with diabetes and their Caregivers: "What am I going to do?" *Diabet Med* 2022;39.
- 42 Lawton J, Rankin D, Elliott J, et al. Experiences, views, and support needs of family members of people with hypoglycemia unawareness: interview study. *Diabetes Care* 2014;37:109–15.