

RESEARCH: EDUCATIONAL AND
PSYCHOLOGICAL ASPECTS

The experience of a severe hypoglycaemic event from the perspective of people with diabetes and their caregivers: “What am I going to do?”

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Funding information

Research funding was provided by Eli Lilly and Company, Indianapolis USA.

Abstract

Aims: Among people with diabetes using insulin, severe hypoglycaemia (SH) can be a life-threatening complication, if untreated. The personal experiences during an SH event from the perspectives of people with diabetes and their caregivers are not well-characterized. This study assessed the perceptions of the event and the decision making processes of people with diabetes (T1D $n = 36$; T2D $n = 24$) and their caregivers during SH events.

Methods: In-depth one-on-one telephone interviews were conducted with dyads of people with diabetes and caregivers in the United States ($n = 120$). An initial synopsis and inductive codebook schema were used to analyse the data with two independent coders ($\kappa = 0.87$ – 0.89). Themes were developed from the codes, and codes were re-mapped to the themes.

Results: Four themes were formed: (1) Caregivers scramble to do the right thing and support people with diabetes in treating SH; (2) Decision making capacity is impaired during an SH event, often a panicked time; (3) People learn to manage SH events through their own experiences and frequently make lifestyle changes to prevent and treat future events; and (4) Discussion with healthcare providers about SH, and particularly SH treatment, is limited.

Conclusions: SH events are stressful and often evoke emotional reactions that can impair decision making. Thus, advance treatment planning of SH events needs to occur. Much of the knowledge about SH treatment derives from prior experience rather than healthcare provider guidance, suggesting a need for healthcare providers to initiate proactive discussions about SH treatment.

KEYWORDS

caregivers, decision making, diabetes mellitus, hypoglycaemia, psychosocial support systems

1 | INTRODUCTION

Hypoglycaemia can be life threatening and is a feared complication among people with diabetes using insulin.^{1–5} Initial symptoms can include anxiety, sweating, tremor, cognitive impairment and behavioural changes.⁶ Hypoglycaemia can be managed by ingesting carbohydrate-containing foods or liquids (oral carbohydrates). However, factors such as impaired hypoglycaemia awareness, lack of knowledge about or access to treatment and challenging emotions can delay appropriate corrective action,^{7–11} this delay can lead to a point at which people with diabetes cannot safely swallow carbohydrates. At its worst, severe hypoglycaemia (SH) can cause loss of consciousness, seizures, coma or death.^{6,12} Per the International Hypoglycaemia Study Group (IHSG) and the American Diabetes Association (ADA) guidance, during severe events, ‘characterized by altered mental and/or physical status (i.e., cognitive impairment) requiring assistance for recovery’, glucagon may be administered by a third party, such as a caregiver (e.g., spouse/partner, parent), if indicated.^{12,13}

Unfortunately, SH is common: an estimated 22%–46% of people with type 1 diabetes and 21% of those with type 2 diabetes using insulin experience at least one SH event per year.^{2,12,14} In recognition of the importance of SH management, the ADA recommends that ‘Occurrence and risk for hypoglycaemia should be reviewed at every encounter and investigated as indicated’.¹³ Despite this, studies have reported that conversations around SH are uncommon in clinical practice. Recently, the multinational Conversations and Reactions Around Severe Hypoglycaemia (CRASH) Study found that most people with diabetes do not bring up recent hypoglycaemic events with their healthcare providers, proactive treatment planning was not happening as often as guidelines recommended and that many people with diabetes did not have glucagon on hand even after experiencing an SH event.^{10,15–17}

To inform clinical initiatives regarding SH management and help healthcare providers prioritize care appropriately, it is important to understand the experiences of people with diabetes and their caregivers during an actual SH event. However, few studies have evaluated these perspectives in this emergency situation. In one study, 16 people with diabetes in Canada were interviewed about their roles in preventing or self-managing hypoglycaemia.^{6,18} Other studies have focused on the fear of hypoglycaemia or the impact of hypoglycaemia and impaired awareness about hypoglycaemia on the day-to-day lives of people with type 1 diabetes and their family members.^{19–27} Generally, however, primary data regarding the experiences of people with diabetes, including those with type 2 diabetes who use insulin, and their caregivers in managing an SH

Significance of the Study

What is already known about this subject?

- Many people with diabetes using insulin and their caregivers feel unprepared for or fearful about severe hypoglycaemia (SH) events.
- However, personal experiences of people with diabetes and caregivers during an actual SH event are not well characterized.

What this study has found?

- Caregivers actively in support people with diabetes during hypoglycaemia.
- Decision making capacity is limited during SH event, often a panicked time.
- Knowledge regarding SH treatment largely derives from personal experience.
- Discussions with healthcare providers about SH, and particularly treatment, are limited.

What are the implications of the study?

- These findings can help healthcare providers better understand the challenges faced by people with diabetes and their caregivers during an SH event and identify avenues for providing more education and support.

event are lacking. To address this gap in the literature, the present study explored the experiences during SH events among adults in the United States from the perspectives of both people with diabetes who use insulin and caregivers who assist them in order to inform healthcare providers and in hopes of elevating conversations about SH risk and management.

2 | METHODS

2.1 | Study design and participants

A cross-sectional study was conducted with 60 dyads in the United States ($N = 120$) comprising people with diabetes who use insulin and who recently experienced SH events as well as their caregivers. Each individual participated in a one-on-one telephone interview. Eligible people with diabetes had diagnosed type 1 diabetes or type 2 diabetes, were using insulin, and had received help from their current caregiver during an SH event occurring after at least 1 year of insulin use and within the prior 3 years. Consistent with IHSG and ADA guidelines, SH events were defined as events in which a person with diabetes’ glycaemic level dropped so low that they needed assistance from someone else to recover.^{12,13} A caregiver was

defined as a person living with the person with diabetes who was aware of the person's diabetes when they assisted with the SH event. People with diabetes and caregivers were excluded if they were under 18 years old, had professional experience treating patients in a clinical setting as such training could alter their ability and approach to recognizing and managing an SH event, or had a self-reported serious functional limitation that might limit the generalizability of their experiences (e.g., dementia). Finally, the study sample excluded individuals who reported having ever filled a prescription for newer formulations of glucagon (i.e., nasal powder or premixed syringe), as early adopters of treatment technology may not represent the general population of people with diabetes who use insulin.^{28,29}

The study was exempted from institutional review by the New England Independent Review Board, Needham, MA (now part of WCG IRB, Pullayup, WA).

2.2 | Study procedures

Participants were recruited from market research panels maintained by Dynata LLC, comprising individuals who have voluntarily agreed to participate in survey and interview-based studies. In order to enrol in the panels, participants complete eligibility screeners including questions about their medical history which allows targeted recruitment. For this study, participants were contacted using traditional methods (e.g., email, phone) as well as more contemporary modalities such as social media outreach. Interested participants completed a brief online screener to ensure they met the study inclusion and exclusion criteria noted above. Self-reported demographic and clinical characteristics were also collected through the brief online screener.

For eligible participants, telephone interviews were conducted using semi-structured guides developed using findings from previous literature and discussions with experts, including Dr. Stuckey. Each interview lasted 45–60 min and covered topics including circumstances of the most recent SH event, the SH event's impact on perspectives towards hypoglycaemia management and information received from healthcare providers. Interviews with caregivers were conducted separately from people with diabetes and additionally addressed questions around decision making during the SH event. Questions included in the interview guide are presented in Table S1.

Interviews were conducted by a moderator trained by the lead investigator (Dr. Stuckey) and were audio-recorded, transcribed and de-identified for coding. Participants were required to provide informed consent before joining the study.

2.3 | Analysis

Participant characteristics were summarized quantitatively for people with diabetes and caregivers using numbers and proportions. Analyses were conducted using SAS Enterprise version 7.15. An inductive thematic analysis was used to identify recurrent concepts from the interview data.³⁰ In the first phase, transcripts were reviewed to identify frequently reported concepts and apply labels (codes) to preliminary groupings of similar phenomena (categories). An initial codebook was developed by HS, then the research team tested the codebook against two transcripts to make further revisions. Two independent researchers coded each transcript using NVivo 12 PRO software, and the text in the transcriptions were not double-coded; in other words, extracts from the participants were only coded once into the code that best described the nature of the text.

Inter-rater reliability was assessed using Cohen's kappa (people with diabetes = 0.870; caregiver = 0.887); discrepancies were adjudicated through discussion with the lead investigator. In the second phase, HS created a coding summary of each code and created a narrative that described the main concepts from the codes. The narrative became the basis for the themes, which was refined further based on discussions with the study team. As the themes and codes were finalized, a few codes were divided further into subcodes (e.g., the code 'mentioned how to prepare, prevent, treat' was divided into three subcodes of prepare, prevent, treat). The primary coders recoded the data and another 'coding summary' was created to become the basis of the analysis and quotes used in the results section of this paper. For transparency, the frequency with which each code appeared was reported and example quotes for key codes were identified. The complete codebook is included as Table S2.

3 | RESULTS

3.1 | Participant characteristics

Sixty dyads of people with diabetes and their caregivers ($N = 120$) were included (Tables 1 and 2). Most had lived together for ≥ 3 years ($n = 52$), and in most cases, the caregiver was the person with diabetes' spouse/partner ($n = 48$). Most people with diabetes were female ($n = 43$), while most caregivers were male ($n = 38$). Mean age was 48 years among people with diabetes and 49 among caregivers. Among people with diabetes, 36 (60%) were type 1 diabetes and 24 (40%) were type 2 diabetes. Most ($n = 50$) had been using insulin for ≥ 6 years.

TABLE 1 Characteristics of people with diabetes ($N = 60$)

Male gender, n (%)	17	(28%)
Age category, n (%)		
18–24	2	(3%)
25–34	9	(15%)
35–44	12	(20%)
45–54	17	(28%)
55–64	13	(22%)
65+	7	(12%)
Age, mean (median)	48	(47)
Race/ethnicity, n (%)		
Black/African American	9	(15%)
Latino/Hispanic/Chicano	4	(7%)
Non-Hispanic White/Caucasian	45	(75%)
Multiple racial/ethnic backgrounds	1	(2%)
Other	1	(2%)
Employment status, n (%)		
Working full-time	29	(48%)
Working part-time	8	(13%)
Not working	23	(38%)
Diabetes type n (%)		
Type 1	36	(60%)
Type 2	24	(40%)
Initiated insulin 6+ years ago, n (%)	50	(83%)
Number of SH events within past 3 years, n (%)		
1–3	6	(10%)
4–6	17	(28%)
7–10	12	(20%)
11+	25	(42%)
IAH (Gold score 4+), n (%) ^a	20	(33%)
Type of insulin(s) currently used, n (%)		
Insulin pump	25	(42%)
Basal (long-acting) insulin injections	30	(50%)
Meal-time (short-acting) insulin injections	25	(42%)
Pre-mixed (long and short-acting) insulin injections	5	(8%)
Number of comorbid health conditions, n (%)		
0	20	(33%)
1	16	(27%)
2	6	(10%)
3	11	(18%)
4+	7	(12%)
Most recent HbA1c, n (%)		
≤ 53 mmol/mol ($\leq 7\%$)	18	(30%)

TABLE 1 (Continued)

53–86 mmol/mol (>7 to 10%)	39	(65%)
>86 mmol/mol ($>10\%$)	3	(5%)
Most frequent HCP seen for diabetes, n (%)		
Doctor in a primary care or family practice	22	(37%)
Endocrinologist or doctor in diabetes specialty practice	35	(58%)
Nurse practitioner in a primary care or family practice	2	(3%)
Nurse practitioner in an endocrinology or diabetes specialty practice	1	(2%)

Abbreviations: IAH, impaired awareness of hypoglycaemia; SH event, severe hypoglycaemic event.

^aAssessed using the 7-point Gold scale for hypoglycaemia awareness (1 = always aware, 7 = never aware).

One third of people with diabetes reported impaired hypoglycaemia awareness (Gold score 4+³¹). Over 40% of people with diabetes using insulin ($n = 25$) reported having experienced 11 or more severe hypoglycaemia events within the prior 3 years, 12 people reported having experienced 7–10 SH events and an additional 17 people reported experiencing 4–6 SH events. For 49 people with diabetes, the most recent SH event occurred within the year prior to the interview. Most recent glycated haemoglobin (HbA_{1c}) was ≤ 53 mmol/mol ($\leq 7\%$), 53–86 mmol/mol (7%–10%) and >86 mmol/mol ($>10\%$) in 18, 39 and 3 people with diabetes, respectively. Over half ($n = 35$) of people with diabetes reported usually receiving diabetes-related care from an endocrinologist or in a diabetes specialty practice while 22 people usually saw a primary care physician and three saw a nurse practitioner (Table 1).

3.2 | Symptoms of hypoglycaemia and SH

Primary initial symptoms reported by people with diabetes or caregivers were sweating ($n = 60$); confusion ($n = 57$); shakiness ($n = 55$), having blood glucose that is, or *feels* low ($n = 46$), feeling tired/exhausted ($n = 43$) and dizziness ($n = 29$). More than one third of the participants ($n = 46$) described the people with diabetes as having impaired hypoglycaemia awareness or recognizing initial symptoms (based on subjective assessments; not Gold score). As the hypoglycaemic event progressed, most participants reported that people with diabetes were either unable to follow directions and experienced extreme

confusion ($n = 80$); were unable to stand up or felt general weakness ($n = 49$); had severe sweating ($n = 47$); felt they do not *look* or *feel* right ($n = 32$); experienced shakiness ($n = 30$), or were unable to speak or speak clearly ($n = 27$). Thirty-four people with diabetes and caregivers mentioned that the person with diabetes lost consciousness during an SH event.

3.3 | Management of SH and associated challenges

Four themes were formed from the data: (1) how the caregiver supports the person with diabetes in treating SH; (2) how decision making is impaired during an SH crisis; (3) how people with diabetes and caregivers learn about SH through experience and what worked in the past; and (4) how the healthcare provider could provide more support/education. These themes and supporting data are described below. The frequency of references to key codes is summarized in Table 3.

3.3.1 | Theme 1. Scrambling to do the right thing: how the caregiver supports the people with diabetes in treating SH

For people with diabetes, the first *arsenal* to combat the onset of hypoglycaemia consisted of oral carbohydrates. Caregivers described being ready and willing to help keep things from *getting out of hand*, and people with diabetes often received assistance even during milder hypoglycaemia. However, some people with diabetes hesitated to reach out for help, as they did not perceive the event to be very severe and had a desire to handle their condition without feeling like a burden to their caregiver. As hypoglycaemia worsened, people with diabetes looked for *what works* to shorten the duration. Caregivers typically handled SH by providing more carbohydrates, often *scrambling* to find more. Some caregivers described needing to urge the person with diabetes to eat or drink more while some had to take the lead on administering the carbohydrates: one described *literally dumping Coca-Cola down [the person with diabetes'] throat*.

I immediately think of what is it that's going to act the fastest to get her sugar levels up. That's really, "What do I have? Do I have orange juice? What do I have?" Bam. "What do I have?" It's more of what do we have on hand.—Caregiver

TABLE 2 Caregiver characteristics ($N = 60$)

Male gender, n (%)	38	(63%)
Age category, n (%)		
18–24	4	(7%)
25–34	9	(15%)
35–44	13	(22%)
45–54	13	(22%)
55–64	10	(17%)
65+	11	(18%)
Age, mean (median)	49	(49)
Race/ethnicity, n (%)		
Black/African American	10	(17%)
Latino/Hispanic/Chicano	3	(5%)
Native American	1	(2%)
Non-Hispanic White/Caucasian	45	(75%)
Other	1	(2%)
Employment status, n (%)		
Working full-time	27	(45%)
Working part-time	4	(7%)
Not working	29	(48%)
Most recent year caregiver helped person with diabetes with an SH event, n (%)		
2017	1	(2%)
2018	2	(3%)
2019	8	(13%)
2020	49	(82%)
Relationship to person with diabetes, n (%)		
Spouse/partner	48	(80%)
Child	5	(8%)
Parent/legal guardian	4	(7%)
Roommate	2	(3%)
Sibling	1	(2%)
Length of time person with diabetes and caregiver have lived together, n (%)		
Less than 1 year	4	(7%)
At least a year, but less than 3 years	4	(7%)
3 years or more	52	(87%)
Diagnosed with diabetes, n (%) ^a	12	(20%)
Diabetes type, n (%)		
Type 1	2	(17%)
Type 2	10	(83%)
Currently using insulin, n (%)	5	(42%)

Abbreviations: SH event, severe hypoglycaemic event.

^aPercentages in the subsequent rows are reported using caregivers diagnosed with diabetes ($n = 12$) as the denominator.

TABLE 3 Codes used in qualitative analysis related to themes^a

Theme	Code	Sub-code	# of people with diabetes/caregivers	% of people with diabetes and caregivers (N = 120)	Quotes	
Theme 1. Scrambling to do the right thing: How the caregiver supports the person with diabetes in treating SH	Initial actions of hypoglycaemia	Person with diabetes drinks and/or eats something by self	82	68%	192	
		Person with diabetes asks for help or is given help by caregiver	96	80%	271	
	Caregiver actions during SH	Caregiver gave food and/or juice	113	94%	389	
		Called 911 or medics	69	58%	142	
	Glucagon	Glucagon administered by caregiver	16	13%	36	
		Caregiver/person with diabetes has one or more glucagon kits	39	33%	58	
	Glucagon	Not aware of glucagon	46	38%	81	
		Additional information needed about glucagon and treatment options	42	35%	61	
	Theme 2. Facing an emotional challenge: How decision making is impaired during an SH crisis	Initial emotions	Person with diabetes/caregiver anxiety or worry	82	68%	150
		SH emotions	Person with diabetes/caregiver rising anxiety, worry or panic	78	65%	187
Theme 3. Figuring it out as we go: How people with diabetes and caregivers learn about SH through experience and what worked in the past	Learn about treatment of hypoglycaemia	Person with diabetes or caregiver's own experience	57	48%	103	
		Online or own research	27	23%	35	
	Person with diabetes' changes in day-to-day life because of SH	Diet, insulin, exercise	88	73%	166	
		Focus on avoiding hypoglycaemia	38	32%	54	
	Caregiver changes in day-to-day life to support the person with diabetes	Strategies re: when to correct a low	11	9%	17	
		Caregiver changes in day-to-day life to support the person with diabetes	46	38%	59	

TABLE 3 (Continued)

Theme	Code	Sub-code	# of people with diabetes/caregivers	% of people with diabetes and caregivers (N = 120)	Quotes
Theme 4. Knowing how to treat SH: How the healthcare provider could provide more support/education	Discussion of hypoglycaemia with healthcare provider	Healthcare provider doesn't talk about hypoglycaemia	43	36%	71
		Healthcare provider mentioned how to prevent, prepare or treat hypoglycaemia ^b :	79	66%	190
		a. Preventing (i.e., check blood glucose)	63	53%	93
		b. Preparing (i.e., have things on hand)	31	26%	38
		c. Treating (i.e., drink juice)	44	37%	59
		Healthcare provider mentioned glucagon as treatment	46	38%	93
		Past SH events—did discuss	66	55%	112
		Past SH events—did not discuss	31	26%	45

^aSee Supplementary Table S2 for the full codebook used in qualitative analysis and corresponding number of quotes, overall and separately for people with diabetes and caregivers.

^bDoes not equal the sum of a, b and c because there are some participants who stated more than one subcode.

He's depending on me to help him because he can't get up and walk to the kitchen or somewhere to get something to drink, so I'm in a scuttle trying to hurry up and get to him to make sure that he's OK. So it's a little scattered.—Caregiver

If oral carbohydrates did not prevent SH, caregivers sometimes felt helpless, and thought that the *only option [was] to call for emergency help*. When *nothing else* worked, caregivers sometimes administered glucagon.

I will ask him, "Do you need help? Do you need me to call 911?" And when he doesn't respond, saying, "No," I know it's time to call.—Caregiver

I knew I wasn't going to get any juice down her. I squirted the gel in her mouth and a minute goes by, two minutes go by, three minutes go by, and there's no change, I start thinking, "Oh s***. What's next?" After maybe seven or eight minutes, probably less than 10, I decided that wasn't working. That's when I went for the glucagon.—Caregiver

While some people with diabetes and caregivers had heard of or administered glucagon, nearly a third had not, and some had misconceptions about its use or effects.

3.3.2 | Theme 2. Facing an emotional challenge: how decision making is impaired during an SH crisis

People with diabetes described SH events as *foggy*, *cloudy* periods where *things are in slow motion*, making it nearly impossible to think quickly at a time when speed was of the essence. People with diabetes often experienced disorientation, making it difficult to collect thoughts and make simple decisions—in one case, after having a cold washcloth applied to her forehead, the person with diabetes asked why there was a *wet fish* on her head. Many people with diabetes were so disoriented they did not remember the event. One described being in a dream, or *virtual reality*; others described a *separation of body and soul* and *near-death event*.

I'm confused. A lot of times, I'll wake up and think, "This is easy to deal with." Then, your mind goes, "What's next? -- It's easy to deal with -- What's next?" It's good angel,

bad angel on your shoulders. “You’re fine -- You’re not fine.”—Person with diabetes

I couldn’t see, I couldn’t talk, I couldn’t move ... then when I came back to, I had this huge bruise on my leg and I had three people sitting around me. And I was like, what’s going on?—Person with diabetes

Caregivers also described scenes of confusion, where people with diabetes walked aimlessly, stared at the ceiling, talked like they were *in another world*, or became uncoordinated.

She’ll get confused. She just doesn’t realize the seriousness of [her blood glucose] getting low, and when she’s in that state of mind, she’s kind of slow in getting [food/drink] into her system.—Caregiver

However, most caregivers recognized the urgency of the situation and were desperate to find a remedy to help the people with diabetes recover from the event. Caregivers described SH events as scary, panicky, alarming and dangerous, and felt *fearful that [the person with diabetes] may pass out or worse*. Caregivers often reported feeling a rising sense of panic and questioning their actions.

There’s a sense in which she’s always eventually wake up, but there’s a part of me that fears that it only takes one time where that doesn’t happen.—Caregiver

Both people with diabetes and caregivers stated the importance of having a plan in the event the person with diabetes needed to *call out for help*.

You have something in plan in your mind, because the worst thing you want to do is stand in the middle of your kitchen saying I don’t know how to help myself. I don’t know what to eat. I don’t know what to do.—Person with diabetes

Learn facts before you need to implement them so that you can know what to do, rather than just reacting emotionally, even if you have to physically go through the exercises to get it down. If someone’s blood sugar is reaching a certain point, then OK this is what I do so that it becomes instinct and not reactionary.—Caregiver

However, help was not always available: some people with diabetes reported experiencing SH while alone, describing these moments as *pivotal, between life and death*. Some described feeling weak and sitting on the floor drinking juice while waiting to recover; one said, *By the grace of God, I made it to the kitchen*. Many wondered what was going to happen, and whether they should call 911.

My son was six months old. He was in the car seat in the back. I remember driving right past my exit having no idea where I was going. I just kept driving and driving and finally pulled off. Homemade applesauce was in the passenger seat... [I] was downing applesauce in the car.—Person with diabetes

3.3.3 | Theme 3. Figuring it out as we go: how people with diabetes and caregivers learn about SH through experience and what worked in the past

People with diabetes and caregivers described learning to manage and treat hypoglycaemia by *figuring it out yourself, do[ing] it yourself, educat[ing] yourself*. People with diabetes felt that experience and *good luck* taught them how to treat SH; caregivers felt like they learned something new from each episode, by doing their own research, and by asking the people with diabetes or the people with diabetes’ healthcare provider questions.

I feel like hypo, I’ve had to learn so much of it myself. It’s manageable and you learn as you go, but it would definitely be nice to have more resources more available to help people with those episodes.—Person with diabetes

If the disease changed, like going from oral meds to alternative insulin..., we should have had some education along with each of those changes in our status and the medications, but it just didn’t happen, hasn’t happened. It’s an unfortunate failing.—Caregiver

People with diabetes described changing behaviours and attitudes after an SH event to avoid further episodes, emphasizing the importance of checking their blood glucose and learning about symptoms of hypoglycaemia, carbohydrate content, insulin duration and the impact of exercise. As one person with diabetes said, *I try to be proactive instead of reactive to a low*. By becoming *attuned to what [their] body is*

saying through trial and error, people with diabetes often discovered that the threshold of action for preventing SH depended on their individual circumstances.

I'm consistently evolving as I go and learning new things. I have changed my diet... And activities, I steer clear. I'll go on hikes, because it's not as strenuous. But even when I go on hikes, I'm still very conscious.—Person with diabetes

Caregivers also changed their lifestyles to help people with diabetes avoid SH, including staying at home more often and carrying oral carbohydrates. Caregivers described paying attention to how the person with diabetes was feeling, being on *high alert* for hypoglycaemia or changes in demeanour or behaviour indicative of SH—such as sleeping longer than usual or being absent longer than expected—and checking on the person with diabetes regularly, even in the middle of the night.

I'm not going to go to any more conferences and I don't want to be away if she has a low blood sugar overnight.—Caregiver

3.3.4 | Theme 4. Knowing how to treat SH: how the healthcare provider could provide more support/education

Some people with diabetes reported discussing recent SH events with their healthcare provider, *walk[ing] through* what happened. People with diabetes on continuous glucose monitors (CGMs) sometimes reviewed their device's data with healthcare providers. However, although healthcare providers generally talked about hypoglycaemia early during the person with diabetes' insulin therapy, several people with diabetes reported not having continued conversations with their healthcare providers about SH. Some people with diabetes mentioned that they did not think about bringing up hypoglycaemia unless asked.

To me, a hypo is just—it's done and you move on with your life kind of a thing. It's not anything that I would have ever brought up in a medical setting, unless I was—I had to go to the hospital or something. I haven't had to yet.—Person with diabetes

When I get a low blood sugar, and I feel that it's low, and I check my blood sugar, and it is low, I can feel it, and it's not serious, I just handle it myself, and it's not a big deal. I don't

talk to my physician on a regular basis about hypoglycemia.—Person with diabetes

Discussions about SH with healthcare providers generally pertained to prevention: healthcare providers' main message was to check BG levels frequently, eat smaller meals at regular intervals throughout the day and match basal rates or insulin dosages to carbohydrate consumption. One person with diabetes reported starting to use a CGM because his healthcare provider said *they're going to find me dead in bed* otherwise. Some participants reported having discussions with healthcare providers regarding how to be better prepared in case their blood glucose started to drop. Healthcare providers' messages about preparation were clear: don't leave home without something to correct a low and become aware of hypoglycaemia's signs to be prepared to act.

However, healthcare providers' messages about treating SH varied widely, and most people with diabetes did not recall receiving information about treatment options beyond calling 911. Some people with diabetes and caregivers recalled receiving information about glucagon, but it was minimal and while they knew glucagon would bring up blood glucose levels relatively quickly, most could not describe the treatment; several caregivers confused glucagon with an EpiPen or described it as a vial of *water and sugar*. A number of people with diabetes and caregivers mentioned wanting more education regarding hypoglycaemia management, as what they had received was not sufficient to handle an event.

[Glucagon] was such a very small part of the introductory treatment that they give you. It was just basically like, "We're going to give you this prescription, read the instructions if you ever need to do it".—Person with diabetes

I think the medical profession focuses on, here's how many carbohydrates you should eat and blah, blah, blah, but they really don't talk about the hypoglycaemia events. We've learned by doing, and I don't think that's a good thing.—Caregiver

4 | DISCUSSION

An SH event is a crisis situation that can be life-threatening if not treated appropriately or immediately. Even with consistent routines, unpredictability of life events can still lead to an SH event, potentially cascading quickly, therefore advance planning by people with diabetes and caregivers is of utmost importance.^{19,23} In this study,

caregivers were prepared to assist people with diabetes even during non-severe events, typically by providing oral carbohydrates; though some people with diabetes delayed requesting help, potentially underestimating the impact of hypoglycaemia. For many participants, mild symptoms often quickly progressed to SH requiring urgent action from the caregivers. The difficulty of mitigating hypoglycaemia during this short window was compounded by the emotionally challenging nature of these events, which impeded decision making. When things worsened, caregivers called 911 or administered glucagon, but many also reported feeling unsure of what to do or had inadequate knowledge about treatment options. Participants also reported that much of their knowledge about managing SH events derived from experience and discussions with healthcare providers were limited. Many participants, particularly caregivers, reported making lifestyle changes to prevent and treat future SH events, and expressed a desire for more training and resources from their healthcare providers to support them in SH events.

The emotional challenges reported by participants in this study, particularly caregivers, and the need to make life changes so a person with diabetes is not alone during a future SH event are consistent with the findings reported in the literature.^{5,6,19,23–25,27,28} Additionally, the finding that people with diabetes/caregivers often learn to treat SH through experience—figuring it out as they go—and that people with diabetes/caregiver-healthcare provider discussions regarding treatment plans are lacking aligns with the CRASH Study, in which substantial shares of people with diabetes reported not discussing recent SH events with healthcare providers.^{10,16–18} Other studies have also reported on the need for providing more education and support to people with diabetes and their caregivers regarding the management of SH events.¹⁹ These findings suggest that healthcare providers' awareness regarding the challenges experienced by people with diabetes and their caregivers around managing SH events may be limited.

Additional research is needed to understand the perspectives of healthcare providers regarding strategies to help people with diabetes and their caregivers be better prepared to prevent and treat these potentially life-threatening events. However, in keeping with the ADA's recommendation that healthcare providers discuss hypoglycaemia with people with diabetes regularly, this study's findings provide a basis for strategies healthcare providers can undertake to improve people with diabetes/caregivers' preparedness for SH events. Specifically, healthcare providers can not only discuss previous SH events to identify gaps in preparedness, but also discuss risk of future SH events at each visit, even for people with diabetes who have not experienced SH.¹³ Healthcare

providers can also consider leveraging other diabetes care team members (i.e., Diabetes Educators) if pressed for time to conduct a hypoglycaemia risk assessment for evaluation.^{32,33} Relatedly, pointing people with diabetes to existing educational tools can reduce healthcare providers' burden and provide standardized resources that people with diabetes can turn to, rather than having to recall information received during a previous consultation, and even share with caregivers. One resource is the Blood Glucose Awareness Training (BGAT), a psycho-educational programme that helps people with diabetes anticipate, detect, treat and prevent extreme BG levels.³⁴ This tool may be underutilized: in a 2018 survey of people with type 1 diabetes, fewer than 50% reported ever receiving the BGAT.²¹

Additionally, healthcare providers should allow a broad interpretation of which hypoglycaemic events may warrant assistance. SH events can happen anywhere, any time and may be unrecognized.¹³ While current consensus defines severe hypoglycaemia as an event requiring assistance for recovery, experts acknowledge that this definition is subjective.^{13,35} In this study, some people with diabetes described delaying asking for help—a finding also reported in other studies,¹⁰ or experiencing SH while alone. In such scenarios, survival can depend on the person with diabetes' ability to undertake critical actions while impaired. Even if an event is technically survivable without assistance, third-party help may significantly reduce risk. When discussing recent SH events, healthcare providers should note that it may be difficult for people with diabetes/caregivers to identify or articulate the risk borne by the people with diabetes in self-treating SH events. Furthermore, healthcare providers or other diabetes care team members should help people with diabetes/caregivers understand treatment options and create an action plan, addressing questions like, 'At what point should I call 911? Should we consider glucagon, and when?' Conversations should address each option's efficacy and potential risks, for example, risk of choking if a bystander provides oral carbohydrates to a person with diabetes unable to swallow safely.

4.1 | Strengths and limitations

This study's strengths include the number of dyads interviewed and representation of both type 1 diabetes and type 2 diabetes (60% and 40% of people with diabetes respectively). The study's generalizability may be limited due to its relatively homogenous, convenience sample identified from existing market research panels: people with diabetes were mostly non-Hispanic White, female,

experienced insulin users with access to care; caregivers were generally non-Hispanic White, male, non-insulin-using spouse/partners. Additionally, the sample was limited to English-speaking individuals from the United States who were willing to participate in an interview. As such, study findings may not be generalizable to other populations, and additional research is needed to understand cross-country similarities or differences in experiences during SH events as well as the role of healthcare providers in helping people prevent and treat these events. Furthermore, interview-based studies are subject to self-reporting and recall bias. However, for most dyads, the most recent SH event occurred within the past year (82%) or past 2 years (95%) mitigating recall bias. Finally, this analysis was completed without differentiation between type 1 diabetes/type 2 diabetes or other clinical characteristics such as use of CGM or familiarity with glucagon which may affect people's experiences with SH events, instead giving an overview of the results from both groups. Future research should explore these nuances for stratifications based on other collected patient characteristics.

5 | CONCLUSIONS

While caregivers are active in supporting people with diabetes during a hypoglycaemic event, it could quickly progress to an SH event, creating only a brief window for action. Moreover, decision making capacity is limited during SH events, often a panicked time. Finally, much knowledge regarding SH treatment derives from personal experience rather than formal health education. All together, these findings suggest a critical need for healthcare providers to initiate proactive discussions about SH treatment plans and to provide educational/training resources to people with diabetes and their caregivers.

CONFLICT OF INTEREST

HS has served as a consultant for Eli Lilly and Company. BM and ERH are employees of Eli Lilly and Company. UD, SK, PL and NK are employees of Analysis Group, a company that received funding for this research from Eli Lilly and Company. WL was an employee of Analysis Group at the time of the study.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

How to cite this article: 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:e14745. doi:[10.1111/dme.14745](https://doi.org/10.1111/dme.14745)