# Living With Hypoglycemia: An Exploration of Patients' Emotions: Qualitative Findings From the InHypo-DM Study, Canada

Judith Belle Brown,<sup>1,2</sup> Sonja M. Reichert,<sup>1</sup> Yashoda Valliere,<sup>1</sup> Susan Webster-Bogaert,<sup>1</sup> Alexandria Ratzki-Leewing,<sup>1,3</sup> Bridget L. Ryan,<sup>1,3</sup> and Stewart B. Harris<sup>1,3</sup>

## ABSTRACT

Hypoglycemia is one of the most common adverse events for people living with type 1 or type 2 diabetes. To gain a deeper understanding of patients' emotions regarding hypoglycemia, we conducted a descriptive qualitative study. Purposive sampling was used to recruit participants for a 30- to 45-minute semistructured interview. The 16 participants included both women and men with either type 1 or type 2 diabetes, with a mean age of 53 years and mean time since diagnosis of 21 years. All participants had experienced more than one hypoglycemia event in the past year, ranging from nonsevere to severe. Data collection and analysis occurred in an iterative manner. Individual and team analyses of interviews were conducted to identify overarching themes and sub-themes. Thematic analysis revealed the unique interconnection among the emotions experienced by participants, including fear, anxiety, frustration, confidence, and hope. Time, experience, and reflection helped to build participants' confidence in their ability to manage a hypoglycemia event. Patients' emotions regarding hypoglycemia provide valuable insights into life with diabetes. Although hypoglycemia continues to evoke feelings of fear and anxiety, the role of hope may temper these emotions. Understanding the complex interplay of emotions concerning hypoglycemia can guide health care providers in improving clinical practice and promoting patient-centered interventions. Ultimately, health care providers can build patients' hypoglycemia-related confidence by using a strengths-based approach.

<sup>1</sup>Centre for Studies in Family Medicine, Department of Family Medicine, Schulich School of Medicine & Dentistry, Western University, London, Ontario, Canada

<sup>2</sup>School of Social Work, King's University College, Western University, London, Ontario, Canada

<sup>3</sup>Department of Epidemiology and Biostatistics, Schulich School of Medicine & Dentistry, Western University, London, Ontario, Canada

Corresponding author: Judith Belle Brown, jbbrown@uwo.ca

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©2019 by the American Diabetes Association. Readers may use this article as long as the work is properly cited, the use is educational and not for profit, and the work is not altered. See www. diabetesjournals.org/content/license for details. ffective glycemic control can forestall the onset and advancement of diabetes-related microand macrovascular complications (1,2). However, the use of certain antihyperglycemic medications, namely insulin and insulin secretagogues, to treat type 1 or type 2 diabetes can result in hypoglycemia, a clinical syndrome characterized by abnormally low blood glucose (1,2). Optimal diabetes management is thus a delicate balance between treating hyperglycemia and avoiding the immediate risk of hypoglycemia (3).

Hypoglycemia can result in serious physical (4,5) and psychosocial (6–9) morbidity, and mortality (5,10–14).

Neurogenic symptoms include tremor, palpitations, anxiety, sweating, pallor, and hunger, whereas neuroglycopenic symptoms include cognitive impairment, behavioral changes, psychomotor abnormalities, seizures, and coma (15). Hypoglycemia can affect both quality of life and productivity for people with type 1 or type 2 diabetes (16–19). Consequently, the risk and experience of hypoglycemia have been connected to a range of emotional responses, including fear, anxiety, and concerns about safety (7,20,21).

Frequency and severity of hypoglycemia have been found to be associated with psychological distress and a level

of emotional response that is independent of diabetes type (22,23). It has often been assumed that people with type 1 diabetes experience a greater fear of hypoglycemia due to their greater risk of hypoglycemia events (24,25); however, recent literature has challenged this understanding (26-29). For example, Wardian et al. (30) found that people with type 2 diabetes were more likely than those with type 1 diabetes to experience regimen-related distress, and, specifically, people with insulin-treated type 2 diabetes were more likely than those with type 1 diabetes to experience emotional burden. This finding may be related to emerging evidence suggesting that the incidence of hypoglycemia is more equivalent between type 1 and type 2 diabetes than previously thought (31). For example, the recent Canadian InHypo-DM (UnderstandINg the impact of HYPOglycemia on Diabetes Management: A Survey of Perspectives and Practices) study found comparable incidence rates of hypoglycemia among people with type 1 diabetes and those with type 2 diabetes (31).

The most well-documented emotional response is fear of hypoglycemia, which can be so intense that individuals deliberately maintain blood glucose levels above target (12,21,24,32). Fear of hypoglycemia in both type 1 and type 2 diabetes has been quantified in the literature with several scales, including the Hypoglycemia Fear Survey, the Diabetes Distress Scale, and the Fear of Hypoglycemia Scale (33-35). Research also suggests that experiences of hypoglycemia can also be linked to anxiety (7,32,36), although the recognition of anxiety may be complicated by similarities between symptoms of anxiety and symptoms of hypoglycemia (7,26).

In addition, research has identified positive emotions related to the management of hypoglycemia, such as feelings of self-confidence and hope. Only recently has the attribute of hypoglycemic confidence, defined as patients feeling safe and secure in their ability to manage a hypoglycemia event, been measured (37). Polonsky et al. (37) contend that hypoglycemic confidence goes beyond just the absence of worry and fear and "conveys a sense that hypoglycemia can be, at least to some degree, tamed and managed."

The concept of hypoglycemic confidence follows on previous work on the role of self-efficacy in diabetes. Several scales have been developed to assess diabetes-specific self-efficacy, defined as "the individual's confidence in his or her own ability to perform specific tasks required to reach a desired goal" (27). These include the Grossman Self-Efficacy for Diabetes Scale and the Confidence in Diabetes Self-Care (CIDS) Scale. Research suggests that CIDS scores are positively associated with self-esteem and self-care behaviors and negatively associated with fear of hypoglycemia, anxiety, and depression (27).

The body of literature on the emotional responses of people with type 1 or type 2 diabetes to experiencing a hypoglycemia event has grown substantially through the years. This article extends the extant literature by providing a description of patients' emotional responses in relation to their experiences of hypoglycemia and, importantly, how these emotions initiate a "call to action," including gaining more knowledge about how to manage and prevent a future hypoglycemia event.

## **Design and Methods**

In 2014, we launched the InHypo-DM study in Canada. The objectives of this mixed-methods study were: *I*) to explore, using quantitative and qualitative methods, the psychosocial and situational factors that can facilitate or impede hypoglycemia self-management behaviors among people with diabetes, significant others of people with diabetes, and health care providers (HCPs) involved in their care, and *2*) to improve our understanding of the frequency of hypoglycemia (nonsevere, nocturnal, and severe) in people with type 1 or type 2 diabetes at risk for hypoglycemia (31,38). This study focuses on the first stated objective. Specifically, the qualitative component of the InHypo-DM study used a descriptive qualitative approach (39). The present analysis focuses on the experience of hypoglycemia through the lens of people with type 1 or type 2 diabetes.

### Participant Recruitment

A purposive sample was used to recruit participants from Southwestern Ontario through a local diabetes clinic and by posters placed in various locations (e.g., doctors' offices, pharmacies, and shopping malls). We sought to attain a maximum variation sample (in terms of age, type of diabetes, sex, and age of onset). All participants had to have experienced at least one hypoglycemia event in the previous 12 months. Western University's Review Board for Health Sciences Research Involving Human Subjects approved this study.

### **Data Collection**

After obtaining participants' informed consent, a 30- to 45-minute semistructured interview was conducted with each participant. Examples of interview questions included, "How does experiencing a hypoglycemia event make you feel?" and "What makes you feel hopeful about managing hypoglycemia events?" Hypoglycemia was defined to participants as a low blood sugar (glucose) event, also sometimes referred to as "hypo." The interviews, conducted by members of the research team in a location convenient to the participants, were audiotaped and transcribed verbatim. Data collection ceased after reaching saturation (i.e., when no new themes emerged).

#### Data Analysis

Data analysis was both iterative and interpretative, using individual and team analyses. In the initial phase of the analysis, four members of the research team independently reviewed each transcript to identify key concepts emerging from the data. The team then met to compare independent reviews, culminating in the development of the coding template, which evolved over the course of the analysis. NVivo 10 software (QSR International) was used for coding and organizing the data. After completing this phase, the team met to further synthesize and interpret the main themes, using the techniques of immersion and crystallization (40). Immersion involves researchers' complete engagement in the data, which sensitizes them to the tone, range, mood, and context of the data during the analysis (40). Crystallization reflects the ultimate synthesis of the main themes, as expressed by participants. Throughout the analysis, the team identified exemplar quotes reflecting the main themes. In the Results section, the exemplar quotes are identified by type of diabetes (e.g., T1), sex of participant (e.g., F for female), and participant number.

## Credibility and Trustworthiness

Credibility and trustworthiness of the data were enhanced through verbatim transcripts, field notes generated after each interview, and independent and team analyses. Reflexivity was essential during the analyses. Because the research team members came from different professional backgrounds (e.g., social work, family medicine, and epidemiology), team members reflected on the ways in which our own values and experiences shaped the interpretation and reporting of the data.

## **Final Sample**

The final sample consisted of 16 participants, including 10 women (5 with type 1 and 5 with type 2 diabetes) and 6 men (3 with type 1 and 3 with type 2 diabetes). The mean time since diagnosis was 15 years among those with type 1 diabetes and 21 years among those with type 2 diabetes. The mean age was 40 years (range 22–64) among those with type 1 diabetes and 60 years (range 45–77) among those with type 2 diabetes. All had experienced more than one hypoglycemia event in the past year, ranging from nonsevere to severe.

#### Results

The analysis revealed an intricate pattern describing the participants' emotions regarding their experiences of hypoglycemia, including fear, anxiety, frustration, confidence, and hope, and how these emotions initiated a call to action. A predominant emotion expressed by participants was fear.

"Usually going low at night because it scares me, and I think that is why I can't sleep very well, because I am always scared at nighttime that I will drop into a low and I won't feel it, because I have had that happen to me once before where I woke up in the hospital. So, I think that is the main concern I have.... I get scared. I get really scared. (T1F #1)

Fear was also related to a loss of control over one's life.

"It was devastating because... your way of looking at life and what's going on around you has absolutely nothing to do with really what's happening to you. You are not in control at all. And at that point, you start to realize how fragile life is. (T2M #6)

But fear could also serve as a motivation for taking action and thereby taking control over their condition.

"My greatest fear is the hypoglycemia, with being a type 1 diabetic, and getting a better handle on it is important to me because I don't want it to control me....I don't want it to run my life...." (T1F #3)

The emotion of fear, often connected to dying at night due to a hypoglycemia event, could be reduced by gaining knowledge of what actions could prevent becoming hypoglycemic.

"For a long time, my biggest fear was just the fear of the hypoglycemic event, whereas now it's not that I think it's any less, but I know there's things that I can do. Whereas before, I was sometimes scared to go to bed because I had the 'dead in bed' syndrome." (T1F #5)

Fear could also serve as a motivator and a prompt for expedient action in completing tasks to avoid a hypoglycemic event.

"I think it [fear] helps me because I want to get it done quicker so nothing does happen. So, it just kind of pushes me more and motivates me more to go and get what I need or do what I need to do." (T1F #1)

There was a clear link between fear and anxiety. Participants described how, as their blood glucose began to drop at an unpredictable rate, their worry increased, as did their subsequent anxiety about the best action to remedy the situation. For participants who were living alone, this combination of fear and anxiety was intensified.

"It's when it [blood glucose] is under...usually under 5 [mmol/L] I start getting worried and scared that I don't know how fast it's going to drop. I don't know if I will get there [remedy for hypoglycemia] on time, especially when I am by myself at home." (T1F #1)

Once again, the fear of going to sleep emerged and was linked to anxiety.

"Well, last night I was very disturbed, worrying about going to sleep because of what was happening [blood glucose level too low], and you get anxious when this happens." (T2F #5)

Participants also expressed frustration when, despite their knowledge about preventing hypoglycemia and their best efforts to deal with a hypoglycemia event, they could not get their blood glucose under control.

"...challenge basically because I cannot control the way I want to control. As I say, I'm very motivated, stubborn, and if there's something I can't get, it drives me nuts. "(T1M #2)

In the following scenario, attempts to take action appeared to be ineffective and increased the participant's sense of frustration.

"You know textbook what's supposed to happen if you take this, and then it's not coming up, and then you think why? And then again, if your sugars end up shooting the other way and going super high, then you feel like, 'Oh they're going to think I'm an idiot again.' You think those things [and] it's frustrating." (T1F #5)

Some participants, with time and reflection, said they became confident in their ability to manage a hypoglycemic event.

"Im always trying to analyze it and learn from what did I do different this time that didn't work right ... so that I can avoid it next time." (T1F #3)

Experience was also an important learning opportunity and activated action in future situations.

"Sometimes it just gives you a heads up or a wakeup call. What did I do differently? Oh, I'll know for next time.... So, [the experience] maybe just increases awareness about your glycemic control." (T1F #2)

The ability to take action bolstered participants' self-confidence and feeling of self-efficacy.

"It just makes me feel good because I am doing it by myself. If I am by myself or if someone is helping me, it is like, 'OK, we are going to do this.' I feel confident that I can do it." (T1F #1) Even when patients experienced a "set back" in their glycemic control, they remained confident.

"On my part, there's never any guilt or 'Why did this happen to me?' It's a combination that I didn't get quite right. Diabetes, be it lows or whatever, is always a balancing act." (T2F #5)

Participants described how confidence in their knowledge of and skills for managing hypoglycemia made them feel hopeful.

"I think because I know what to do and because I know I have the tools to treat it on hand, that makes me feel [hopeful]." (T1F #4)

A sense of hope in the capacity to control their hypoglycemia events was rooted in both their own ability to manage their hypoglycemia and in outside sources of confidence, such as education.

"Just the fact that everyone can learn stuff and do things differently all the time, so even if there was something that I was doing wrong, if you learn a new behavior, then it changes what you're doing, so that makes me hopeful." (T1F #5)

Keeping abreast of new research advances also gave some participants hope.

"I always like to stay tuned into what's the best out there, and of course if there's something better than what I'm on, you know, to be able to try that, too." (T1F #3)

Additionally, participants expressed hope that could be viewed as externally driven, such as "Unforeseen medical breakthrough!" (T1M #1) and "Im hoping they come out with some kind of new drug" (T2F #5). Participants acknowledged that ongoing research to identify new treatment regimens made them hopeful for the future.

"There's all kinds of interesting developments in looking for solutions . . . so, hopefully, something will happen!" (T2D #6)

Simply stated, hope was fostered by the belief that researchers "...*can find a cure for diabetes!*" (T2M #7).

However, a few participants expressed a lack of hope, and instead appeared more fatalistic in their approach. The following quote describes their experience.

"Nothing makes me feel hopeful about it. . . . I know what's going on, when it happens, what I have to do to get away from it. I just take it as part of life. You're a diabetic; this is what you have. This is the card you were dealt, deal with it." (T2M #7)

For some other participants, hope was tempered with caution.

<sup>a</sup>I wouldn't say that hopeful would be the proper word. I would certainly be pleased if I could be, but hopeful—I'm highly doubtful." (T1M #2)

### Discussion and Clinical Implications

The findings of this study illuminate the unique interconnection among the emotions experienced by people living with diabetes who are at risk of hypoglycemia. Similar to recent work by Wild et al. (7) and Barendse et al. (21), our findings support the contention that the experiences of hypoglycemia of people with type 1 or type 2 diabetes may be more similar than they are different. All of our participants expressed a congruent set of emotions regarding hypoglycemia. Participants described the common emotions of fear, anxiety, and frustration, but what was particularly salient in our findings was the presence of hope and a sense of "hypoglycemic confidence" (37).

Fear often emerged as an emotion experienced by participants and was often a motivator for reflection, learning, and action (41). These findings support previous research, both qualitative and quantitative, that identified fear as a prominent emotional response for people who experience hypoglycemia (7,42–46). Previous research has recommended screening for fear of hypoglycemia during the early months after diagnosis of diabetes (47). However, all of our participants had been diagnosed for a minimum of 5 years before this study, suggesting that fear of hypoglycemia can persist beyond the initial diagnosis phase and requires ongoing assessment by HCPs.

Fear was also strongly linked to anxiety, which was often described in relation to the unpredictable nature of hypoglycemia and the potential inability to effectively prevent or treat an episode. Participants expressed both fear and anxiety around experiencing a nocturnal event. Previous research has found that fear of hypoglycemia is greater at night and may contribute to poor sleep quality (43). Participants who were living alone were more likely to convey intensified feelings of both fear and anxiety, which resonates with prior research (25, 47, 48).

The emotion of frustration was also articulated by some participants. Despite their knowledge about hypoglycemia or best efforts to manage future events, they could not maintain adequate control of their blood glucose.

However, for some, with time and experience, their frustration waned and was replaced by feelings of confidence, self-efficacy, and hope. The prospect of advancements in diabetes research also fostered a sense of hope among many participants, a finding that has received limited exposure in previous literature (49). In particular, many participants communicated a strong sense of being able to take action against future episodes, findings that resonate with the work of Polonsky et al. (37). Although a lack of hope was expressed by some participants who voiced feelings of fatalism or caution, other participants were hopeful about managing their condition, and this hope was often tied

to self-confidence in their knowledge of hypoglycemia and skills around its management.

"Hypoglycemic confidence," as defined by Polonsky et al. (37), represents the positive side of fear of hypoglycemia and can promote selfcare behaviors. As Tan et al. (41) explained, "Personal awareness of . . . what is happening (hypoglycemia), how it happens (observable symptoms), and why it happens (reasons)" can promote self-confidence in the management of hypoglycemia. Related to hypoglycemic confidence is the concept of resilience as a buffer to diabetes distress. Resilience, as defined by Yi et al. (50), is a combination of self-esteem, self-efficacy, self-mastery, and optimism and can also serve as an antidote to fear of hypoglycemia (50).

For many, these varied emotions served as a call to action for obtaining increased knowledge about hypoglycemia and improving overall glycemic control. The emphasis on hypoglycemic confidence and resilience not only requires the attention of HCPs, but also should be addressed in future research.

With regard to limitations, this study was conducted in one geographical region of Ontario that offers relatively comprehensive care to people with diabetes; therefore, its findings may not be transferable to people with less access to services. Another limitation of this study is that the participants were receiving insulin; thus, the findings may not be reflective of the hypoglycemic experiences of patients on noninsulin diabetes medications.

The findings are not meant to be representative of all people experiencing hypoglycemia, but rather to be transferable; that is, to resonate with other patients' experiences. This qualitative study richly captured participants' diverse emotional responses to hypoglycemia and the impact of these responses on glycemic management, revealing a level of detail unattainable by survey methodology. Future research should explore patients' and providers' strategies for building hypoglycemic confidence. Furthermore, research should focus on potential differences or similarities between how people with type 1 diabetes and those with type 2 diabetes develop hypoglycemic confidence.

This study provides important information to aid HCPs in understanding and recognizing how patients' emotions can facilitate or hinder their ability to self-manage hypoglycemia. The current findings shed light on the need to consider patients' emotions when developing effective self-management support strategies. In particular, understanding the complex interplay of emotions concerning hypoglycemia can guide improvements to clinical practice and promote patient-centered interventions (51). One example of this is to focus on promoting hope. Hope can lead to behavioral change through attention to patients' call-to-action response to hypoglycemia.

These findings support the use of motivational interviewing by HCPs to ultimately encourage patient self-efficacy (52). Instead of aiming to eradicate hypoglycemia-related fear, HCPs can build patients' hypoglycemic confidence using a strengths-based approach rather than a deficit-based approach (25,37,53). In other words, although the coexistence of fear of hypoglycemia and hypoglycemic confidence is evident, HCPs can place greater emphasis on helping patients 'gain, or regain, a sense of mastery and confidence over hypoglycemia" (37). This can be achieved by offering programs and specific learning opportunities that support patients in experiencing, recognizing, and identifying hypoglycemia, thereby strengthening their hypoglycemic confidence (29,41).

## Conclusion

Patients' emotions and actions regarding hypoglycemia provide valuable insights into life with diabetes. Although hypoglycemia events continue to evoke feelings of fear and anxiety, the role of hope may temper these emotions. Building on patients' hope may strengthen their ability to achieve hypoglycemic confidence (37). Together, patients and HCPs may share in reducing the burden of living with diabetes and increasing hope to better manage hypoglycemia (54).

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#### **Duality of Interest**

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#### **Author Contributions**

J.B.B., S.M.R., S.W.-B., A.R.-L., B.L.R., and S.B.H. contributed to the conception and design of the study. J.B.B., S.M.R., S.W.-B., and Y.V. contributed to the qualitative analysis. J.B.B., S.M.R., and Y.V. wrote the manuscript. All authors contributed to intellectual discussion, reviewed manuscript drafts, and approved the final version of the manuscript. J.B.B. and S.B.H. are the guarantors of this work, and as such, had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

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