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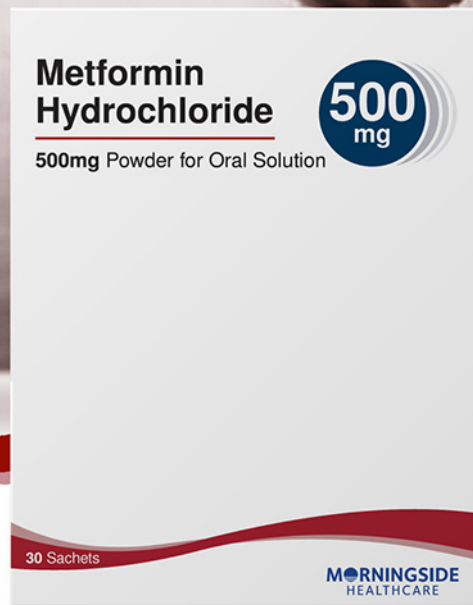
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A convenient alternative to metformin tablets for people with type 2 diabetes and difficulty swallowing tablets[1–3]

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RESEARCH ARTICLE

Unmet support needs relating to hypoglycaemia among adults with type 1 diabetes: Results of a multi-country web-based qualitative study

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Abstract

Objective: Hypoglycaemic episodes and fear of hypoglycaemia can be burdensome for adults with type 1 diabetes. This study explored support needs relating to hypoglycaemia among adults with type 1 diabetes living in Denmark, Germany, the Netherlands and the United Kingdom.

Research design and methods: Respondents participated in a web-based qualitative study involving four open-ended questions that asked what they wished other people understood about hypoglycaemia and what other people could do differently to support them with hypoglycaemia. Responses were analyzed using reflexive thematic analysis.

Results: Participants were 219 adults with type 1 diabetes (mean $\pm$ SD age 39 $\pm$ 13 years; mean $\pm$ SD diabetes duration 20 $\pm$ 14 years). They described unmet needs relating to: (1) *Clinical support*, involving access to new diabetes technologies, training on hypoglycaemia prevention, personalised care and psychological support; (2) *Practical support*, involving family and friends better supporting them with hypoglycaemia management and prevention; (3) *Education for other*

people, involving others becoming more informed about hypoglycaemia; and (4) *An appreciation of the burden*, involving others recognizing the experience and impact of episodes, and the burden of living with the risk of hypoglycaemia.

Conclusions: Adults with type 1 diabetes report several unmet support needs relating to hypoglycaemia. Service delivery should be person-centred and prioritise the individual's support needs. Clinical conversations are needed to identify the individual's support needs and develop tailored support plans. People with diabetes and their family members should be offered hypoglycaemia-specific education and training.

1 | INTRODUCTION

Self management of type 1 diabetes involves complex daily routines to achieve glycaemic targets associated with reduced risk of long-term diabetes complications.[1] However, maintaining glucose levels within the target range can be associated with increased risk of hypoglycaemia.[2] Some adults with type 1 diabetes maintain higher glucose levels to prevent hypoglycaemia,[3] which may lead to higher HbA_{1c} and increased risk of complications.[4] Some adults with type 1 diabetes work tirelessly to manage the risk of hypoglycaemia, to the detriment of their quality of life (QoL).[5] Consequently, hypoglycaemic episodes and fear of hypoglycaemia are associated with decreased emotional well-being and diabetes distress among adults with type 1 diabetes.[6]

Few studies have investigated the support needs of adults with type 1 diabetes in relation to the burden of hypoglycaemia. Qualitative research has revealed unmet needs for informational and emotional support, including wishes for instruction, advice, reassurance, feedback and psychological support.[7,8] However, these findings may only be transferable to people with type 1 diabetes with impaired awareness of hypoglycaemia (IAH) living in the United Kingdom[7] who have attended structured diabetes education.[8] The aim of the current study was to explore unmet support needs relating to hypoglycaemia among adults with type 1 diabetes across four European countries (Denmark, Germany, the Netherlands and the United Kingdom).

2 | RESEARCH DESIGN AND METHODS

2.1 | Design

This study involved a web-based qualitative survey that was conducted as part of a larger study within the

Novelty statement

- This study involved a multi-country web-based qualitative survey to explore support needs relating to hypoglycaemia among adults with type 1 diabetes.
- Participants reported unmet needs for clinical support, practical support, education for other people and an appreciation of the burden. There were no differences in expressed needs by gender, country, experience of severe hypoglycaemia or awareness status.
- The findings imply that service delivery should be person-centred. Clinical conversations are required to identify the individual's needs and develop tailored support plans.
- People with diabetes and their family members should be offered access to education and training.
- Public awareness campaigns could be used to improve awareness of hypoglycaemia and reduce stigma.

Hypo-RESOLVE Project, which aimed to investigate the impact of hypoglycaemia on QoL.[9,10] Target countries were selected on the basis of access to personnel in the Hypo-RESOLVE Consortium who could translate study materials into additional languages and assist with recruitment in local diabetes clinics to improve the sampling strategy. Ethics approval was granted by the University of Southern Denmark Research Ethics Committee (REC) (#19/78420), German Society for Psychology REC (#HermannsNorbert2020-05-12VA), Radboud University Medical Centre REC (#2020-6587), and UK Health and Social Care REC (#20-NI-0054).

2.2 | Participants

Across the target countries, this study was advertised in diabetes clinics, via e-newsletters to members of diabetes associations, and on social media. Respondents were eligible to participate if they were aged ≥18 years, had a diagnosis of type 1 diabetes and were living in one of the target countries. Sample size targets were $N = 50$ from each country, based on past studies of QoL in people with diabetes achieving conceptual saturation with similar sample sizes.[11] Purposive sampling was used with the aim of recruiting approximately 50% of the sample with ≥1 severe hypoglycaemic episode in the past year and/or IAH, to ensure that data were being collected from individuals with recent experiences of problematic hypoglycaemia.

2.3 | Materials

After completing a 'Wheel of Life' activity involving participants' reflections on the impact of hypoglycaemia on QoL,[9] participants were asked four open-ended questions about their support needs relating to hypoglycaemia (see Box 1). The questions were designed to elicit unmet needs for support from other people (including healthcare professionals, family, friends and work colleagues) to prevent, manage and live with the risk of, hypoglycaemia. The wording of questions was informed by a national survey of people with diabetes in which a single open-ended question was used to explore participants' wishes for support from healthcare professionals.[11] Participants were encouraged to provide as much detail as possible in their free-text responses. Five adults with type 1 diabetes piloted the survey and provided feedback on the readability, relevance and importance of questions. The survey

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> **BOX 1 Open-ended questions designed to elicit unmet needs relating to hypoglycaemia**
>
> - What do you wish other people understood about hypoglycaemia?
> - What would you like your healthcare professional(s) to do differently to support you in avoiding or managing hypoglycaemia?
> - What would you like other people to do to support you in preventing and managing hypoglycaemia?
> - What would you tell a close friend about what it's like living with the risk of hypoglycaemia?

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was then translated from English into Danish, Dutch and German in accordance with best practice guidelines.[12]

Participants' demographic and clinical characteristics were assessed using validated measures and study-specific items. Three items of the Hypoglycaemia Awareness Questionnaire (HypoA-Q)[13] measured self-reported frequency and severity of hypoglycaemia in the preceding 12 months. Hypoglycaemia awareness was assessed using the five-item Impaired Awareness subscale of the HypoA-Q[13] and the single-item Gold.[14] Fear of hypoglycaemia was assessed using the six-item Worry subscale of the Hypoglycemia Fear Survey Short Form (HFS-SF).[15] Because this study was conducted during the COVID-19 pandemic, a nine-item adaptation of the Diabetes Attitudes, Wishes and Needs 2 (DAWN2) Impact of Diabetes Profile (DIDP)[16] was used to examine the perceived impact of the pandemic on diabetes management and other aspects of QoL likely to influence participants' current assessment of their support needs.[17] Adaptation of the DIDP involved changing the lead-in sentence from 'How does *diabetes* impact the following aspects of your life?' to 'How is *the COVID-19 pandemic* impacting the following aspects of your life?', and adding 'Diabetes' and 'Feelings about the future' as items.

2.4 | Data collection

The survey was hosted via REDCap,[18] an online survey platform. Respondents could participate anonymously using their computer, tablet or smartphone. First, they answered screening questions to determine their eligibility. Eligible participants were then presented with a Participant Information Sheet and invited to provide consent by selecting checkboxes. Survey responses were monitored daily to check for completeness and determine whether sample size targets had been met.

2.5 | Data analysis

Survey records were imported into SPSS Version 22 and NVivo Version 12. Non-English records were translated using Google Translate and reviewed for semantic equivalence by native speakers of the original language to preserve meaning between versions. Translated responses were analyzed using reflexive thematic analysis.[19] Two researchers (HC and MB) developed the coding framework. HC coded all responses ($n = 863$) and MB coded a randomly selected 20% proportion of responses ($n = 166$) for comparison. Agreement between coders was high (93%), with discrepancies resolved through mutual consensus.

Researchers familiarized themselves with the data, then summarized responses line-by-line to generate initial codes. Line-by-line coding involved summarizing distinct ideas within a response using as many codes as was needed. This meant that a single response could be summarized using a single code or multiple codes. Non-meaningful responses that were unable to be interpreted, usually single word or short responses (e.g., 'take care' or 'everything'), were screened out. Semantically related codes were clustered to form themes. Within-theme extracts were then reviewed for goodness-of-fit, coherence and discrimination from other themes. Descriptive statistics were derived for demographic and clinical variables. Chi-square tests were used to examine between-group differences in support needs (by gender, country and experience of severe hypoglycaemia).

3 | RESULTS

Eighteen of the 237 survey respondents did not attempt the open-ended questions and were excluded from analyses. Those who did not attempt the open-ended questions had higher mean fear of hypoglycaemia and were more likely to be men and engaged in unpaid work, compared to those who responded to the open-ended questions (see Table S1). The final sample included 219 adults with type 1 diabetes, most of whom were recruited via social media (92%; $n = 201$). Table 1 details participants' demographic and clinical characteristics. They had a mean ± SD age and diabetes duration of 39 ± 13 years and 20 ± 14 years, respectively. Eighty-three percent ($n = 182$) were women. Sixty-nine percent ($n = 151$) lived with a spouse or partner. Forty-two percent ($n = 92$) were employed full time. All participants were living in one of the four target countries, which are relatively high-income countries with universal healthcare coverage. Approximately half of the sample had attended a structured diabetes education programme (49%; $n = 108$). Table S2 presents between-country differences in demographic and clinical characteristics.

Seventy-seven percent ($n = 170$) of the sample used continuous glucose monitoring (CGM) or flash glucose monitoring. Fifty-three percent ($n = 116$) used an insulin pump to administer insulin. Forty-seven percent ($n = 102$) used multiple daily injections. Participants reported a median (IQR) of 4 (2-6) hypoglycaemic episodes of any severity in the past week. Thirty-two percent ($n = 70$) of the sample reported ≥1 severe episode in the past year (where they needed help from others/were unable to self-treat). The frequency of severe hypoglycaemia in the past year ranged from 1 to 240 episodes per person, with a total of 624 episodes between 70 participants. Fifty-one percent ($n = 123$) reported another physical/mental

TABLE 1 Participants' demographic, clinical and psychological characteristics

Age (years)	39.4 ± 13.3 (18–79)
Gender	
Women	83.1% (182)
Men	16.4% (36)
Other	0.5% (1)
Country of residence	
Denmark	18.7% (41)
Germany	23.3% (51)
The Netherlands	30.1% (66)
United Kingdom	27.9% (61)
Nationality[a]	
Danish	18.3% (40)
Dutch	29.7% (65)
English	17.4% (38)
German	21.9% (48)
Indian	0.9% (2)
Irish	2.3% (5)
Moroccan	0.5% (1)
Romanian	0.5% (1)
Scottish	5.9% (13)
Welsh	0.9% (2)
Other	1.4% (3)
Highest level of education	
Secondary school or lower	13.7% (30)
Post-secondary vocational education	25.6% (56)
Undergraduate (bachelor's level) education	30.6% (67)
Postgraduate (master's or PhD level) education	25.6% (56)
Other	4.6% (10)
Employment[b]	
Full-time	42.0% (92)
Part-time	23.3% (51)
Self-employed	4.1% (9)
Unemployed	5.9% (13)
Unpaid worker	2.7% (6)
Student	16.4% (36)
Retired	5.5% (12)
Other	5.9% (13)
Current living situation[b]	
Alone	16.0% (35)
With spouse/partner	68.9% (151)
With child(ren)	27.9% (61)
With parent(s)	11.0% (24)
Other	2.7% (6)

(Continues)

TABLE 1 (Continued)

Diabetes duration (years)	20.4 ± 14.1 (1–64)
Frequency of hypoglycaemia (HypoA-Q)	
Number of episodes (of any severity) in the past week	3.5 (2.0–6.0)
≥1 Episode in the past year where they needed help from others	32.0% (70)
Hypoglycaemia awareness status	
Impaired (Gold score ≥4)	39.7% (87)
HypoA-Q Impaired Awareness subscale[c,d]	10.7 ± 2.5 (0–19)
Problematic hypoglycaemia (≥1 severe episode in the past year and/or impaired awareness indicated by Gold score ≥4)	55.7% (122)
Comorbidities[b]	
Diabetes complications (neuropathy, retinopathy, heart disease, vascular problems or kidney disease)	3.8% (9)
Other (autoimmune, psychiatric or other physical health problems)	47.5% (114)
None	47.5% (114)
Fear of hypoglycaemia (HFS-SF Worry subscale)[d,e]	10.5 ± 5.3 (0–24)
Impact of COVID-19 pandemic on QoL (adapted DIDP)[f]	
Composite score	3.3 ± 0.8 (1–7)
Diabetes	3.6 ± 1.3 (1–7)
Sleep	3.6 ± 1.2 (1–7)
Physical health	3.7 ± 1.2 (1–7)
Emotional well-being	3.0 ± 1.2 (1–7)
Financial situation	3.7 ± 1.1 (1–7)
Relationship with family, friends and peers	3.3 ± 1.2 (1–7)
Leisure activities	2.8 ± 1.4 (1–7)
Work or studies	3.1 ± 1.4 (1–7)
Feelings about the future	3.0 ± 1.1 (1–7)
Source of recruitment	
Online	91.7% (201)
Clinic	0.5% (1)
Elsewhere	7.8% (17)
Ever attended structured diabetes education[a]	

(Continues)

TABLE 1 (Continued)

No	48.9% (107)
Yes	49.3% (108)
Within the past year	9.5% (10)
1–5 years ago	17.4% (38)
6+ years ago	21.9% (48)
Around time of diagnosis	9.5% (10)

Note: Data are reported as percentage (*n*), mean ± SD (range) or median (IQR).

[a]Percentages do not sum to 100% due to missing data.

[b]Participants were able to select more than one response option; thus, summed percentages/*n*s may exceed 100%.

[c]Higher scores indicate greater impairment of hypoglycaemia awareness (out of a possible 20).

[d]There are no published cut-off scores to identify individuals with clinically significant problems.

[e]Higher scores indicate greater fear of hypoglycaemia (out of a possible 24).

[f]Lower scores indicate more negative impact (1 = *Very negative impact* to 7 = *Very positive impact*).

health diagnosis, including 4% (*n* = 9) with diabetes complications such as neuropathy, retinopathy, heart disease, vascular problems, or kidney disease. Thirty-nine percent (*n* = 87) self-reported IAH (Gold score ≥4).[14] Mean scores on the HypoA-Q Impaired Awareness and HFS-SF Worry subscales were in the middle of the range. Mean scores on the adapted DIDP revealed that participants' overall QoL had been *slightly negatively impacted* by the COVID-19 pandemic.

Of the 863 responses across the open-ended questions, 96% (*n* = 830) were able to be interpreted. The median length of responses was 15 words, ranging from 1 to 293 words. Reflexive thematic analysis of meaningful responses resulted in four themes being identified: Clinical support, practical support, education for other people and an appreciation of the burden. Table 2 presents codes within each theme, as well as participant quotations and the number of coded extracts within each code. Chi-square tests indicated significant between-country differences in practical support needs (*p* = 0.038); however, post hoc tests revealed no significant contrasts between countries. There were no further differences in the number of coded extracts by gender, country or experience of severe hypoglycaemia (see Tables S3–S5).

3.1 | Clinical support

3.1.1 | Access to new diabetes technologies

Participants believed that new technologies could help them to better predict low glucose and understand their glycaemic patterns so that they could retain

TABLE 2 Hypoglycaemia-related support needs: Themes, codes, quotations and number of extracts coded

Themes/codes	Quotation	Number of extracts[a] (N = 1088)
Clinical support		181
Access to new diabetes technologies	*Give me a CGM so that I KNOW what my levels are… gives reassurance and prevents 'just in case' over-treatment.* (47-year-old woman from the UK)	61
Training on hypoglycaemia prevention	*It would have made sense to have training earlier on so that you don't have to learn everything painfully.* (31-year-old man from Germany)	50
Personalised care	*Really look closely at the causes of hypoglycaemia and work with me to eliminate them.* (26-year-old woman from the Netherlands)	53
Psychological support	*For me, it is more the psychological aspect of living with the risk that creates problems. That part, I do not really expect doctors and nurses to be able to take complete care of, but it is important when discussing the behavioural steps a diabetic can take to be well regulated.* (34-year-old male from Denmark)	5
Positive experiences with HCPs	*My practitioner has trained me well and is at my side with advice/ action.* (35-year-old man from Denmark)	12
Practical support		193
Remain calm during episodes	*Don't make a fuss. Don't attract attention. Just offer something like orange juice and quietly support me. Don't expect interaction as I recover.* (40-year-old woman from the UK)	161
Help with hypoglycaemia prevention	*Take hypo into account when undertaking spontaneous activities. Ask if this works before an activity.* (23-year-old woman from the Netherlands)	32
Education for other people		179
General knowledge about hypoglycaemia	*Know the difference between a hypo and a hyper, the symptoms, and what the person should ultimately do in that situation.* (21-year-old woman from the UK)	135
Understanding of the seriousness	*You don't just have a craving for sweets; it is a painful struggle for survival.* (25-year-old male from Germany)	30
Symptoms can vary	*That not every hypo feels the same. I have the impression that some people sometimes think that you are acting, because sometimes you can still function well during a hypo.* (30-year-old female from the Netherlands)	14
Appreciation of the burden		535
Experience of episodes and their impact	*I am not immediately available again just because my sugars have come back up; no demands should be placed on me.* (25-year-old female from Denmark)	241
Living with the risk of hypoglycaemia	*It feels as if, at almost every moment, you are at risk of needing help to survive, simply on the basis of a minor calculation error. It takes so much focus and the heart of a gambler to push the boundaries of the usual routine.* (34-year-old male from Denmark)	294

[a]Extracts may be coded to more than one theme.

hypoglycaemia awareness, optimize their glucose levels, and *have a normal life*. Some mentioned that they required assistance to seek reimbursement for the financial costs of new devices. Others wished for costs to be covered by the public healthcare system. Participants stated that

new technologies should be offered even if a person's diabetes is not *poorly controlled*, as it *seems like a punishment that I'm not entitled to a Libre as I am too well regulated, whereas a Libre might help me avoid the hypoglycaemia I do have*. Some wished for closed loop systems to be approved

and for problems with their current devices to be resolved (e.g. false alarms on their CGM).

3.1.2 | Training on hypoglycaemia prevention

Participants lacked information about the causes, symptoms and consequences of hypoglycaemia. They wanted more training on how to recognize, prevent and manage hypoglycaemia. Some stated that healthcare professionals could have provided this information and training earlier on, so that they could have been better informed and more prepared. Participants wished for healthcare professionals to address their concerns with diet, exercise and weight loss in the context of hypoglycaemia management.

3.1.3 | Personalised care

Participants wanted healthcare professionals to examine the causes of their recent hypoglycaemic episodes and provide personalised advice on how to prevent future episodes. They explained that healthcare professionals should avoid giving generic advice and instead *give you the feeling that they are really thinking about it*. They wished for healthcare professionals to *take the time to look at recorded values*, analyse glycaemic patterns and make necessary adjustments to their insulin regimen. Some indicated that they wished for healthcare professionals to show more compassion, avoid judgment and be mindful of their language: *Don't call it a snack, it makes me feel like a child. Call it a hypo treatment*. More generally, they wanted healthcare professionals to *talk more about hypoglycaemia* during clinical consultations, such that *it becomes a less shameful topic*.

3.1.4 | Psychological support

Participants reported a need for psychological support to manage their fear and anxiety relating to living with the risk of hypoglycaemia. They suggested that their diabetes practitioner could offer emotional support or refer them to *an experienced psychologist who specializes in hypo anxiety*.

3.1.5 | Positive experiences with HCPs

Some participants stated that they were well supported by their healthcare professionals, who had prescribed CGM and referred them to a dietitian or hypoglycaemia awareness course, as needed. They explained that they had *good*

dialogue with their healthcare professionals and could *think about things together*. Others mentioned that *the responsibility* [of hypoglycaemia prevention and management] *does not lie with the practitioner* and that *it is the task of the patient*.

3.2 | Practical support

3.2.1 | Remain calm during episodes

Participants emphasized the need for others to remain calm during episodes, despite the seriousness of the situation. They explained that *the panic of my friends or colleagues makes it worse* and wished for others to understand that hypoglycaemia can be resolved quickly with appropriate treatment. Participants wanted others to ask how they can help without *making a fuss* or criticizing them. They did not appreciate others *telling me what I did wrong* and wanted *no discussions, no patronizing, no know-it-all, positive feedback only*. Participants stated that others should offer an appropriate hypoglycaemia treatment as soon as possible, then give them *time and space to recover* from hypoglycaemia and *respect that we know what we are doing*. Some expressed a need for others to *take over* and ensure their safety when they are no longer able to care for themselves. Others described a preference to be left alone.

3.2.2 | Help with hypoglycaemia prevention

Participants wanted family and friends to carry emergency hypoglycaemia treatments, help them with healthy eating and carbohydrate counting, and keep hypoglycaemia in mind when planning activities with them. They suggested that others could help by *monitoring for the first signs* of hypoglycaemia and *being ready to point them out*. Some wished their employers would offer them more flexibility in terms of modifying their work hours or taking meal breaks as needed to manage hypoglycaemia.

3.3 | Education for other people

3.3.1 | General knowledge about hypoglycaemia

Participants wanted their family, friends, colleagues and the public to become more informed about the symptoms and treatment of hypoglycaemia, including *what to do to help if needed*. They wanted common misunderstandings to be corrected: *It should be treated with glucose, NOT insulin; hyperglycaemia and hypoglycaemia*

are often swapped around. Some wished for educational resources and training courses for their family and friends. Others proposed leaflets for their work colleagues and awareness campaigns for the public. They explained that, if others had a better understanding of the symptoms (i.e. cognitive and behavioural changes), they could avoid situations in which their hypoglycaemia is mistaken for intoxication.

3.3.2 | Understanding of the seriousness

Participants mentioned that family, friends, and the public *often underestimate what [hypoglycaemia] is.* They wished for others to understand that hypoglycaemia can be dangerous and lead to seizure, coma and long-term cognitive impairment. They explained that episodes can be life-threatening, so they must act immediately: *It can be lethal. If you're not sure whether it's a hypo, treat it as if it is.*

3.3.3 | Symptoms can vary

Participants wanted their family and friends to be aware that episodes can vary greatly in terms of their symptoms and severity, such that they may not *look the same each time.* They explained that they may appear as if they are functioning well, but they are in fact *much worse off.* In addition, hypoglycaemic episodes differ in terms of impact and recovery time, with some episodes able to be *treated on the run* and others necessitating longer periods of rest.

3.4 | Appreciation of the burden

3.4.1 | Experience of episodes and their impact

Participants wished that others could understand *how [hypoglycaemia] feels in the mind and body*, namely the acute discomfort and unpleasantness. They wanted family and friends to recognize that they find it difficult to manage their mood during episodes: *I'm not myself in that moment; some things I say are snappy or argumentative, but they are not meant that way.* Participants wanted others to understand the emotional impact of hypoglycaemia, including their feelings of *self-blame*, *frustration*, *anger*, *disappointment*, *[feeling] stupid and misunderstood*, *helplessness*, *powerlessness*, *loneliness*, *sadness* and *discontentment.* They wished for others to appreciate that episodes are physically and mentally exhausting, and that it can take a long time to fully recover.

3.4.2 | Living with the risk of hypoglycaemia

Participants wanted others to recognize that they greatly fear hypoglycaemia: *It hangs over your head all the time.* They wished for others to appreciate that they feel drained from *always thinking about/working on [hypoglycaemia prevention]* and *never having time off.* They wanted their family and healthcare professionals to be more understanding of the fact that some episodes are unavoidable despite their best efforts: *They have nothing to do with a bad attitude or lack of care for your condition.* They stated that episodes are never deliberate or intentional, so they should not be blamed for recurrences: *It can happen at any time and it's not my fault.* Participants wanted others to recognize that their lives were severely limited by hypoglycaemia and they were often unable to be as spontaneous as they would like. Some explained that the risk of hypoglycaemia could be managed *with the right preparation and attention*, but that other people should understand that this is *annoying* and *a nuisance.*

4 | DISCUSSION

This multi-country, web-based, qualitative study highlights several unmet support needs relating to hypoglycaemia among adults with type 1 diabetes. While participants mentioned satisfaction with some aspects of the support they received, the majority expressed unmet needs for clinical support, practical support, education for other people and an appreciation of the burden of hypoglycaemia. The finding that participants wanted more structured clinical support and more understanding from other people is consistent with previous studies of support needs relating to diabetes self management more broadly.[11,20] In addition, this study revealed several novel findings in terms of unmet needs relating specifically to hypoglycaemia.

Participants wanted healthcare professionals to address their personal challenges with hypoglycaemia and provide personalised, rather than generic, advice. This finding may indicate that adults with type 1 diabetes do not always perceive themselves to be at the centre of their diabetes care. Participants further reported divergent wishes for others' involvement in hypoglycaemia management, whereby some wanted family and friends to be actively involved during episodes, and others wished to be left alone. This finding indicates that an individual's preferences cannot be assumed and that conversations are required to ascertain the individual's wishes.

The most frequently cited theme was the need for other people to appreciate the burden of hypoglycaemia. Participants described feeling misunderstood, judged, or blamed for recurrences of hypoglycaemia. Given

the physical, psychological and social consequences of diabetes-related stigma,[21] this finding indicates that stigma-reducing interventions and mitigating strategies are needed. Public awareness campaigns could help to improve awareness of hypoglycaemia and minimize societal stigmatization. Adults with type 1 diabetes could be offered peer support and/or counselling to mitigate the personal impact of stigma.

4.1 | Strengths and limitations

Data were collected from a large, heterogeneous, multi-country (albeit mostly European) sample. The web-based survey format enabled recruitment of groups that are hardly reached and offered participants the opportunity to consider their responses carefully. The fact that participants were assured anonymity likely promoted more candid responses, though the 'Wheel of Life' activity that preceded open-ended questions may have additionally increased the depth of participants' responses to open-ended questions about support needs. Participants reported that the COVID-19 pandemic had had a slightly negative impact on their overall QoL, which could have influenced their expressed needs and the degree to which those needs were currently being met.

This study may have been biased towards recruitment of socially advantaged participants, including those with internet access and greater engagement with social media. Web-based data collection further meant that researchers were unable to seek clarification from participants where their meaning was unclear, though the findings are largely consistent with past research.[7,8] While the sampling strategy was aimed at recruiting participants with severe hypoglycaemia and/or IAH, this study was likely subject to self-selection bias. There was a higher rate of IAH in this sample compared to previous studies with unselected cohorts.[22] Nonetheless, the majority self-reported intact awareness and there were no significant differences observed between the free-text responses of people with intact and impaired awareness.

The finding that there were no between-country differences suggests that support needs may be similar for adults with type 1 diabetes in the four countries targeted. Since the participants were from high-income countries with universal healthcare coverage, the findings may be less transferable to adults with type 1 diabetes living in lower-income countries with less access to resources, including structured diabetes education. Further research is needed to examine the support needs of adults with type 1 diabetes from different cultural backgrounds, as their experiences of hypoglycaemia may differ.[23] Finally, it should be noted that there was an over-representation

of women in this sample, though there were no significant differences observed between the free-text responses of men and women. Future studies should further explore hypoglycaemia-related support needs among men with type 1 diabetes, especially given emerging sex differences in the incidence of severe hypoglycaemia.[24]

4.2 | Implications

The findings imply that service delivery should be person-centred and prioritise the individual's support needs. Past research shows that a person-centred approach to diabetes care is associated with significant improvements in clinical outcomes.[25] Most participants in this study reported no episodes of severe hypoglycaemia in the past year and intact hypoglycaemia awareness, which suggests that the presence of severe hypoglycaemia and IAH are not the only indicators of need. Some individuals may wish to prioritize their needs relating to diabetes management more broadly, whereas others may wish to address their needs relating to the unique challenges of hypoglycaemia.

Participants in this study indicated that hypoglycaemia was a shameful topic to talk about in clinical consultations as it was not regularly discussed. Clinicians should ask individuals about their experiences of hypoglycaemia and associated needs for support, which could help to normalize discussion of hypoglycaemia. In doing so, clinicians should use respectful and non-judgemental language, and ask open-ended questions in a sensitive way.[26] Clinicians should be aware that individuals may be reluctant to talk openly about hypoglycaemia due to previous experiences of judgement.[11] Clinical tools, such as the Type 1 Diabetes Consultation (T1C) Tool,[27] could be used to guide discussion of support needs. Gaining a better understanding of an individual's support needs is key to developing tailored support plans that will suit the person's circumstances.

The finding that adults with type 1 diabetes and their family members lacked hypoglycaemia-specific information and training indicates that access to education needs to be improved. This likely requires intervention at many levels. First, adults with type 1 diabetes should be offered access to structured education programmes. Programmes should address how to prevent, recognize and manage hypoglycaemia, with some focus on diet, weight management and physical activity, as suggested by participants. While some may benefit from this education as early as possible such that they feel more informed, others may find this overwhelming. Some may benefit from peer support groups with other people with diabetes, where they can learn practical tips that are more easily implemented in their everyday life.[28] Second, family members could be included in discussions about diabetes care and offered

hypoglycaemia-related information. Third, diabetes associations could develop information leaflets that people with diabetes could share with their family, friends and colleagues.

Finally, diabetes associations could implement awareness campaigns aimed at educating the public about hypoglycaemia and reducing stigma, such as broader implementation of the Australian and USA-based 'Lowdown' campaigns. Although some of the unmet needs described by participants in this study could be addressed with person-centred care, others would require systemic or policy-level changes (e.g. healthcare systems funding new diabetes technologies).

4.3 | Conclusions

Adults with type 1 diabetes report several unmet needs for support in preventing, managing, and living with the risk of hypoglycaemia. The variation in expressed needs indicates that conversations are required to identify the individual's needs and address the burden of hypoglycaemia. Service delivery needs to be person-centred to ensure that the individual's support needs are met. People with diabetes and their family members should be offered access to education and training. Public awareness campaigns could be used to improve awareness of hypoglycaemia and reduce stigma.

CONFLICT OF INTEREST
The authors declare no conflicts of interest.

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SUPPORTING INFORMATION

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

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