

ARTICLE

Hyperglycaemia aversion in type 1 diabetes: A grounded theory study

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Abstract

Objective: Very little is known about the circumstances under which hyperglycaemia aversion develops and is maintained. The present study aimed to identify psychological factors involved in the process of hyperglycaemia aversion and to understand how it affects people's self-management of type 1 diabetes.

Design: Qualitative, in-depth interviews were used.

Methods: A constructivist grounded theory study, using semi-structured participant interviews, was undertaken to build a theoretical model of the process of hyperglycaemia aversion.

Results: Eighteen participants were interviewed. Fifteen were considered hyperglycaemia averse and included in the analysis. A theoretical model was developed to describe and explain processes involved in hyperglycaemia aversion. Many participants held very high standards for themselves and often had a strong preference for control. While some participants described anxiety associated with higher blood glucose, the most proximal driver of their approach was self-criticism and frustration associated with not meeting their own high standards for blood glucose. A number of attentional processes and beliefs, mostly related to hypoglycaemia, maintained and reinforced their blood glucose preference. Diabetes technology served as an enabler, raiser of standards, and additional critical judge of participants' hyperglycaemia aversion.

Conclusions: The trans-diagnostic concept of emotional over-control is used to understand the proposed model of processes of hyperglycaemia aversion. The present study offers new insight which will aid clinicians in identifying and

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supporting those who may be at risk of psychological distress and harm associated with a preference for avoidance of higher blood glucose levels.

KEYWORDS

diabetes psychology, hyperglycaemia, hypoglycaemia, perfectionism, type 1 diabetes

INTRODUCTION

Type 1 diabetes is an autoimmune condition affecting approximately 400,000 people in the United Kingdom (JDRF UK, 2022). Insulin-producing beta cells in the pancreas are destroyed, and individuals must monitor their blood glucose levels and manage these levels using exogenous insulin. Exposure to extremes of blood glucose concentration, both high (hyperglycaemia) and low (hypoglycaemia), is inevitable for people with type 1 diabetes, even users of state-of-the-art glucose monitoring and insulin delivery technologies such as hybrid closed-loop therapy (Boughton et al., 2022; Schoelwer et al., 2021). Frequent and prolonged exposure to hypoglycaemia is associated with impaired awareness of hypoglycaemia, which is, in turn, a major risk factor for severe hypoglycaemia requiring the assistance of third party for active treatment. Severe hypoglycaemia is a cause of significant morbidity and even mortality for people living with type 1 diabetes (The International Hypoglycaemia Study Group, 2019).

A proportion of people with type 1 diabetes maintain higher blood glucose due to concerns about hypoglycaemia. The Hypoglycaemia Fear Survey was developed in 1987 to assess these concerns (Cox et al., 1987). Conversely, some people have concerns about hyperglycaemia and prefer to self-manage their glucose to a lower target. Suggested reasons for this include fear of long-term complications and to avoid unpleasant physical symptoms associated with hyperglycaemia (Singh et al., 2014).

Hyperglycaemia aversion, which does not yet have a clear definition, is an overlooked problem in type 1 diabetes, although 16.4% of one study population were hyperglycaemia averse (Polonsky et al., 2021), defined as having a consistent preference for hypoglycaemia over hyperglycaemia. While this group did spend higher mean percentage times in the glucose target range, they also spent higher mean percentage times below range and reported higher rates of impaired awareness of hypoglycaemia (IAH) and recurrent severe hypoglycaemia (SH) than a non-hyperglycaemia-averse group. There were no differences on measures of well-being, general life stress, and diabetes distress.

Cognitions about hyperglycaemia are important in understanding the experiences and motivations of people with IAH. Some people with IAH overestimate the impact of hyperglycaemia and describe extreme behavioural responses to avoid it (Rogers et al., 2012), prioritizing hyperglycaemia concerns more than those with intact awareness (Cook et al., 2019). Psychological barriers to early SH prevention in people with IAH have been identified, including a focus on hyperglycaemia avoidance (Speight et al., 2014). Concerns about avoidance of hyperglycaemia have been associated with SH in people using diabetes technologies including continuous glucose monitoring (CGM) and closed-loop therapy (Lin et al., 2022).

While hyperglycaemia aversion is a reasonable preference for avoiding long-term complications (Polonsky et al., 2021), there is evidence that it may contribute to problematic hypoglycaemia (IAH and/or recurrent SH; Choudhary et al., 2015). Very little is known about the circumstances under which hyperglycaemia aversion develops and is maintained. In order to ensure that these individuals can be identified and supported appropriately, it is important to develop an understanding of hyperglycaemia aversion.

The present study aimed to identify psychological factors involved in the process of hyperglycaemia aversion and to understand how it affects type 1 diabetes self-management. Given the limited research in this area, a constructivist grounded theory approach was taken (Charmaz, 2014). Constructivist

Statement of contribution

What is already known on this subject?

- Hyperglycaemia aversion in people with type 1 diabetes is poorly defined and often overlooked; however, it can be associated with difficulties such as severe hypoglycaemia and impaired awareness of hypoglycaemia.
- One recent study found that participants with a consistent preference for hypoglycaemia over hyperglycaemia spent higher mean percentage times in the glucose target range and below range, and reported higher rates of impaired awareness of hypoglycaemia and recurrent severe hypoglycaemia than a non-hyperglycaemia-averse group, but there were no differences on measures of well-being, general life stress, and diabetes distress.

What does this study add?

- This study presents the first theoretical model of hyperglycaemia aversion in type 1 diabetes.
- This model will support identification and support of people who may be at risk of, or are experiencing, hyperglycaemia aversion.

grounded theory is a qualitative methodology that considers how individuals make sense of their experiences, through systematic analysis and comparison of participant interview data, in order to generate a theory of the phenomena being studied.

RESEARCH DESIGN AND METHODS

Research design

In-depth qualitative interviews were undertaken and analysed using a constructivist grounded theory (Charmaz, 2014) approach.

Recruitment

The study was approved by the Cornwall and Plymouth Research Ethics Committee (Integrated Research Application System no. 20/SW/0174).

An email was sent to 465 people with type 1 diabetes who had consented to be contacted for research. These individuals had either taken part in previous research studies at Imperial College London, had consented for research contact at their diabetes clinic appointment at Imperial College Healthcare NHS Trust, or had contacted the research team about participation in the present study through learning of it on a public registry of research studies. Participants completed online questionnaires and provided demographic and diabetes information. Eligibility criteria were as follows: aged ≥ 18 years; type 1 diabetes ≥ 1 -year duration; not pregnant; adequate English to complete the survey. There were no specified exclusions.

Two hundred and fifty-three complete responses were received (252 online, one paper, 54.4% response rate). The present study is concerned with the qualitative interviews and not the questionnaire study.

Semi-structured interviews were initially undertaken with participants identified by their clinician as hyperglycaemia averse. Later in the study, an answer of ≤ 10 mmol/L to the Hyperglycaemia Avoidance Scale (HAS-UK; Barendse et al., 2011) item “On a typical day, what is the highest blood glucose level that you would feel comfortable with?” was used to identify participants, initially with Gold score ≥ 4

(indicating IAH; Gold et al., 1994) and history of SH in the past 12 months, suggestive of problematic sequelae from hyperglycaemia aversion. The HAS-UK questionnaire item was then used in isolation, with participants who responded with ≤ 8 mmol/L. Participants were not given any material incentive to participate in any part of the study.

Eighteen participants were interviewed. Three were clinician identified, and three were recruited from having a highest comfortable glucose of ≤ 10 mmol/L and IAH or at least one SH in the past year. Following this, 18 participants with a preferred glucose level of ≤ 8 mmol/L were invited to interview, and 12 were interviewed. Of the six who were not interviewed, five did not respond to an email invitation to interview. One did respond but was unable to participate in the scheduled interview, and following this, it was not possible to contact them to reschedule the interview.

In line with grounded theory methodology, as the study progressed, purposive sampling of participants with certain characteristics or experiences was used to look further into emerging concepts and ideas. The concept of theoretical sufficiency was used to determine sample size: data collection stopped when the research team agreed there was sufficient depth in themes and analysis to build a theory (Dey, 1999).

Interview schedule

A semi-structured interview schedule was developed by the research team, which included diabetes-specialist clinical academics, diabetes educators, diabetes-specialist, and academic clinical psychologists. The interview schedule was revised in response to information from interviews to further explore hypotheses and developing theoretical ideas (Table S1). Interviews were conducted by video call or telephone, were audio-recorded, and lasted 40–90 min.

Data collection

The first author, who conducted the interviews and led the analysis, is a type 1 diabetes-specialist clinical psychologist, experienced in conducting research interviews and qualitative analysis, and received additional training and supervision from the fourth author.

Data analysis

Interviews were transcribed verbatim, with identifying details removed. A constructivist grounded theory (Charmaz, 2014) approach was taken, involving simultaneous data collection and analysis, with ongoing analysis and hypotheses informing development of interview questions and participant selection.

Interview transcripts were coded descriptively on a line-by-line basis using QSR International's NVivo (QSR International Pty Ltd, 2020) and then compared within and between participants through focused coding. Significant or important focused codes were grouped into theoretical codes, which were built into conceptual models through increasing levels of abstraction and constant comparison. Throughout the analysis, memos were used to record conceptual and theoretical reflections. They were sorted and integrated as part of the development of theoretical links between categories.

Credibility checks

Guidelines for ensuring the quality control of qualitative research were followed (Elliott et al., 1999). Data analysis conversations took place regularly within the research team, and two researchers with experience in qualitative research and the psychosocial aspects of diabetes each audited the coding on two separate interview transcripts. No significant discrepancies or disagreements were raised.

Reflexivity

The first author used a reflective journal and discussions with the rest of the research team to consider and address the role of any assumptions or preconceptions that might influence the analysis (Charmaz, 2014; Elliott et al., 1999), and to ensure fully grounded theoretical development of participant data. None of the interview participants were known to the first or fourth authors.

RESULTS

Of the 18 interview participants, three were not considered to be hyperglycaemia averse and were therefore excluded from the analysis. These individuals were the only users of self-monitoring of blood glucose who were interviewed. One was recently diagnosed and described significant anxiety about many aspects of diabetes. The other two did not describe hyperglycaemia aversion. Both reported that a comfortable highest level of 8mmol/L, as reported in their HAS-UK response, related to glucose concentration, for example, several hours after eating.

Table 1 describes the 15 hyperglycaemia-averse participants; Table 2 describes individual characteristics of the 18 interviewees.

Grounded theory was used to build a theoretical model of the process of hyperglycaemia aversion (Figure 1). The content and nuance of the model is described below, using the theoretical categories from Figure 1 as subheadings. Participants' preference for control and high standards interacted with and influenced: their sense of threat from high or rising blood glucose levels; difficulties sitting with associated discomfort; approach-focused coping style. These all influenced their approach to the management of their blood glucose levels. Their actions led to lowering of their blood glucose, or maintained low blood glucose, which meant that the threats associated with high blood glucose were alleviated or avoided, which was reinforcing, though ultimately led to standards being raised further and being even harder to meet. Several beliefs served to maintain participants' hyperglycaemia aversion, and diabetes technology also played a role in the maintenance of the psychological and behavioural processes.

Control and high standards

All participants demonstrated elements of holding high standards and a preference for control. This related to diabetes self-management and their lives more broadly. Extreme high standards, perfectionism, and self-criticism were often reported, as well a strong preference for control:

TABLE 1 Hyperglycaemia-averse participant characteristics.

N	15
Sex (% female)	60
Ethnicity	100% white
Age, years, mean (SD)	41.2 (12.7)
Duration of diabetes, years, mean (SD)	26.3 (17.8)
Insulin delivery, MDII/CSII, n (%)	5 (33.3)/10 (66.7)
Blood glucose monitoring method, n (%)	
Intermittently scanned continuous glucose monitoring	4 (26.7)
Real-time continuous glucose monitoring	11 (73.3)
HbA1c ^a , % (mmol/mol), mean, SD, (mean, SD)	6.2, .6 (43.9, 6.4)

^aTaken from clinic notes, or self-reported.

TABLE 2 Individual participant characteristics.

Participant number	Diagnosed aged <18 years (C) or ≥18 years (A)	Highest comfortable blood glucose (mmol/L)	IAH Y/N	SH in past year Y/N
1	C	12	Y	N
2	A	6.7	N	N
3	C	11	Y	Y
4	C	9	Y	Y
5	A	9.5	N	Y
6	C	8	Y	Y
7 ^a	A	6	N	N
8	C	7	Y	N
9	C	7	Y	N
10	A	7	N	N
11	C	7.5	N	N
12	C	7.5	N	Y
13 ^a	A	8	N	N
14	A	8	N	N
15 ^a	A	8	N	N
16	C	8	N	N
17	C	8	N	N
18	C	7.8	N	N

^aExcluded from analysis, and not included in Table 1.

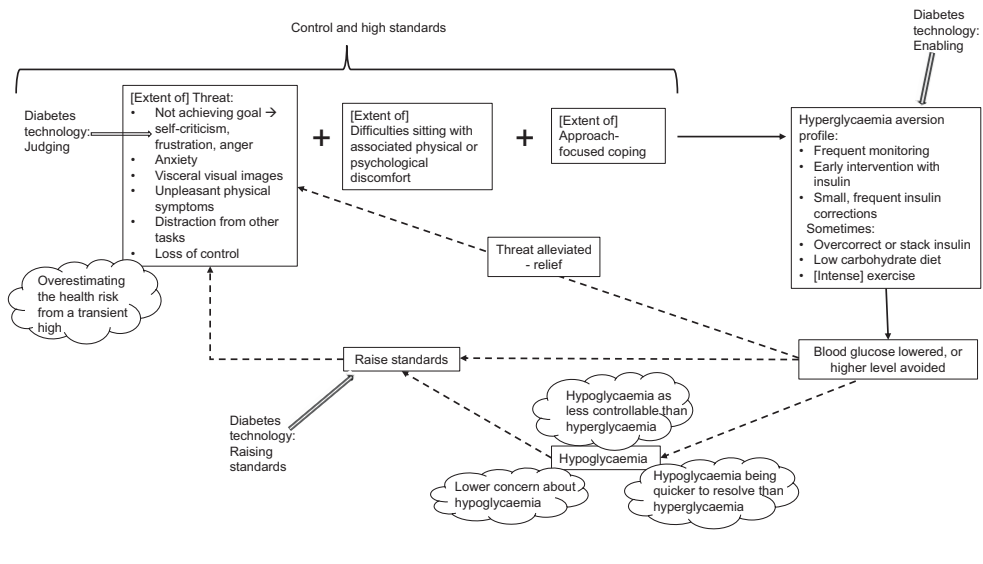


FIGURE 1 Theoretical model of the process of hyperglycaemia aversion. Maintaining beliefs and attentional processes. Role of diabetes technology. Overarching process.

I don't go as far as self-loathing, but I'm on that journey towards just not liking the person I am, at all. Because that's driven by perfectionism, and I'm not living up to the standard I've set myself in my head, which is completely unachievable

(P16)

you can't do an operation on the pump, you've got to be taken off it, put on a drip and all that sort of stuff, which, that caused anxiety, because then I'm out of control
(P9).

Many participants demonstrated and described inhibited emotional expression and difficulties recognizing or attending to their own needs:

to go off topic slightly, my mum died erm, 10 years ago. A lot of my friends don't know about that. And I knew them at the time [laughs] you know, and I never told them because again, I'm not comfortable going, here's this massive thing. You need to give sympathy to me. And, you know, I am so not comfortable with anything that kind of goes into that... area
(P1)

I am very bad at that, very bad at recognising when I need things. Yeah, very bad indeed
(P12).

At times, this involved an incongruence between a described situation and its reported significance:

I was just too... underweight, I think. Like, you know, I was sort of passing out periodically, nothing too... dramatic, erm. I say, er... still, still, still dramatic enough, definitely, erm, but yeah, I, I got down to about five and a bit stone, so I ended up in an eating disorders place
(P11).

Some described difficulties associated with perfectionism and control, including anorexia nervosa (Dahlenburg et al., 2019) and longstanding, difficult to treat depression (Blatt et al., 1998), though difficulties associated with preference for control were not always reported.

Some participants were diagnosed with type 1 diabetes as adults and applied pre-existing control-related strategies or personality traits to diabetes self-management:

I don't think they're anything I focused on from diagnosis. They are all just life traits
(P10).

Some spoke of the transactional relationship between their preference for control and living with type 1 diabetes:

I think personally with my living with diabetes, is sometimes you feel like you don't have a lot of control. So you want to implement control in whatever other ways of your life possible
(P18).

Threat, sitting with discomfort, and approach-focused coping

Participants described several threats related to high or rising glucose. The most prominent and powerful threat experienced was self-criticism and frustration:

I just feel like I shouldn't be going high, so if I have there's a rea-, it's my fault, because I've either under-bolused or not given it far enough in advance, like, pre-bolused far enough in advance, or... had a pint that will push it up quicker. Just, yeah, annoyed with myself
(P2).

This was in many cases as significant as “a real, visceral anger” (P8) at oneself for not meeting their own high standards.

A smaller number of participants reported anxiety associated with a high or rising glucose, typically about diabetes-related complications. In only one case was anxiety reported without self-criticism. In this instance, and in others, participants struggled to articulate their thoughts and feelings around hyperglycaemia, either due to it becoming a conditioned, and therefore automatic, response, or relating to a broader trend seen in participants, of difficulties or discomfort with articulating their internal world of thoughts and feelings:

some of these subconscious things are not necessarily driven by rational, but more like emotions

(P6).

Another threat to alleviate or avoid was visceral mental images of damage occurring when glucose was high, rather than living with complications in the future:

it's really this image of seeing the sugar in the nerve, getting inside and eating at it. Erm, and the same thing with my retinopathy for example, so getting in the retina and eating at it, that's the image that I've got. Erm, almost like, like, almost like acid, like burning, acid burning through the nerves, that's, that kind of image, that I get

(P5).

Further threats included: a sense of loss of control; unpleasant physical symptoms which were typically reported at relatively normal glucose; and frustration at feeling compelled to thoroughly analyse why levels were elevated. The latter two threats often linked to participants holding high standards in other areas of life, and concern about diabetes-related factors interfering with performing other tasks.

Some participants described feeling threatened with diabetes-related complications as children, which “was frightening” (P12), and an awareness that there was “an asymmetric kind of, consequence picture” (P6) focused on the risks of high, but little about low, glucose. The impact of feeling told off or threatened is likely to be felt particularly acutely in this group of individuals, who can hold high standards and be self-critical:

bear in mind, I was a good kid, okay. I did very well at school, I was you know, I was well behaved, no-one ever criticised me. Teachers didn't criticise me. To go to a doctor and be criticised for something that you don't have the skills to do anything about, ...is, it's tough

(P1).

While many participants described motivation to avoid complications, and some expressed anxiety about complications, this was typically not the primary in-the-moment driver or maintainer of their management approach:

in the moment I don't know that I'm thinking about that long-term impact. I think I am just like, arghhhh, I'm so annoyed

(P17).

Often a desire to avoid complications merged with aspects of high standards and a preference for control. For example, being advised to avoid higher glucose levels to avoid complications was accompanied by setting themselves high standards around this goal, and then experiencing self-criticism and frustration when those standards were not met.

medical people will say between 4 and 10, but I'm like, if it was between 4 and 10, why wouldn't everyone be between 4 and 10? Why is that just the diabetic guideline? So, I'd, I'd happily bolus for, like, a 9

(P11)

I am a high achiever, I'm a control freak in my everyday life. And I feel like I just want to be good at what I do. And I also want to be good at managing my disease, however odd that may sound. So I feel like that is really the prime motivator for me

(P5).

Participants described other, less proximal, motivators including to feel special, to feel normal, and to prove themselves to others. As P10 noted:

there's so much more on the scale than just a, you'll lose a limb. There's so many steps in between it.

These threats felt very difficult for participants to sit with, perhaps because they often threatened an individual's self-evaluation or sense of self, which is why many were motivated to "try to avoid high blood glucose at all costs" (P16):

I don't care if I crash. I don't want to have a high blood sugar. This is wrong. This is not what I'm, I'm special, I am a diabetic who knows this stuff. I am not going to be high. It was a matter of principle and emotion

(P8).

As is often seen in controlled individuals, many participants described a dispositional tendency towards taking action in the face of a perceived problem (Lynch, 2018), and this approach-focused coping (Gol & Cook, 2004) was also described in relation to glucose self-management:

the initial reaction is pretty much, what corrective action can I take, coz I feel like I'm pretty, erm, like, action oriented as a person. I'm pretty much, what can I do?

(P5).

Some participants reported being unable to turn their attention away from hyperglycaemia until it was falling. Several, including some of those who felt unable to turn their attention away, reflected at interview that taking action may not be necessary:

quite often highs actually sort themselves out. You know, they'll rise up and then they'll drop down again naturally. Erm, which, if you're constantly over-monitoring things, maybe they don't get a chance to do.

(P1).

Acting quickly to lower their glucose prevented them seeing how it might stabilize, as well as getting used to tolerating the difficult thoughts and feelings associated with hyperglycaemia.

Hyperglycaemia aversion

Participants tended to: monitor their blood glucose frequently; take early action with insulin, either in response to an upward arrow on monitoring technology or at a lower hyperglycaemia threshold than typically recommended; take small, frequent insulin corrections. Some stacked or

overcorrected with insulin, adopted low carbohydrate diets, or used (sometimes intense) exercise to manage hyperglycaemia.

with the benefit of CGM, I would start correcting a high probably at about 7
(P1)

Sometimes that happens because I am so frustrated with being high that I'll just keep adding more and more corrections and occasionally I'll... have to guzzle a lot of juice or something, but... usually it's just very small amounts throughout the day to bring me down
(P2).

Once an individual acted on their glucose level, its associated threat was avoided or alleviated. For some participants, this provided a sense of relief, which was reinforcing. In some cases, their action led to hypoglycaemia. Many participants spoke of how they continued to raise their standards for self-management, and this was described by those wanting to avoid hypoglycaemia and those who were not motivated to avoid it.

Inevitably, more demanding standards were harder to meet, which fed into people experiencing further self-criticism.

because I now can be so much better that it just means I have lowered the, the limit of my frustration. The ceiling is lower.
(P8).

Diabetes technology: enabling, raising standards, and judging

Diabetes technology played a role in enabling participants' hyperglycaemia aversion. P6 described “the curse and the blessing of CGM” whereby:

it can be a tool which really helps. It can be a tool [laughs] which makes things worse, yeah, because you start to tend to be a bit more overreacting on things.

CGM gave participants more information and enabled them to self-manage at lower glucose than they could have done, or may have been inclined to do, otherwise.

CGM raises the obsession level, if you see what I mean. Because you can inspect it and watch it. If I couldn't watch it, I wouldn't be able to keep it low. So therefore it wouldn't become an issue
(P9)

Regarding CGM, there are certain features on it that I wish I could turn off because I know that they appeal to the bit of my brain that's just like, keep the numbers down, keep the numbers down
(P14).

Some described how insulin pump therapy facilitated their preference:

my PDM [personal diabetes manager] for Omnipod, it's so easy. Yeah, you just click on it and boom, off you go. It's like, it's like a video game
(P6).

Linked to the tendency of hyperglycaemia-averse individuals to hold high standards, several participants described technology's role in further raising their standards and targets around glucose management, which sometimes included making riskier self-management decisions:

with the CGM, it starts much lower. Erm, because the CGM defaults to saying 10 is the point at which you are high. Erm, therefore I kind of now see that as the benchmark for high (P1).

Many participants reported high standards and associated self-criticism, and some spoke of feeling judged by, or their own self-criticism increasing due to use of, monitoring technology:

Regarding the traffic light system on CGM: the logical part of me goes, don't be stupid, it's a colour, and the other part of me goes, the colour says you've done it wrong, the colour says you've done it wrong (P14)

Regarding CGM: because I am more able to sort of see and marry where certain things have, have made an impact, I think that more closely ties it to my action, and therefore my guilt, because it was my action (P18).

There was often a tension articulated by participants whereby technology supported optimization of diabetes self-management, and for some, it had been associated with a reduction in frequency of hypoglycaemia, sometimes reducing their, and others', anxiety. Yet, participants described increased burden, self-blame, and other anxieties, although one was keenly awaiting a hybrid closed-loop system "because then, also, I can blame the pump and not myself" (P17).

Maintaining beliefs and attentional processes

Participants described a range of beliefs and attentional processes that contributed to and maintained their glucose management approach.

Hypoglycaemia being quicker to resolve than hyperglycaemia

Participants spoke of how much quicker hypoglycaemia was than hyperglycaemia. This was seen as advantageous for several reasons. The most commonly discussed aspect was that hypoglycaemia was easier and less time-consuming to manage, and quicker to recover from.

It's just so much faster. I mean, if you're high, and then you need to wait for your insulin to kick in and then have you done enough to deal with whatever that made you high. Whereas, like, quick low, you know, three jelly babies, you're good to go (P11).

Participants also spoke of implications for health risks:

So if there's a bit of potential damage from a hypo, it's going to be a smaller time frame than the damage caused by a hyper (P2).

One participant reflected that “you get more time to sort of, ponder on your own errors, in that slower correction space” (P16). For some, the relative speed and perceived ease of hypoglycaemia meant they would prefer to deliberately induce and then treat hypoglycaemia than wait for a higher reading to fall slowly:

the implementation lag you have is a problem. So for instance, what I, that's why I tend to sharper correct a high sugar, because I know if I give it a bit more, it goes down faster, erm, but I can recover the lower one fast as well

(P6).

Lower concern about hypoglycaemia

Participants fell on a continuum from fearing hypoglycaemia and wishing to avoid it to seeing SH as “priced in” (P8) to their self-management approach. One (P4) reported greater concern about hypoglycaemia than hyperglycaemia but still preferred to run their glucose low, despite recommendations from their health care team to increase their glucose targets. Relatively low concern about hypoglycaemia was seen in participants with and without IAH. Linked to difficulties with articulating feelings, several of those with IAH intellectually recognized that hypoglycaemia could be problematic, but did not appear to connect with this emotionally:

I don't feel any-, I feel cold, erm, about that. It doesn't, I mean I would, I want to say that theoretically, if I kind of, carked it, I'd feel, erm, bad for my [partner] and my children

(P8)

you can end up in a bit of a mess sometimes... Erm, but you know, I haven't killed myself yet, so you know, it's all good [laughs]

(P1).

P11 wondered whether their previous IAH allowed them to be less confronted by the risks associated with frequent hypoglycaemia:

maybe it's just easier to stay a bit more in denial, like if you don't, if you don't really feel it as a problem... and then at some point you correct it, it's, not as if it didn't happen, but, you know what I mean, it's, it's like it doesn't really count if I never felt low. What damage could it possibly be doing? And I am sure there's an answer to that question, I'm not sure I want to know it.

(P11).

Several participants described themselves as not being very ‘sensitive’ to hypoglycaemia, which was seen as advantageous for their glucose management preference:

I go down to 2 and I haven't got a clue, erm, so, that any minute now I am about to fall over. So that's, that's very lucky in a way, as long as you can pick up on it. And I can pick up on it because I've got continuous glucose monitor things

(P9).

Two participants reported conceptualizing hypoglycaemia differently from their health care teams:

I remember healthcare professionals saying, so what's a hypo, for you. I'd go, mmm, probably anything under 2. And they'd go, you know, what the actual. Erm, it's like, well yeah, but I don't feel anything and I'm fine

(P8).

Hypoglycaemia as less controllable than hyperglycaemia

A minority of participants described hypoglycaemia as being more inevitable and less in their control than hyperglycaemia:

I do tend to go towards the lower side

(P4)

there's only certain things that are going to cause you to go high, erm, all of which I can generally control or should have factored in, erm. Going low is slightly different in that, you know, the, I know there are certain things that make me go low and regardless of what I do, it doesn't matter

(P14).

Overestimating the health risk from a transient high

Some participants described concern about the longer-term health implications of transient hyperglycaemia:

the longer I stay in those high sugar levels, the, kind of, it's, it might be completely not true, but in my head it's like it's almost like the earlier I will die. I know it's really grim to say this, but it's like, in my, it's almost like I'm losing time from the end of my life

(P5).

Only one participant described concern about diabetic ketoacidosis. Concern about the health implications of transient hyperglycaemia was not present for all participants, and many intellectually recognized that this was not a significant risk factor for future health complications. For this latter group, hyperglycaemia was often more associated with self-criticism than anxiety.

CONCLUSIONS

This study presents the first model of the process of hyperglycaemia aversion in type 1 diabetes. People with type 1 diabetes are advised to avoid hyperglycaemia to reduce their risk of future health complications. Yet, only a minority develop hyperglycaemia aversion, characterized by detail-focused attention to in-the-moment glycaemia and early intervention for rising or high glucose. The use of 'aversion' rather than 'fear' is deliberate, as many participants did not describe anxiety or fear related to hyperglycaemia. Diabetes technology served to further enable people's preference, raise their standards, and act as an additional critical judge of their self-management. People acted early to alleviate or avoid threats associated with higher glucose, which often included high levels of self-criticism or other threats to their sense of self. Participants described beliefs and attentional processes that served to maintain their glycaemia preference.

We propose that emotional over-control serves as a useful trans-diagnostic concept for understanding the development and maintenance of hyperglycaemia aversion in people with type 1 diabetes. Individuals predisposed to certain characteristics such as hypersensitivity to threat and diminished reward sensitivity can develop emotional over-control in an environment where value is placed on performance, mistakes are seen as intolerable, and self-control is imperative (Lynch et al., 2015). People adopt a range of coping strategies; over-control is a multi-faceted construct incorporating several factors, including hyper-perfectionism, high level of detail focus, self-criticism, inhibited emotional expression, and difficulties attending to own needs. Individuals are often motivated by long-term goals and can use compulsive approach-coping and fixing, even if this is harmful. Over-control is 'expressed discreetly'

and often downplayed, such that most people do not access mental health support and people outside the individual's immediate family may be unaware of their distress (Lynch, 2018).

For people with a dispositional threat focus, a type 1 diabetes diagnosis in childhood is likely adequate to develop emotional over-control, for example, feeling threatened by complications and value being placed on self-management performance, typically the avoidance of high, rather than low, readings (King et al., 2017). For those diagnosed as adults, pre-existing control strategies can be applied to diabetes self-management. Some things, such as glucose, can never be 'perfectly' controlled, which is particularly problematic for those with high levels of perfectionism, whose self-evaluation is heavily dependent on meeting their goals (Shafran et al., 2002). If targets are met, they may be evaluated as insufficiently demanding and more stringent ones set, even if they are associated with adverse consequences (Shafran et al., 2002), such as hypoglycaemia.

Avoidance of hyperglycaemia is encouraged in the self-management of type 1 diabetes, and high standards and a preference for control are likely to be helpful characteristics for living with type 1 diabetes (Waller et al., 2013). However, there is a group in whom this can become 'too much of a good thing' (Lynch, 2018), with risk of high levels of distress and frequent hypoglycaemia, and possible IAH and SH. Hyperglycaemia aversion did not reach this point for all participants in our study. While there are certain factors, such as reduced concern about hypoglycaemia, and a stronger compulsion for approach-based coping, that are likely to increase vulnerability to difficulties, it was not possible to ascertain individual factors that increased the likelihood of people experiencing difficulties related to hyperglycaemia aversion. This may in part relate to the sense that some participants were downplaying or under-reporting their difficulties or finding it difficult to access and articulate their internal world.

Messaging about glucose

There may be a risk that in situations where people with diabetes, or their parents and carers, tend towards emotional over-control, clinicians place additional emphasis on the requirement for in-range glucose, due to the apparent lack of emotional response or reaction to their messages (Hempel et al., 2018), inadvertently exacerbating the perceived threat, consequent self-criticism, and possibly dangerous self-management decisions.

Faced with perceived high risk of hypoglycaemia, clinicians may sometimes encourage people with type 1 diabetes to raise their glucose target (Shin et al., 2021). Given the complex interaction between high standards, control, and concern about complications, it should be noted that reassurance that an increase in glucose will not be detrimental to future health is unlikely to be acceptable or adequate, even for those who report that their motivation is to avoid complications.

Assessing hyperglycaemia aversion and distress

There was at times an incongruence between the situations participants described and the significance or distress ascribed to them. While this may have had implications for the analysis of the present study, it also has clinical implications. The psychological and diabetes-related concerns of this cohort may well be under-reported or not volunteered (Waller et al., 2013), and the use of screening tools such as the HAS (Barendse et al., 2011; Singh et al., 2014) may be useful in aiding assessment of hyperglycaemia aversive thoughts and behaviours.

Monitoring technology

The role of diabetes technology, particularly CGM, is key in hyperglycaemia aversion. Our study raises questions about whether the described manifestation of hyperglycaemia aversion would be possible in

those who are not using a continuous sensor, or if it is, whether the question about highest comfortable glucose concentration is appropriate to assess for it. Indeed, the three users of self-monitoring of blood glucose who were interviewed based on their answer to this question were excluded from analysis due to not describing hyperglycaemia aversion at interview.

Monitoring technology is likely to be accessed by those who are predisposed to hyperglycaemia aversion due to engagement in self-management, and sometimes safety concerns (Heinemann et al., 2018; National Institute for Health and Care Excellence, 2022). Given increasing use of monitoring technologies in recent years, it may be that most hyperglycaemia-averse individuals are now using CGM. This study has highlighted the need for further research into the role of monitoring technologies in hyperglycaemia aversion, and meanwhile, clinicians should be encouraged to collaboratively consider how to ensure engagement with continuous data in a way that best supports mental and physical health.

IAH and SH

Hyperglycaemia-averse individuals have an interacting suite of risk factors for SH and IAH. A number of participants reported frequent, albeit not severe, hypoglycaemia, a risk factor for IAH (Choudhary & Amiel, 2011). In people with a tendency towards emotional inhibition, reduced concern about hypoglycaemia may extend to inhibited hypoglycaemia fear and thus a riskier approach to hyperglycaemia avoidance (Gross & Levenson, 1997). Additionally, in those with problematic perfectionism, adverse consequences associated with striving for a goal (such as hypoglycaemia) can be interpreted by the individual as a good sign that they have set a sufficiently demanding target (Shafran et al., 2002), and thus, motivation for avoidance may be low.

Alongside inhibited emotional expression, over-controlled individuals have low awareness of bodily sensations (Lynch, 2018), so the hyperglycaemia-averse cohort may already possess a tendency towards reduced, if not impaired, awareness of hypoglycaemia. The construct of alexithymia describes difficulty in identifying and describing feelings and in distinguishing feelings and bodily sensations of emotional arousal, and an externally oriented thinking style (Taylor et al., 1991). Alexithymia scores correlate positively with the “hyperglycaemia avoidance prioritized” factor of the Attitudes to Awareness (A2A) questionnaire, and respondents with IAH are more likely to score highly for alexithymia than those without (Naito et al., 2021). Those with IAH are additionally more likely to have either high or low levels of perfectionism, and perfectionism scores correlate with “hyperglycaemia avoidance prioritized.” We hypothesize that those with IAH and high levels of perfectionism may possess similar characteristics to the hyperglycaemia aversion profile described here.

Limitations

Hyperglycaemia aversion has been a poorly described and defined concept, which had implications for the present research. We cannot guarantee that our participant selection process included all manifestations of hyperglycaemia aversion. We did, however, use several participant selection strategies to minimize this risk. All of the hyperglycaemia-averse participants were of white ethnicity, which reflects the responses to the survey (93.3% white). Those who participate in research, predominantly of white ethnicity, may not reflect the full range of hyperglycaemia aversion experiences. While we recognize that the sample may not be representative, we anticipate that the findings would be transferable (Lincoln & Guba, 1985).

This study has developed a theoretical understanding of hyperglycaemia aversion, but is not able to offer insight into prevalence of hyperglycaemia aversion in populations of people with type 1 diabetes, nor on the best tools or approaches for assessing hyperglycaemia aversion.

Future research

Future research would benefit from investigating whether there are particular psychological processes or diabetes self-management approaches that might make a hyperglycaemia-averse individual more likely experience problematic consequences such as IAH or SH. The role of monitoring technologies in the development and maintenance of hyperglycaemia also requires further attention. Furthermore, development and evaluation of tools for the identification and assessment of hyperglycaemia aversion is also important.

The evidence base for psychological interventions for the treatment of clinical perfectionism (Pinto et al., 2017; Robinson & Wade, 2021; Shafran et al., 2017) and difficulties related to other aspects of over-control (Gilbert et al., 2020; Lynch, 2018; Lynch et al., 2015) is growing, and the development and evaluation of a trans-diagnostic evidence-based psychological intervention that includes attention to hyperglycaemia aversion would be a useful addition to this.

In conclusion, in this first systematic qualitative study of hyperglycaemia aversion, we present an emerging model of the process of hyperglycaemia aversion, with new insights to aid in identifying and supporting those who may be at risk of psychological distress and harm associated with a preference for the avoidance of higher glucose levels.

AUTHOR CONTRIBUTIONS

Vicky McKechnie: conceptualization (lead); methodology (equal); formal analysis (lead); writing – original draft (lead). **Nick Oliver:** conceptualization (supporting); supervision (equal); methodology (equal); writing – review and editing (equal). **Stephanie A. Amiel:** writing – review and editing (equal). **John R. E. Fox:** supervision (equal); methodology (equal); formal analysis (supporting); writing – review and editing (equal).

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CONFLICT OF INTEREST STATEMENT

None.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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