ORIGINAL ARTICLE OPEN ACCESS

'*It's a Balancing Act*'. A Qualitative Study of the Everyday Management of Type 1 Diabetes Among People with Unexplained Persistent Hyperglycaemia

Berit Kjærside Nielsen[1] | Annesofie Lunde Jensen[2,3] | Anna Ryberg[1] | Steen Bønløkke Pedersen[2,3] | Sten Lund[2,3] | Stina Lou[1,3]

[1]DEFACTUM—Public Health Research, Central Denmark Region, Aarhus, Denmark | [2]Steno Diabetes Center Aarhus, Aarhus University Hospital, Aarhus, Denmark | [3]Department of Clinical Medicine, Aarhus University, Aarhus, Denmark

Correspondence: Berit Kjærside Nielsen (berini@rm.dk)

Received: 3 July 2024 | **Revised:** 22 November 2024 | **Accepted:** 4 February 2025

Funding: The authors received no specific funding for this work.

ABSTRACT

Background: Despite advances in diabetes care, many people with Type 1 Diabetes (T1D) still experience persistent hyperglycaemia, leading to reduced quality of life and increased risk of long-term complications. For some, this hyperglycaemia is linked to factors like co-morbidities, socio-economic challenges, or low health literacy. However, for many, persistent hyperglycaemia remains clinically unexplained, indicating a gap in understanding the contributing factors.

Aim: To explore the lived experiences and everyday management of T1D among adults with clinically unexplained persistent hyperglycaemia (HbA1c $\geq$ 70 mmol/mol), with the goal of informing caring practices that support better health outcomes.

Methods: Using an anthropological approach, we conducted in-depth interviews with 19 adults. The interviews were digitally recorded and transcribed. Data was analysed using reflexive thematic analysis.

Results: The analysis identified four themes: (1) 'Embodied diabetes' described how the risk of low blood sugar shaped daily management as it could impact productivity and social interactions, highlighting the need for empathetic support. High levels were more tolerable, yet frustratingly unpredictable and perceived as 'unruly.' (2) 'Inescapable diabetes' described diabetes as a presence that had to be navigated alongside life's complexities and how the participants sought to balance immediate concerns that were often prioritised over perfect glucose levels, underscoring the importance of holistic care approaches. (3) 'Desire for normalcy' described the weighing between concealment and disclosure of T1D and the detailed planning required to integrate diabetes seamlessly into everyday life, suggesting a need for personalised care strategies. Finally, (4) 'Diverse interactions with the diabetes clinic' described experiences from sincere interactions to feelings of resignation. Clinical advice was sometimes dismissed due to perceived ineffectiveness or lack of relevance, indicating opportunities for improving patient-provider relationships.

Conclusion: This study highlights the complexities of daily diabetes management and emphasises the importance of a caring and holistic approach that incorporates the myriad obligations, concerns and desires that adults with T1D navigate and prioritise alongside or in competition with their disease. By understanding these lived experiences, healthcare professionals can better support patients through patient-centred care practices that address both medical and personal dimensions of living with T1D.

Scandinavian Journal of Caring Sciences, 2025; 39:e70001
https://doi.org/10.1111/scs.70001

1 | Introduction

Type 1 diabetes (T1D) is a chronic autoimmune condition that impacts millions globally, profoundly altering their daily lives and necessitating continuous self-care [1]. Management of T1D requires continuous attention, involving regular monitoring of blood glucose, administering insulin and making vital lifestyle decisions [2]. The role of healthcare professionals in providing compassionate, patient-centred care is essential in supporting individuals in these self-care activities. However, despite this many people with T1D continue to experience persistent hyperglycaemia, reflected by high glycated haemoglobin (HbA1c) levels exceeding the recommended target [3]. Persistent hyperglycaemia is associated with various challenges that impact quality of life. Research shows that those who struggle to consistently regulate their blood sugar may experience diminished well-being, resulting from both physiological effects of glucose fluctuations and psychological responses, such as frustration or hopelessness [4, 5]. Understanding and addressing these emotional and psychosocial aspects are critical components of caring for individuals with T1D. In the long-term, insufficient management of T1D also increases the risk of severe complications, including cardiovascular disease, nephropathy, retinopathy, and neuropathy, further affecting quality of life [6, 7].

Previous research has shown structural, social and individual barriers to effective diabetes management. Structural barriers encompass issues such as healthcare system complexities and the availability of medical resources [3, 8]. Social barriers involve lack of support from family, friends and the broader community [9, 10], while individual barriers comprise personal factors including knowledge, beliefs, and emotional responses to living with a chronic condition [11–13]. While these studies have been important in identifying the challenges faced by people with T1D, the specific day-to-day lived experiences of those who face persistent hyperglycaemia remain unexplored from a caring perspective.

Further complexity arises because persistent hyperglycaemia is not always fully explained by known factors, such as comorbidities, socio-economic challenges, or low health literacy [14, 15]. This poses a challenge to the biomedical understanding of diabetes self-management, indicating for a more comprehensive, caring approach that explores the personal experiences of people living with T1D.

Diabetes consultations traditionally revolve around statistical risks, encompassing concerns, for example, elevated blood glucose levels, potential late complications, and the effectiveness of self-management strategies. However, connecting the scientific definition of 'risk' with the concept of 'situated risk' as understood and contextualised by people with T1D is not a straightforward task [16]. Exploring 'situated risk' involves moving beyond epidemiological definitions to understand the values and uncertainties that hold significance for each person navigating life with T1D. This perspective emphasises the unpredictable outcomes of 'a risk,' acknowledging that these are ultimately unknowable in terms of their impact [16, 17].

The present study focuses on people with persistent hyperglycaemia despite seemingly adequate resources and efforts. Building upon previous research that examines structural, social, and individual barriers [3, 8–13], the aim of the study was therefore to explore the lived experiences and everyday management of T1D among people who face clinically unexplained persistent hyperglycaemia. By gaining deeper insights into their experiences, we aim to inform and enhance caring practices that support better health outcomes.

2 | Methods

The study was set within an anthropological research paradigm, characterised by its iterative-inductive approach, which emphasises ongoing reflexivity and cumulative data development [18]. This paradigm is particularly suited to exploring human experiences within specific social and cultural contexts. It integrates diverse theoretical perspectives, remains adaptable in its methodological practice and recognises the interlinked nature of data collection, analysis and interpretation throughout the research process. Anthropology, as a discipline, is grounded in a diverse epistemological foundation. In this study, the approach is grounded in a critical realist and contextualist perspective. Critical realism assumes an independent material reality but acknowledges that our experiences are shaped by social, cultural, and political contexts [19]. Contextualism emphasises that meaning is constructed within specific social and cultural settings, acknowledging that knowledge is situated and influenced by the context in which it is produced [20]. This perspective views knowledge as contextually located and provisional, reflecting researchers' positionings.

2.1 | Participants and Setting

Participants were adults with T1D registered as patients at the Steno Diabetes Center at Aarhus University Hospital in Denmark at the time of recruitment. Using purposeful sampling, the inclusion criteria were established by the research team [21]. Patients were eligible to participate if they had a confirmed diagnosis of T1D, were between 25 and 55 years of age, had persistent hyperglycaemia (HbA1c ≥ 70 mmol/mol) for a minimum of 2 years, and had attended a minimum of four clinic visits over the past 2 years. This latter criterion was set to identify patients who had persistent hyperglycaemia despite regular clinic visits. Moreover, achieving a balanced distribution of male and female participants, along with individuals with varying durations of diabetes, was pursued. Participants with severe long-term complications or complex psychosocial problems were excluded as the clinical experience was that having these significant additional health issues could often explain difficulties in managing diabetes, including persistent hyperglycaemia.

The recruitment process involved two strategies. First, 72 potential participants were identified by two clinicians from outpatient lists based on the inclusion criteria and informed about the study via email, which included a link to the survey platform 'SurveyXact'. This strategy yielded positive responses from 15 individuals, with 11 consenting to participate in the study. To increase the number of participants, support staff at the diabetes clinic, specifically medical students, directly approached eligible patients. These staff members provided patients with an information sheet and obtained consent for the research team to contact them, thus maintaining a degree of separation from the primary healthcare providers. This second strategy successfully recruited an additional eight participants. Ultimately, 19 participants consented to and were interviewed for the study.

2.2 | Data Collection

Data is based on semi-structured interviews (Appendix 1). An interview guide was developed through a two-fold approach. First, a scoping review of existing T1D literature was undertaken to identify key themes and gaps pertaining to daily living and diabetes self-management [18, 22]. Second, the interviewers conducted participant observation at the diabetes clinic, engaging with healthcare professionals and patients to understand clinical and personal aspects of T1D. This approach ensured that the interview guide was both informed by academic insights and grounded in clinical observations. The final interview guide focused on participant's daily living with T1D, including knowledge and beliefs, family and work, self-management and interaction with the healthcare system [18]. All interviews lasted on average 61 min (range: 43–87 min) and were conducted by phone ($n = 16$) or at the participants' homes ($n = 3$) by the first and last author, who are both experienced in qualitative interviewing. All interviews were digitally recorded and transcribed verbatim.

2.3 | Data Analysis

We conducted a reflexive thematic analysis of the interview data, adhering to Braun and Clarke's six-phase methodology, emphasising the importance of the epistemological foundation in shaping the analytical process [23, 24]. Grounded in a critical realist and contextualist perspective, our analysis recognised participants' experiences as both real and socially interpreted within specific cultural contexts. Critical realism allowed us to understand the impact of diabetes as a real condition in participants' lives, while also acknowledging that their living experiences are shaped by societal norms and personal interpretations [19]. This dual lens provided a foundation for analysing how participants' experiences of Type 1 diabetes intersect with social practices.

2.3.1 | Initial Familiarisation and Coding

The initial phase involved familiarisation with the data through repeated reading of transcripts by the first, third, and last authors, fostering a nuanced understanding of each participant's narrative [20, 23]. Notes and preliminary interpretations were recorded, guiding the development of inductive, descriptive codes focusing on segments linked to everyday experiences of Type 1 diabetes, such as 'feeling in control' and 'future hopes and dreams'. We created a codebook to systematically define and delineate each code, ensuring consistency and transparency. This codebook served as a foundation for analytical discussions among the research team, allowing us to refine initial codes collaboratively. NVivo software facilitated data management, helped maintain consistency in coding, organising data segments systematically to support the thematic analysis.

2.3.2 | Theme Development and Refinement

Following initial coding, we organised codes into broader patterns and began identifying potential themes, which we defined as clusters of shared meaning central to the research question [23]. Themes were iteratively reviewed and refined by comparing them with the entire dataset and through reflexive discussions, where the research team critically examined each theme's alignment with participants' voices and the study's objectives [20, 24]. We used thematic maps to visualise relationships between themes, testing and refining thematic structures as part of our ongoing reflection process. For example, we initially titled a theme 'the meaning of bodily sensations,' which was later renamed 'embodied diabetes' to holistically capture participants' descriptions of living with diabetes as a part of their bodily experience.

2.3.3 | Finalising Themes

In the final phases, we defined and named each theme to ensure conceptual clarity, articulating the essence of what each theme represented. Writing was integrated throughout the analytical process to develop and sharpen analytical insights, identify contradictions, and address potential weaknesses. To illustrate key insights, we selected relevant quotes, which are presented in a table format to maintain a balance between interpretive analysis and participants' voices. Throughout the process, we engaged in reflexive discussions, examining our interpretations critically to ensure alignment with participants' perspectives and the study's objectives. This reflexive approach allowed us to deepen our understanding and achieve a more nuanced interpretation of the data.

2.4 | Ethical Considerations

This study focused on individuals considered 'dys-regulated' within a biomedical discourse, often perceived as 'unable' or 'unwilling' to adhere to dominant health norms. A central ethical consideration was avoiding the reproduction or reinforcement of dominant norms regarding 'correct' or 'responsible' health behaviour and we were aware of using sensitive, inclusive and non-judgmental language in interviews. Also, recognising the potential emotional nature of the topics, participants were encouraged to contact researchers for support if needed.

According to the Scientific Ethics Committees for the Central Denmark Region, ethical approval was not required due to the absence of human biological materials. The study was registered in the Internal Directory of Research Projects in the Central Denmark Region (r. no. 1-16-02-189-22).

3 | Results

A total of 19 adults (10 women, 9 men; mean age 40 years) with a varied duration of T1D (7–28 years) participated in the study. Diabetes technologies played a role in diabetes self-management, with five participants utilising both pump and sensor, 12 relying solely on a sensor, and two using a traditional blood glucose meter.

TABLE 1 | Participant characteristics.

	(*n* = 19)
Gender	
Women	10
Men	9
Age in years	
20–30	5
30–40	3
40–50	9
+50	2
Diabetes duration	
0–10 years	9
10–20 years	5
+20 years	5
Use of technology	
Pump & sensor	5
Sensor	12
Blood glucose meter	2
Educational level	
Low	2
Medium	11
High	6
Current employment status	
Full-time employed	9
Part-time employed	1
Disability pension	1
Vocational rehabilitation	1
Under education	5
Unemployed	2

For a more detailed presentation of participant characteristics see Table 1. Using thematic analysis, we identified four themes and nine sub-themes, which are presented in Figure 1 to provide an overview of the results. To give the participants a clear voice, illustrating quotes for each theme are presented in Tables 2–5.

3.1 | Theme 1: Embodied Diabetes

This theme describes how bodily sensations and responses shaped the participants' everyday experiences and management of diabetes.

3.1.1 | Low Blood Sugar, no Thanks!

The analysis revealed how the unwelcome risk of having 'too low' blood sugar was central to the participants' daily negotiation of diabetes, as it could impact the rest of one's day (Table 2, quote 1). Recovery from a situation of 'low blood sugar' was described on a continuum, ranging from feeling nauseous and tired, to experiencing extreme exhaustion and the sensation of the body being 'thrashed' (Table 2, quote 2). Having (too) low glucose levels was described as 'the ultimate loss of control' which concerned both the bodily sensation of extreme craving for carbohydrates and the feeling of losing control over the physical body and being dependent on others (Table 2, Quote 3). Feeling ashamed and worrying about bodily responses during low blood sugars were of concern in public and social situations, such as work or being with their children (Table 2, Quote 4), and thus a motivation for prioritising higher glucose levels in a range of social situations.

Some participants described feeling 'heavy' and 'tired' during high glucose levels, while others did not feel them or feel them 'as much'. There was a general understanding that—as a bodily sensation—'a little too high' was much preferable to 'too low' (Table 2, Quote 5). Also, some participants suggested that the body over time could adapt to higher glucose levels, so that the body primarily responded to rapid changes in blood sugar. As some of the participants did not always feel a higher glucose level in their bodies, it could sometimes come as a surprise—and be a source of frustration—when a measurement turned

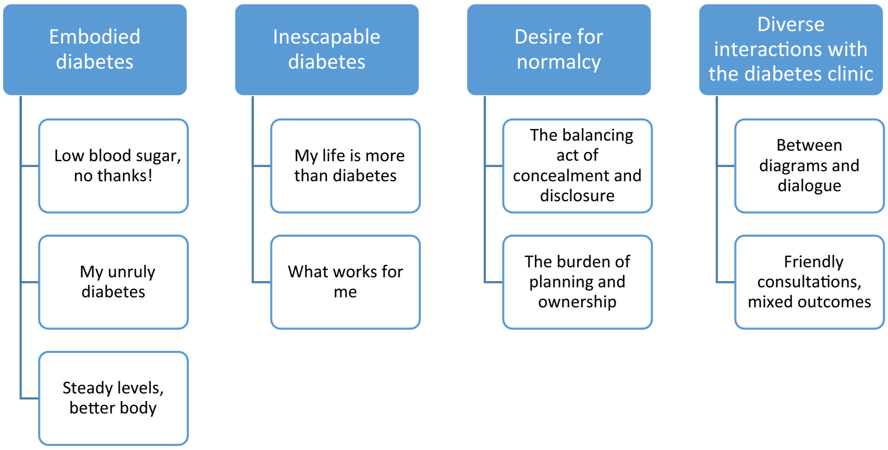

FIGURE 1 | Thematic map.

TABLE 2 | Illustrative quotes from theme 1.

Theme 1: Embodied diabetes		
#	Sub-theme	Illustrative quotes
1	Low blood sugar, no thanks!	'If I lie too low, then I just start sweating, and then I start feeling bad, and then I'm actually tired most of the day.' (Conny, > 40 years)
2		'Within twenty minutes, my blood sugar starts to stabilise, and then it becomes nice, but then when you stabilise your blood sugar you're left with the bill afterward, because it's as if the craving for carbohydrates in the body subsides. Your body feels completely drained of energy, and it feels like you've run a half marathon or really exerted yourself physically, so you feel that the muscles are at a low level of energy, and your head feels like you've been working for twelve hours straight.' (Victor, < 40 years)
3		'[After low blood sugar one morning], one of my roommates had to keep an eye on me and make sure I got some sugar. He had been in contact with my mom, who had called him and was worried. I remember that I didn't cry so much at that time in my life, but right there, I cried because I was so embarrassed and apologised for him having to spend the whole Sunday helping me.' (Henrik, < 40 years)
4		'And I can't handle it at all if my son were to come home and find me with low blood sugar. I mean, it will affect him for the rest of his life. That he finds his father like that. So yes, better too high than too low. And I'm well aware, then there's all this with the side effects…'
5		'High blood sugar is, of course, also a problem, but it's a lesser problem because I usually just get tired. But not like falling-asleep tired. It's just sluggish, so it's usually easier to react to, and it's not nearly as time critical as with low blood sugar.' (Michael, > 40 years)
6	My unruly diabetes	'Let's say that I've gotten up one morning, and my blood sugar is at 9.5, and then I take the units I need without having eaten anything or done anything. My blood sugar can then decide to rise to 15, 16, or 17, even though I haven't eaten anything, and I'm also tired of that. And why it does that? I can't explain.' (Jacob, > 40 years)
7		'It's like being in a strong gale and trying to sail against the wind when the wind is erratic. In that sense, there are some days when you're insulin intolerant. You can take insulin, and nothing happens. When does your insulin intolerance stop?' (Thomas, < 40 years)
8	Steady levels, better body	'So, if my blood sugar is not in control, I usually feel that I cannot think as logically as usually. And basically, my brain just doesn't work well. I'm feeling super stupid.' (Irma, < 40 years)

out high. The contradictory signals from both body and technology heightened the perception of diabetes as unpredictable and uncontrollable.

3.1.2 | My Unruly Diabetes

While a few participants currently experienced diabetes to be 'predictable' and 'manageable', most recognised diabetes as something that could change character, be influenced, and behave in unpredictable ways (Table 2, Quote 6). Participants described the challenge of understanding the reasons behind their body's varied responses to food, insulin, or exercise, sometimes finding it confusing or even impossible to decipher. Also, emotional turmoil, such as stress, trauma, or grief, was experienced as potentially 'altering the diabetes' to behave in new and unpredictable ways, for example, by not responding to insulin as expected and thus remaining with high glucose levels. As such, diabetes was portrayed as highly individual and always in change in ways that was 'beyond reason' or 'difficult to explain' (Table 2, Quote 7). This unruliness was depicted as particularly frustrating when it hindered desired activities such as sports, social activities, or having a good night's sleep.

3.1.3 | Steady Levels, Better Body

When reflecting on the experienced value of a 'well-managed' and 'stable' diabetes, the participants pointed out bodily experiences such as more energy, better sleep and more 'clear thinking' (Table 2, Quote 8). Following a self-described 'negligent period', one participant described how he had realised that not attending to his diabetes made him feel much worse both physically and mentally than to make diabetes a priority. Subsequently, this participant had experienced success in predicting and managing the body and diabetes via sensor and pump. However, despite their strong desire to better control diabetes and achieve lower and/or more stable glucose levels, some participants continued to grapple with maintaining habits and reaching their desired outcomes.

TABLE 3 | Illustrative quotes from theme 2.

Theme 2: Inescapable diabetes		
#	Sub-theme	Quotes
9	My life is more than diabetes	'And I believe—at least I've always been told—people have always had the perception that I wasn't sick, and it has been extremely important for me to maintain that perception people had of me because I never thought of myself as sick either.' (Julie, < 40 years)
10		'It's like a branch on the road. It's not really a big problem when you see it, and every once in a while, you might stumble over it, and then things go wrong. It's not a catastrophe in any way. It's just another obstacle on the path of life that you have to jump over from time to time.' (Jacob, < 40 years)
11		'There are some days when I just find it difficult to get out of bed because it hurts so much [due to chronic pain]. And I also know that it's not good because it means I can't go out and get some exercise or maintain an activity level that helps manage my diabetes better. So, it's a constant struggle, balancing how much my body can endure and how my diabetes can be managed under these circumstances.' (Victor, < 40 years)
12		'When I'm at concerts there are usually some quiet songs, and it's almost a guarantee that during one of those quiet moments, the sensor runs out of power. The alarm goes off—something happens. There's no warning, and then it just beeps really loudly. So now I put it in my bag where I can't hear it.' (Linda, > 40 years)
13		'I remember when I wasn't that aware of my diabetes, then I worried a lot about that. But right now, that I know that I do what I can to avoid later consequences, I'm not really worried because anyway I'm doing my best, so why should I be worried. That's the max what I can do.' (Irma, < 40 years)
14	What works for me	'In addition to school I worked like 40 hours or kind of full time. During the night, I worked as a bartender to like get enough money for a living. And I also needed to like finish my degree and study a lot, and of course I wanted to go out sometimes. So, it was super hard to keep my life together and also of course because a lot of stress my blood sugar was horrible. And I remember at that time I didn't really have time to do any exercise, or go for a run, or gym or something. So that also caused some problems as well the diabetes.' (Irma, < 40 years)
15		'I just want to say, I'm not one of those really diligent people who inject themselves all the time. I inject myself too little—I know that. I try to do it like three times a day.' (Susanne, > 40 years)
16		'So, it means something to me, and it makes me conscious of it right now when I have my daughter. I eat a bit more, if you understand, in that way, so my blood sugar is higher. Because I simply feel that getting tired, well, I can relate to that. But dealing with low blood sugar is not something a three-year-old daughter—soon to be four—should have to deal with. So, I make some conscious life choices—and I must say, my dear professor has also been a bit after me… That it went too far up now. In that way.' (Anders, > 40 years)

3.2 | Theme 2: Inescapable Diabetes

This theme describes the different ways the participants situated and navigated diabetes as constant and inescapable in their everyday life. The subtheme 'My body is more than diabetes' describes how other aspects of the participants lives required their attention, and the subtheme 'What works for me' describes how participants found ways and routines that could make diabetes fit into their everyday lives.

3.2.1 | My Life Is More Than Diabetes

While on one hand recognising that diabetes is a chronic condition, many participants rejected categorising diabetes as 'a disease' (Table 3, Quote 9). They believed such categorisation would require disproportionate attention to diabetes compared to other issues in their lives. Rather, they formulated diabetes as 'a presence in my life' or 'something I will have with me forever'. However, all described how the nature and acceptability of this 'presence' could change over time (Table 3, Quote 10). This ties to the fact that diabetes must be managed and navigated alongside all other issues that life has to offer, and it did not always have a privileged position compared to family, work, mental health, or financial issues. For example, one participant described how the main issue in his life currently was that his son was getting involved with 'the wrong crowd' and that situation was more important than 'time-in-range'. Another participant in her 40s admitted to a current state of 'semi-denial', prioritising her stress-related mental health issues over diabetes. Others described having several health issues to attend to, for example, how chronic fatigue or ADHD were more impactful on everyday life than high blood sugars (Table 3, Quote 12). These issues took more attention or de-motivated diabetes self-management.

TABLE 4 | Illustrative quotes from theme 3.

Theme 3: Desire for normalcy		
#	Sub-theme	Quotes
17	The balancing act of concealment and disclosure	'Well, I actually find it to be private, and I think that thing about how everyone has an opinion. I mean, if you have low blood sugar, you get aggressive—no, I actually didn't know I did that. I mean, I don't, but people—they have this idea that you do, or should you eat that? Or should you drink that? Or what if you get high on that or...? Those kinds of things. People have a lot of opinions because diabetes is so well-known, and someone knows someone who has it, and they've heard about this and that.' (Linda, > 40 years)
18		Interviewer: 'So, are you closer to understanding why it's allowed to take up so much space?' 'Well, I'm also the type that when I need to attach my pump, change my pump, or my sensor, I attach both the sensor and pump on my buttock because that's where there's the least chance that people will notice it. Many have them on their forearm and triceps because they recommend placing the sensor there. But I've always thought that made it too visible. So, this thing about not wanting it to be visible takes up a lot of space, and I keep telling myself that it doesn't matter, and these days it's quite normal. But I don't know, I just can't bring myself to change the habits I have.' (Henrik, > 40 years)
19		'And the same goes for when I'm at concerts. Often, there's some quiet music, and it's guaranteed to happen during one of those quiet songs where I can't predict that it's the sensor that's run out of power or that the sensor needs to be replaced—something like that. There's no warning, and then it just starts beeping loudly, and I'm just sitting there thinking, "Who's the idiot that didn't turn off their cell phone and is looking everywhere else?" Right? But if I'm wearing a thin blouse, then I have a light in my belly. So...' (Linda, > 40 years)
20	The burden of planning and ownership	'At my workplace, when it's time for lunch, I don't measure it [blood sugar] or anything. I just eat and then when I am off work, I go home and see how it looks [blood glucose level]. And I know that...—my doctor has asked me to do so—it's a good idea to measure your blood sugar before a meal so you can take some insulin before you eat. But it is just not going to happen.' (Susanne, > 40 years)
21		'In my previous workplace, I was always on guard because if there were people nearby, I wouldn't do it. I would just wait and later carry my little kit in my hand and go to the restroom to take it. So yes, it has actually meant that I didn't take it at the right time.' (Casper > 40 years)
22		'Now, I've never really... I've never had a girlfriend before, and I've always found it difficult because, during intercourse, it's likely that, well... In some way, I've taken off my pump, and we haven't talked about it. I mean, it's not something I mention. And then I end up with higher blood sugar levels because I'm not getting any insulin, so... Yeah, it's a bit problematic.' (Henrik, < 40 years)

The participants emphasised that being and feeling healthy is a lot more than 'perfect glucose levels' and that feelings of joy and well-being, having positive experiences and loving family relations all counted in living a healthy life. The importance of 'balance' was often stressed in the interviews and that the presence of diabetes should not always outweigh other activities that enhanced mental and physical health (Table 3, Quote 12). Several participants enjoyed sports and physical activities which paradoxically meant that they often prioritised having a higher glucose level to be able to perform these activities.

Finally, the analysis showed how the daily navigation of the multiple desires and demands of everyday life often outweighed the more diffuse concerns about the potential diabetes-related risks and complications of a distant future. While all participants were aware of and acknowledged the diabetes-related risk of future health complications, many also emphasised that worry would be futile, as the future holds many, unpredictable scenarios. Some emphasised that 'the future is uncertain for all of us' (Table 3, Quote 13). One woman described how the late onset of her diabetes made her less concerned about late complications as she simply had 'fewer years' to develop them. However, a few participants expressed concerns about future health issues which motivated them to put diabetes self-management higher up on the agenda of all the things and issues to be managed in their everyday life.

3.2.2 | What Works for Me

Some participants considered themselves currently 'in a good place' regarding diabetes self-management. They perceived their current diabetes routines as 'successful' with diabetes 'behaving predictably' in response to carbohydrates and insulin. These participants often compared the present situation to previous periods in life (Table 3, Quote 14), where diabetes

TABLE 5 | Illustrative quotes from theme 4.

Theme 4: Diverse interactions with the diabetes clinic		
#	Sub-theme	Quotes
23	Between diagrams and dialogue	'Instead of simply stating my blood sugar is fine, it's nice that he goes a bit more specific. And that he also shows me some of the things he bases his statements on instead of me feeling that it's an estimate or a shot in the dark, that he can then say, based on these and these data points, you can see this and this.' (Mathias, > 40 years)
24		'I may need a bit more specificity directed towards the individual… yeah, like… what can we do for you, considering your high level of physical activity. Let's focus on that. That's your main concern because your blood sugar keeps staying high. Using time more wisely and perhaps a bit more specific to each individual. Instead of it being the same kind of control every time.' (Linda, > 40 years)
25	Friendly consultations, mixed outcomes	Interviewer: 'And now you have a consultation scheduled for next week? What do you expect from that consultation?' 'I expect her [the clinician] to ask how things are going and then she will look at some blood sugars and then… well, if the long-term blood sugars look good, then everything is fine. And if they are a bit too high, then you have to think a bit more. And then I will say, "Yeah, but I also need to make sure I don't crash when I'm out walking," and then it is just a bit of small talk. Because I don't really have anything I want to ask her about either.' (Susanne, > 40 years)
26		'But now I'm getting back to biking, and of course, it needs some adjustments from my diabetes side. So, I went to the dietician, and she also recommended some different things, like how to manage it, with biking and sports taking on a bigger role in my life.' (Irma, < 40 years)
27		'But sometimes, you might feel like, for instance, when it comes to seeing a dietitian, it's okay if they tell you what to count and all, and then maybe I can do it for a week, but then I just lose interest completely. So, it just doesn't work for me.' (Karen, > 40 years)
28		'Now that I have [name of doctor], I have good support. I like that he accepts my alternative approach to managing my diabetes. And he has the best of intentions when suggesting some good tools to use, right? But as I say, I don't think I need them.' (Helle, > 40 years)
29		Interviewer: 'If they were to support you in a good way, if their resources were not an issue at all, what could the clinic do for you?' 'I don't know. I think I have hoped and believed that there could be improvement for so many years, and yes, it has only turned out to be the opposite, so I have kind of stopped hoping for anything.' (Victor, < 40 years)
30		Interviewer: 'Are you motivated yourself for it to be lower [blood glucose levels], or is it fine where it is now?' 'I mean, yes, if you ask me and all, but they want it to be lower, but I just feel that when I get it much lower, I become uncomfortable.' (Thomas, < 40 years)
31		'Not really, no. I have a reminder the day before "remember to upload your blood sugar measurements. Period." So that's it, but I'm also not someone who feels the need to sit with doctors and talk to them for a long time.' (Susanne, > 40 years)

had been less of a priority, more difficult, or less motivating to manage.

Many participants described how a pragmatic approach to diabetes self-management was currently what worked for them, even though they recognised this approach as 'suboptimal' compared to official healthcare standards (Table 3, Quote 15). Many relied on routines regarding food intake and insulin administration, and common to this group was that they often intentionally accepted higher glucose levels to be able to perform activities, for example, not worry about falling while working as a scaffolder. A divorced participant described being 'on the straight and narrow' every other week but would maintain 'too high' glucose levels during custody week for his children not to experience hypoglycaemia (Table 3, Quote 16). Others described, how diabetes was high on the agenda and given relatively much attention during the week to 'let a little bit loose' during weekends.

3.3 | Theme 3: Desire for Normalcy

This theme describes participants' pursuit of normalcy by integrating diabetes into their daily lives without letting it disrupt their social interactions or define their identity.

3.3.1 | The Balancing Act of Concealment and Disclosure

Participants recurrently described engaging in a delicate balancing act between concealing and disclosing their diabetes-related activities. The nuances of this balancing act were evident in various aspects of their daily lives, reflecting a substantial impact on their interactions and self-perception. The participants articulated a rigorous effort to privately manage aspects of their diabetes care, such as blood sugar measurements and insulin administration. This discreet approach meant to keep these activities away from public inspection (Table 4, Quote 17). By doing so, they sought to maintain a semblance of normalcy in their lives, protecting themselves from potential judgement or unwanted attention, even if it meant accepting higher blood sugar levels.

Several of the participants disclosed how they in detail would plan their actions prior to participating in social events with family, friends, and colleagues. This detailed planning was a proactive measure to navigate social situations without drawing unnecessary attention to their diabetes routines. They spoke of carefully orchestrating their actions to seamlessly integrate diabetes care into their daily lives, minimising disruptions to the flow of social interactions. To avoid social stigma, many participants voiced a keen interest in not being visibly linked to their diabetes technology (Table 4, Quote 18). This sentiment was particularly vivid in one participant's description, who expressed his preference for wearing a sensor on his buttock rather than his arm, despite the clinic's preference for the latter. He highlighted the personal challenge this posed when being intimate with a woman, as it felt intimidating having the sensor in such a private area. Another participant illustrated this further by recounting how she would occasionally disable her insulin pump to avert the risk of it sounding an alarm (Table 4, Quote 19). She shared an experience of it going off during a concert venue, prompting her to sometimes proactively stop the device to avoid such disruptions.

3.3.2 | The Burden of Planning and Ownership

Through the analysis this balancing act also exposed a tension between punctilious planning and the strong wish for personal ownership of one's life (Table 4, Quote 20). Participants often felt compelled to thoroughly plan their lives to effectively manage their diabetes. However, this planning inherently conflicted with their desire for normalcy and spontaneity.

In certain situations, participants would intentionally deviate from their thorough planning, taking a temporary pause from the routine demands of their diabetes. During these moments, they would assert some kind of ‘ownership’ over their lives, and they would temporarily distance themselves from the intricate diabetes-related routines that typically had a tight grip on their daily living. This ‘parking’ was their way of reclaiming a degree of control over their lives and, in essence, disentangle themselves from the constant presence of their diabetes.

The participants' ability to temporarily shed the weight of planning and assert control over their lives reflected the intricate nature of their striving for normalcy. It showed the subtle balance they had to strike between conforming to diabetes management demands and asserting their independence (Table 4, Quote 21). This complex interplay between planning and ownership further underscored the multifaceted challenges that participants faced in their pursuit of normalcy.

The participants' desire for normalcy shaped how they dealt with in their everyday lives, hopes, and dreams (Table 4, Quote 22). These multifaceted experiences not only emphasised the complexities of living with TD1 but also emphasised the resilience and adaptability of the participants as they continued to strive for a sense of normalcy amidst their circumstances.

3.4 | Theme 4: Diverse Interactions with the Diabetes Clinic

This theme describes the participants' varied and evolving experiences with the diabetes clinic. It underscores that there's no universal approach to consultations, even though certain findings stood out more than others.

3.4.1 | Between Diagrams and Dialogue

First and foremost, the information and medical advice provided by the health care professionals at the consultation was overall regarded as comprehensible, though in some cases described as ‘medicalized,’ with a distinct focus on numbers, statistics, and graphs. For some participants, this way of communicating was regarded as the preferred method and as simply ‘stating the facts.’ They preferred the consultations to be this way, revolving around time-in-range, managing blood glucose levels, and insulin doses (Table 5, quote 23). Other participants described this way of communicating to be detached from everyday life, almost unaware of how they should subsequently integrate the advice. They expressed a desire for a more pedagogical approach (Table 5, quote 24), and thus called for personalised advice on more challenging topics, such as stress management and significant life events.

3.4.2 | Friendly Consultations, Mixed Outcomes

The participants outlined their consultations with the clinic as overall pleasant with an informal and friendly tone. Often perceived as ‘nice chit-chats,’ these interactions contributed positively to the participants' overall experience (Table 5, quote 25). Some of the participants integrated advice offered by the clinic when returning home. For instance, one woman described how the advice of a dietician had a positive impact on navigating her food intake in relation to physical exercise (Table 5, quote 26). Other participants felt that the advice given during consultations didn't significantly change their daily diabetes management. However, it made them more aware of the various ‘wrongdoers’ that were obstructing their efforts to better manage their condition. A woman gave insight as to trying to count calories for a short period of time after a consultation with the clinic, but it became too time-consuming quickly afterward (Table 5, quote 27). Usually, this had to do with some of the aforementioned experience of diabetes as 'inescapable', and thus it faded into the background when life in general took up time. For instance, one woman described her bodily knowledge concerning diabetes as more extensive than the clinicians and the advice they provided (Table 5, quote 28), and so she disregarded their advice and continued to do what she had always done in managing her diabetes.

At other times, the consultation's lack of impact on everyday life had to do with feelings of resignation towards managing diabetes. For example, one man explained how there seemed to be no solutions offered to him by the clinic concerning his ongoing periods of extremely low blood sugar during his sleep. This led to him feeling lost towards managing his diabetes in an effective way, even though he wanted to do so (Table 5, quote 29). Some participants described similar experiences, such as seeking explanations for why stress appeared to impact their blood sugar levels without being met with satisfactory answers. Others simply disagreed with the medical conclusion that their diabetes was dysregulated, holding contrary views about the state of their condition, even though they were met with doctorly opinions saying otherwise (Table 5, quote 30). When confronted with questions concerning whether the participants prepared themselves for the consultation, the answer was usually no (Table 5, quote 33). Some participants provided information as to why, usually explaining their lack of preparation with a sort of intuitive insight as to whether their blood glucose levels were too high or not. Others expressed just not having enough motivation for doing so, sometimes relating to the aforementioned experience of already knowing how to manage their diabetes.

4 | Discussion

The present study exploring the lived experience of people with T1D handling persistent hyperglycaemia highlights the critical role of caring practices in supporting people in managing their condition effectively. It provides insights into the multifaceted nature of T1D, encompassing not only the clinical aspects of the condition but also the personal experiences, societal perceptions, and psychological impacts that influence a person's management strategies.

First, the results show how participants rejected categorising diabetes as a 'disease', which could be interpreted as a result of low health literacy or avoidance behaviour. However, from a caring perspective, this rejection can be understood as an expression of individuals striving to maintain a sense of normalcy and autonomy in their lives. Looking through the lens of 'situated risk' [16], these results suggest that the rejection of disease is not a matter of ignorance but grounded in a more holistic approach to health where cultural beliefs, personal experiences, and social relationships are integral to the management and prioritisation of everyday health and disease. Caring practices should therefore acknowledge these perspectives, engaging with patients in a manner that explores their view of health. In this context, diabetes is one of many factors that must be weighed against a myriad of other issues of importance including work, family, and social network. The participants demonstrated knowledge about the relation between lifestyle choices, daily routines, and effective self-management of T1D and they acknowledged the benefits of keeping diabetes 'well-regulated'. Sometimes, these benefits were however overruled, for example, when keeping glucose levels high to be able to perform enjoyed activities. From a caring perspective, it is important to recognise and validate these personal priorities and work collaboratively with patients to find a balance between effective diabetes management and quality of life. To provide person-centred care for people like our participants, these prioritisations of the risks of T1D must be acknowledged and rather than attempting to correct an 'inadequate understanding' of the condition, clinicians must engage in their patients' situated risk scenarios where the love for family pizza nights, enjoying busyness at work or concern about one's teenager may overrule clinical concerns. Thus, this study resonates previous research calling for the importance of emphasising personal experiences and situated risk assessments in the management of T1D [25].

Second, the psychosocial aspects of living with T1D found in our study, such as the roles of social support, stigma, maintaining control, and striving for a semblance of normalcy, are well-documented in existing literature [1, 26–28]. Navigating life with T1D involves decisions about whether and how to disclose their condition, particularly in settings like the workplace [29, 30]. Factors influencing this decision include the need for medication during work hours, the impact of the condition on work performance, access to support, potential stigma, and the prevailing organisational culture [27]. Our findings further reveal how disclosure is not simply a 'yes or no' decision but a complex continuum of choices that impact a person's well-being and sense of being cared for. While many participants described a general openness with family, friends, or colleagues, they often chose a more selective disclosure, mainly in regard to the problems and frustrations that accompanies living with T1D. Moreover, this selective disclosure continues to the diabetes clinic, where some of the participants choose to discuss only issues directly related to diabetes management, leaving out other aspects of everyday life that might directly or indirectly impact their T1D. This selective disclosure underscores the importance of establishing trusting, caring relationships between healthcare professionals and patients, where individuals feel safe and supported in sharing all aspects of their lives. It also raises questions about how healthcare professionals can ensure they have full access to their patient's life world, in order to engage in more holistic dialogues about everyday life and diabetes management. Understanding the nuances of this disclosure continuum is important for developing holistic approaches to treatment and support that recognise the complex aspects of living with T1D. Our study highlights the importance of acknowledging these disclosure practices as central to the management of the condition.

Third, our findings add to the growing body of research that attend to the experienced 'unruliness' of diabetes. From a 'situated risk' perspective, in these situations the object of risk, diabetes, is a shapeshifter that may change from without warning. Similarly, Wijk and colleagues, recently described the frustrations of people with T1D with unexpected glucose levels that changed from day to day [31]. Similarly, our results document the experienced frustration when agreed-upon diabetes management strategies fail to have the expected effects due to the experienced unruliness of diabetes. Caring practices should involve acknowledging these frustrations and providing empathetic support, helping patients navigate these challenges without judgement. While practical and informational errors that may result in failed diabetes management are essential to identify and address in clinical encounters, continued focus on investigating the patients' lived experience of unruliness and take them at face value will be fruitful. As glucose regulation frequently can be a trial-and-error experience that is influenced by many issues like stress, sleep, ovulation, and even beyond. This speaks in favour of continuing to collectively investigate the unruliness of the individual person's diabetes and assist them in experimenting with and finding individually acceptable solutions if possible.

A strength in our study is the use of qualitative methods to thoroughly investigate the complex beliefs, attitudes, and behaviours associated with unexplained hyperglycaemia, offering detailed insights into the psychosocial and cultural factors at play. To enhance trustworthiness, we maintained reflexivity throughout the research process, employed researcher triangulation to challenge the material and initial interpretations, and aimed to provide a transparent and thorough account of the decisions made during the entire research process. Dependability was addressed by keeping detailed notes of methodological decisions and the analysis process. However, although telephone interviews facilitate access to a wide array of participants and may encourage more honest disclosures, they also present challenges in capturing nonverbal communication and establishing rapport. Moreover, the present study faced potential selection bias due to recruiting from a specific clinic list with a low response rate, yet purposeful sampling was employed to achieve sufficient information power [32]. Future research should include broader minority representation.

5 | Conclusion

This study reveals that managing T1D is not only about knowledge gaps but also about navigating daily life complexities and contextual or situated risks. Through a caring perspective, we uncover the nuanced 'continuum of disclosure' where people with T1D manage privacy around their condition. Additionally, the perception of diabetes as 'unruly' reflects its unpredictable nature, resisting even well-informed self-care strategies. It is therefore essential for healthcare professionals to engage in compassionate, patient-centred care, understanding their patients' life worlds and genuinely validating their experiences to effectively support both regulated and dysregulated diabetes.

Author Contributions

Berit Kjærside Nielsen, Annesofie Lunde Jensen, Steen Bønløkke Pedersen, Sten Lund and Stina Lou contributed to the conceptualisation, design, and planning of the study. Berit Kjærside Nielsen and Stina Lou conducted the interviews. Berit Kjærside Nielsen, Stina Lou and Anna Ryberg independently analysed the data, and the entire research team participated in discussions to consolidate the analysis. Berit Kjærside Nielsen and Stina Lou wrote the original draft, and the remaining authors contributed to the revisions and final approval of the manuscript.

Acknowledgements

The authors wish to thank Mette Holsting and Liselotte Fisker who contributed with engaging clinical discussions throughout the project, connected us with the clinic, and invited us to morning meetings where we gained new insights that helped inform the study. Most importantly, we extend our warm gratitude to all the participants who took the time to share their experiences with us.

Ethics Statement

According to the Committee on Health Research Ethics in the Capital Region of Denmark, ethical approval was not required for this study, given its absence of involvement with human biological materials. The study was registered in the Internal directory of research projects in the Central Denmark Region (r. no. 1-16-02-189-22). Adhering to ethical principles outlined in qualitative research with human subjects, participation in interviews was voluntary and based on informed consent.

Conflicts of Interest

The authors declare no conflicts of interest. Three of the co-authors are employed at Steno Diabetes Center Aarhus, from where the study originates.

Data Availability Statement

The data presented in this study are available (in Danish) on reasonable request from the corresponding author. The data are not publicly available due to confidentiality.

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Appendix 1

Semi-Structured Interview Guide

Topic	Questions	Notes
Introduction and purpose of the study	The study aims to understand what daily life is like for people with Type 1 diabetes who often have high blood sugar levels that are hard to control. It focuses on their thoughts and feelings about living with diabetes and their experiences with healthcare.	Ensure participants are informed about consent and confidentiality.
Background and daily life	Could you start by telling me a bit about yourself? (age, living situation, daily activities)	Collects demographic.
Diabetes history	Before we talk more about your daily life now, can you tell me a bit about when and how you were diagnosed? How would you say type 1 diabetes impacts your everyday life? What equipment do you use to manage your diabetes? How often do you check your blood sugar? Have there been times when diabetes has affected your daily life more significantly?	Establishes background information on diabetes onset, management, and impact over time.
Everyday life and diabetes	Can you walk me through a typical day and explain when diabetes comes to mind or requires attention? Are there times when you forget or deliberately ignore your diabetes? Are there any particular worries or future concerns you have about diabetes? Could you describe any triggers or situations where managing diabetes becomes more challenging?	Discusses how diabetes is integrated into or disrupts daily routines and explores specific challenges and concerns.

Appendix 1 (Continued)

Topic	Questions	Notes
Interaction with healthcare services	Do you attend regular check-ups for your diabetes? Where do you go, and what are those visits like for you? Could you describe your last check-up or follow-up appointment? Do you feel healthcare staff understand you and take you seriously? What would an ideal level of blood sugar control look like for you, and how could healthcare professionals better support you?	Focuses on interactions with healthcare providers and any perceived support or gaps.
Support and community	Are you part of any community or group with others who have type 1 diabetes? Is there anything else you would like to add or anything you expected to discuss that we haven't covered?	Explores social support and any unmet discussion needs.
Closing	Thank participants for their time and input.	