



Living with Type 1 Diabetes as Experienced by Adults with Prolonged Elevated HbA1c: A Qualitative Study

Ingrid Wijk · Susanne Amsberg · Sissel Andreassen Gleissman ·
Eva Toft · Therese Anderbro · Unn-Britt Johansson

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ABSTRACT

Introduction: High HbA1c levels in type 1 diabetes (T1D) are associated with increased risk of micro- and macrovascular complications and severe diabetes distress. A more comprehensive understanding of the adult perspective of living with T1D can improve the quality of care. We aimed to describe experiences of living with T1D as an adult with prolonged elevated HbA1c.

Methods: Thirteen adults with T1D and HbA1c > 60 mmol/mol (7.6%) for at least 1 year were individually interviewed via a digital

platform. The interviews were transcribed verbatim and analyzed using qualitative content analysis.

Results: The analysis identified an overarching theme, “a lifelong follower”, and generated two main categories describing study participants’ experience: constraining and manageable. Constraining experiences were explained in obligated control, loss of control, environmental impact, and consequences of diabetes. Manageable experiences were described in everyday life, approach to diabetes, and support in life. Diabetes knowledge in health care and in the general public, and individualized care were important factors in feeling understood, safe, and supported.

Conclusions: The findings revealed the diverse experiences of adults with prolonged elevated

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I. Wijk (✉) · U.-B. Johansson
Department of Health Promoting Science,
Sophiahemmet University, P.O. Box 5605, 114 86
Stockholm, Sweden
e-mail: ingrid.wijk@shh.se

S. Amsberg
Department of Health Care Sciences, Marie
Cederschiöld University, Stockholm, Sweden

S. Andreassen Gleissman
Department of Nursing Science, Sophiahemmet
University, Stockholm, Sweden

E. Toft
Department of Medicine, Ersta Hospital, Stockholm,
Sweden

E. Toft · U.-B. Johansson
Department of Clinical Sciences and Education,
Södersjukhuset, Karolinska Institutet, Stockholm,
Sweden

T. Anderbro
Department of Clinical Sciences, Danderyd
Hospital, Karolinska Institutet, Stockholm, Sweden

T. Anderbro
Department of Psychology, Stockholm University,
Stockholm, Sweden

HbA1c. Living with T1D, a lifelong non-chosen follower, could be perceived as constraining but manageable in different degrees. A person-centered care approach addressing both dimensions may be beneficial. Experiences of living with and managing diabetes are multifaceted and intertwined with life context and medical prerequisites.

Keywords: Adults; Content analysis; Experiences; HbA1c; Qualitative research; Type 1 diabetes

Key Summary Points

Why carry out this study?

Adults with T1D and high HbA1c are at greater risk for long-term complications, mental comorbidity, and distress.

The patient perspective is essential in care development and in society.

This study aimed to describe experiences of living with T1D as an adult and with prolonged elevated HbA1c.

What was learned from the study?

A spectrum of experiences were described involving constraining and manageable elements.

In this study, individualized care, and diabetes knowledge in health care and in the general public were key areas for feeling supported.

Exploring the constraining and manageable factors that each person with T1D experiences is part of a person-centered care practice.

complications is well known [1, 2]. A third or less of adults with type 1 diabetes (T1D) are within the general treatment targets in Sweden and in many other countries [3, 4].

The increased risk of mental health comorbidity and distress among individuals with T1D [5] has been addressed in recent guidelines [6]. Diabetes distress is the emotional stress of living with and managing diabetes [7]. The prevalence of high diabetes distress is 20–30% in individuals with T1D and is associated with higher levels of HbA1c [8]. The association is more pronounced than the link between depression and glycemic levels [9, 10]. Moreover, microvascular complications and high HbA1c are significant predictors of severe diabetes distress [11].

In the DAWN2 study health care professionals (HCPs) acknowledged the importance of psychosocial support in diabetes care. Still, only half of the participating HCPs asked patients about the impact of diabetes on their lives [12]. Furthermore, Litterbach et al. [13] showed that people with T1D want the HCPs to be more knowledgeable about the perceived obstacles in life with diabetes.

Experiences of living with T1D have mainly been described from the perspective of adolescents [14–16] and young adults [17–21]. Recent qualitative research has generated a more profound understanding of the adult perspective in different areas: diabetes burnout [22], key factors for reaching treatment goals [23], and experiences of a long duration of diabetes [24, 25] and of diabetes care [26]. Persson et al. [27] explored attitudes and experiences regarding self-management in adults with suboptimal HbA1c using insulin pumps. However, the experiences of adults of a wider age range and with high HbA1c over an extended period have not been studied extensively.

There are indications that diabetes distress is associated with high glucose levels. In addition, high levels of HbA1c are linked to an increased risk of micro- and macrovascular complications. Consequently, we were motivated to gain a deeper knowledge of how persons with elevated HbA1c perceive life with T1D. Qualitative findings can contribute to an increased understanding and identify need for support which

INTRODUCTION

The association between long-term high glycosylated hemoglobin (HbA1c) and the development of micro- and macrovascular

are essential conditions for further care development. Moreover, society's understanding of what it means to live with T1D may improve. Given these arguments, the study aimed to describe experiences of living with T1D as an adult with prolonged elevated HbA1c.

METHODS

Design and Study Participants

A qualitative interview study with an inductive approach was conducted. Advertisements with study information were placed in a waiting room in an endocrinology clinic, on the website of a patient organization in Sweden, and on social media in groups for persons living with diabetes. Seventeen individuals registered interest in the study via e-mail to the research group. Further contact was made by telephone or e-mail (first author IW). The inclusion criteria were age ≥ 18 years, duration of T1D > 2 years, and HbA1c > 60 mmol/mol (7.6%) for at least 1 year. The inclusion criteria were self-reported. The ability to understand and speak Swedish was also required. Detailed information about the study was later sent by post, together with a written consent form to be signed and returned if the individual was still interested in participating. Fourteen individuals returned written informed consent forms and dates for the interviews were sequentially scheduled. One participant withdrew from the study before the interview. The remaining 13 study participants were from nine health care regions (of 21) from north to south of Sweden and included persons from urban and rural areas.

Procedure

A semi-structured interview guide was developed (see the appendix in the electronic supplementary material) on the basis of previous research and in collaboration with two persons living with T1D. Invitation links to digital video interviews and manuals of digital meetings were sent in e-mails to participants. The digital meeting room was secured and only accessible

to the interviewer and the participant being interviewed. The interviews were audio recorded with separate dictaphones and were performed between May and September 2022. Conducting the interview digitally for practical and technical reasons was impossible in two cases. These two interviews were performed via telephone with no video. The length of the interviews ranged from 30 to 80 min [mean (SD) 47 min (18 min)]. Two researchers with backgrounds as diabetes nurses performed the interviews (first author IW, 8 interviews; second author SA, 5 interviews). The semi-structured interview guide was followed in each interview with a variation of follow-up questions depending on the study participant's replies. The audio recordings were transcribed verbatim by IW and SA.

Inductive Qualitative Analysis

The transcribed data were analyzed using qualitative content analysis. The framework of Graneheim and Lundman was applied [28]. The research group (IW, SA, UBJ, SAG) read the material repeatedly as a whole, and thereafter meaning units were selected, condensed, and coded (IW). The codes were labeled close to the text and were divided into subcategories. This process was performed back and forth from the data material and led to the final categorization with a higher level of abstraction [29]. A map was created to show how the categories were built and to summarize the findings (Fig. 1). The coding and the categorization were discussed several times in the research group to strengthen conformability and credibility. Two research group members (UBJ and SAG) were experienced in qualitative research. The study is reported according to the COnsolidated criteria for REporting Qualitative research (COREQ) checklist [30].

Compliance with Ethics Guidelines

This study complies with the guidelines of the Helsinki Declaration [31]. The participants were informed that participation was voluntary, confidential, and that they could withdraw

from the study anytime. Oral and written information was given about the study’s aim and procedure. Written informed consent was collected from all participants. The study was approved by the Swedish Ethical Review Authority (Dnr 2022-00754-01 and 2022-02793-02).

RESULTS

Participant characteristics are described in Table 1. Five men and eight women with a mean age of 52 (SD 16.5) years participated in the study. Half of the participants were diagnosed before 18 years of age, and the duration of diabetes ranged from 5 to 50 years. All but one participant used a sensor-based glucose monitoring system (this participant used self-monitored blood glucose) (Table 1).

Theme: A Lifelong Follower

The common thread running through the categories was the overarching theme—a *lifelong follower*. The presence of T1D was static throughout life but the impact on life was dynamic. The described experiences of the participants were divided into two main categories,

constraining and manageable. Although these are separate main categories, the aspects are usually experienced simultaneously. For some participants, the main point may lean towards constraining, whereas manageable is more accurate for others (Fig. 1).

Main Category: Constraining

Participants described life with T1D as constraining in several aspects. This main category were constructed of the following categories: feelings of obligation and loss of control, environmental impact, and experiences of consequences. These categories were built from the subcategories labeled in Fig. 1 and described in the text below.

Obligated Control: Feeling Like You Have to Be in Control

Several participants described life with diabetes as never being free. The disease is unrelenting, needing attention around the clock: *“it’s a full-time job, and you can never take some time off... you can’t seem ever to pause diabetes, as it is always there”* (Interviewee 13). Another common reflection was to always be one step ahead. There was a constant need for planning and

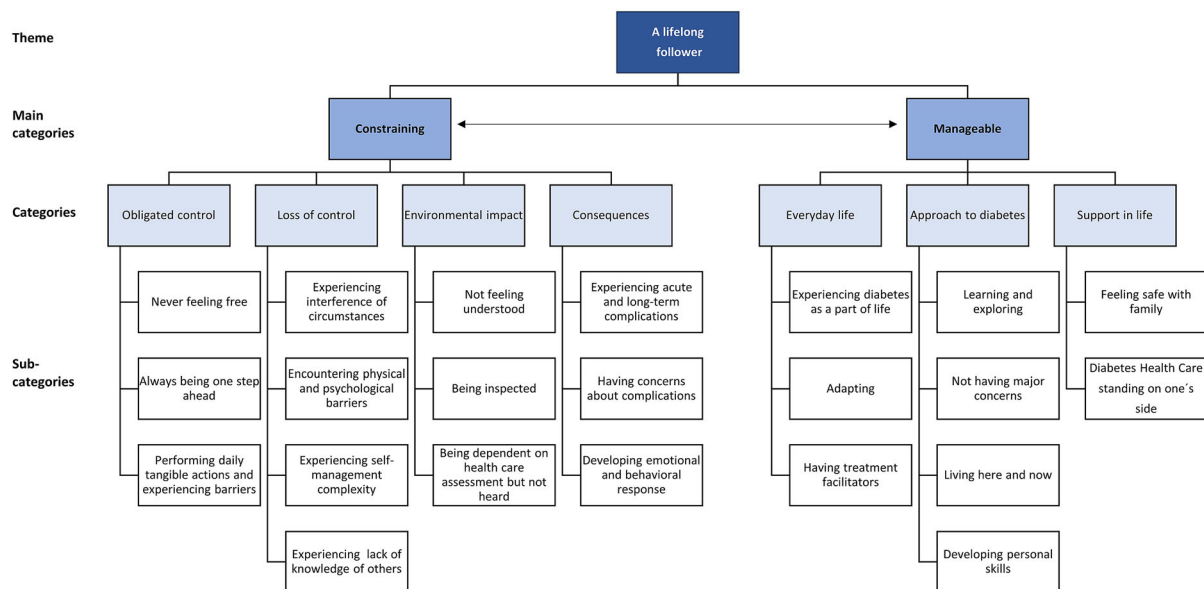


Fig. 1 Map of experiences of living with type 1 diabetes with prolonged elevated HbA1c

Table 1 Characteristics of the study participants

Characteristics	<i>n</i> = 13
Age (years), mean (SD), range, median	52 (16.5), 27–80, 48
Women <i>n</i> (%)	8 (61.5)
Duration of diabetes (years), mean (SD), range, median	28.2 (13.7), 5–50, 28
Diagnosis before 18 years of age <i>n</i> (%)	7 (53.8)
Diagnosis between 18 and 40 years of age <i>n</i> (%)	5 (38.5)
Diagnosis after 40 years of age <i>n</i> (%)	2 (15.4)
rtCGM/isCGM <i>n</i> (%)	12 (92.3)
CSII <i>n</i> (%)	6 (46.2)
Post-secondary education <i>n</i> (%)	
University	2 (15.4)
Vocational	4 (30.8)
Working <i>n</i> (%)	6 (46.2)

SD standard deviation, *rtCGM* real-time continuous glucose monitoring, *isCGM* intermittently scanned glucose monitoring, *CSII* continuous subcutaneous insulin infusion

imagining different scenarios in advance, both in everyday life and on special occasions. It was also described as problematic to be spontaneous and just to come along and join activities: “*can’t just get away as you used to... I can do spontaneous things but then sort of plan certain things around it...yeah, it can be a bit more complicated, yeah*” (Interviewee 12).

When living with diabetes, several self-care activities must be performed daily such as taking insulin, checking glucose levels, caring for injection sites, healthy eating, exercising, blood testing and other assessments, health care visits, making sure to have medicine and materials for technical aids, bringing along fast carbohydrates (dextrose), maintenance of equipment, having extra material (for technical aids) at hand, caring for the feet, managing hypo/hyperglycemia, planning and keeping all actions

in balance. Some participants reported experiences related to performing self-management as constraining, feeling demands of having complete control, and mentally draining. Identified obstacles relating to technical aids were when the technical equipment did not synchronize with life. Some participants experienced it as a physical barrier such as having something attached to the body. One participant experienced the continuous glucose monitoring (CGM) device as a source of stress because: “*you can see the blood sugar all the time...*” (Interviewee 9). For some, trusting in the technique was also an issue: “*Yeah, it is the pump. Yeah, I don’t trust it. I know how much I should have on each unit after all these years, but it doesn’t work in that way at all... it usually tells me how much insulin I should take, but that doesn’t seem right... I usually get low instead, it’s not much fun*” (Interviewee 2).

Loss of Control: Feeling That You Do Not Have Complete Control

Participants had experienced the impact of numerous factors on their glucose levels that were impossible to control, as many things in life affect diabetes and blood glucose. External circumstances (e.g., the work situation, warm weather, or a car breakdown) can directly affect glucose levels, putting everything on hold. Other participant reflections were feeling unsafe in the outside world, including belonging to a risk group during the Covid-19 pandemic and thoughts of having limited or no access to insulin in case of a war situation. Internal factors could also impact the glucose levels to a large extent. For instance, stress, comorbidity, hormones, and pregnancy impact glucose control and make self-management more complicated: “*I get very high blood sugar when I get these bouts [of an inflammatory disease]...*” (Interviewee 1). “*So it’s how you feel as a whole...both physically and mentally actually, how it affects you more than you think*” (Interviewee 8).

Managing T1D is complex. Some of the participants experienced unpredictable glucose levels. Even if everything was done in exactly the same way on different days the glucose levels could end up being different. Some participants felt insecure about their capability, such as when carbohydrate counting did not to

work: “you feel all the time uh...like uh you have done something wrong or that you are somehow not good enough to treat this diabetes” (Interviewee 6).

Most participants reported a lack of knowledge in the general public and health care services. One participant lost a job because of a hypoglycemic event, and the staff at the workplace feared it would happen again. Several participants mentioned feeling unsafe because of the public’s lack of knowledge if something were to happen: “many places you can feel unsafe because you think like this that uh...people don’t know what to do if I get really sick now; they might think I’m drunk or affected by some drug or...” (Interviewee 6). Some noted that people often do not know the difference between T1D and type 2 diabetes (T2D). Most participants also pointed out a lack of knowledge in health care outside the endocrinology unit. Participants had experienced that other health issues were ignored, not thoroughly investigated, and explained as diabetes-related by health care personnel. Some participants had experienced mistreatment or misjudgement caused by a lack of knowledge about diabetes: “Then I was sent for MRI, and by then I had been on medications for 6 months with pills for foot pain. And then they saw I had Charcot foot” (Interviewee 1). The perceived lack of knowledge could sometimes lead to low confidence in the health care system and feelings of insecurity.

Environmental Impact: Feeling Affected by the Effects of Others

Several participants have had feelings of not being understood. People generally had little understanding of the extent of the disease and the impact T1D has on life. Some study participants had been exposed to prejudices and sometimes annoyance when, for example, an insulin pump beeped. Diabetes was by some participants described as an invisible disease where urgent needs could be questioned: “I actually got a little angry and pulled up my shirt [showing the insulin pump] and asked, is this good enough for you?” (Interviewee 9). Not being understood could be experienced as tiring, frustrating, and stressful. Some participants were afraid of burdening anyone. In younger years, one participant chose not to commit to

someone in a relationship. Some also expressed feelings of guilt: “So you are also very much affected by how others handle it around you. So there is a certain amount of shame and guilt in this, even if it [the disease] is not one’s fault” (Interviewee 6).

Sometimes participants experienced feelings of being inspected by others. This feeling of being observed can involve the surrounding people that notice their actions and sometimes have to defend choices. These feelings can also emerge when attending diabetes health care visits. The body is the focus, where samples are taken, and assessments are performed. Some participants did not want people to know they had diabetes and did not tell their colleagues at work. Some reported sneaking away when they had symptoms of low blood glucose: “Then it has also been the case that I have sneaked about my diabetes and when I’m feeling low” (Interviewee 4).

Living with T1D entails a dependence on health care services to access treatment. Sometimes the participants reported a gap between the need for diabetes health care support and the actual care provided. This problem could occur if issues were generalized and not individualized from the perspective of the HCP. Treatment decisions must be motivated and discussed, not just prescribed, as one participant put it. Some participants expressed needing adapted and extended support because of difficulties in executive functions. Some also said that, as an adult, it was expected that issues in managing diabetes should be independently solved by themselves, which could be challenging. The demands on people with T1D could be experienced differently compared to other diseases: “It feels like there is a separate rule book regarding diabetes. Yeah, you should be able to influence so much yourself. Yeah, but now it feels like if you get bleedings in your eye, well, well, you should have managed your blood sugar better; well, you have got a wound on your foot that won’t heal; well, you should have managed diabetes better. It is like this all the time. It feels that you have to improve all the time. It never feels like you’re reaching the finish line...it’s a bit like that” (Interviewee 5).

Consequences: Experiencing Consequences of Type 1 Diabetes

Participants had experiences of long-term and acute complications related to T1D. Some had established long-term complications (e.g., retinopathy, neuropathy, and foot complications). These issues affected daily life and could result in limited mobility, impaired intestinal motility, and neuropathic pain, impacting the participants' mindset. These restrictions in everyday life might affect blood glucose. Most participants had experiences of hypoglycemia, some of which had needed health care assistance. High or low blood glucose could result in stressful bodily consequences, including pain, nausea, and severe discomfort in addition to medical repercussions. Blood glucose levels could change quickly, and when the balance was disrupted, it took time to restore it: *"If you really drop and get low blood sugar, it really takes such a long time before you're back in the game again"* (Interviewee 13).

Several participants had concerns about acute and long-term complications. One participant had thoughts about it every day, especially when blood glucose was high: *"when you know about it when you have a high blood sugar, then you realize 'wow, this is not good' and then secondary diseases and complications..."* (Interviewee 11). A sense of relief was felt if the annual diabetes control showed no signs of complications. Some felt concerned that having diabetes would increase the risk of diabetes or other diseases for their children.

Living with diabetes involves emotional and behavioral consequences. Participants believed that diabetes complicated life. One participant with adult-onset diabetes described life as new and difficult. Some participants experienced the disease as exhausting and some expressed a psychological impact on life (such as having developed an eating disorder or an intense fear of hypoglycemia). Participants requested more psychological support during life with diabetes. Some participants avoided certain activities (e.g., long trips, music festivals far from a city, and bathing because of self-management obstacles and lack of access to emergency health care). Fear of hypoglycemia could lead to neglecting insulin doses or avoiding an activity.

Main Category: Manageable

Participants described diabetes as manageable in some aspects. The categories everyday life, approach to diabetes, and support in life summarized the features of this main category. The subcategories that create the foundation for the categories are labeled in Fig. 1 and described in the text below.

Everyday Life: Feeling That Life is Ongoing

Participants believed diabetes was part of life and several described the management as a well-known habit: *"For my part...considering I have had diabetes such a long time that it is in my backbone, it's like...normal for me"* (Interviewee 11). Some expressed that daily routines helped in managing diabetes. Everyday life with diabetes was experienced as changeable, sometimes easy and sometimes difficult. Most participants felt that diabetes did not affect their social relationships.

Several participants had learned to adapt their life to diabetes or their diabetes to life. Examples could be more intensive diabetes management during pregnancy or eating sweets to ensure enduring a stressful work situation. One participant said: *"You have to adjust to the disease to feel as well as possible"* (Interviewee 1). Some participants expressed wanting to live like everyone else. Diabetes did not always have priority. Life is ongoing and other issues could be of greater importance. Some participants expressed how they put the needs of others first. As a parent, a participant with children with special needs expressed: *"I haven't had time to think about myself that much"* (Interviewee 4).

Participants experienced that modern insulin analogues and technical equipment (e.g., CGM and insulin pumps) facilitated a person's life with diabetes. These treatment facilitators may contribute to an increased feeling of security and help to support daily decision-making. The devices helped some participants overcome specific self-management barriers, such as forgetting or avoiding insulin doses. Some participants noted that having CGM was *"an incredible freedom"* (Interviewee 11) because they did not have to prick their fingers. Many participants

have experienced the positive impact of technical development over the years. Participants expressed gratitude for living in a country with insulin and advanced technical aids, without cost to the participant. Moreover, several participants discussed hope for the future. Some hoped for a cure, although this was not considered realistic for themselves but for future generations.

Approach to Diabetes: Navigating Through Life with Diabetes

Most participants described the importance of learning and exploring their diabetes. Essential items included learning from experiences, living with an illness, and finding solutions and strategies. One participant remarked: *“I want to know, I enjoy knowing... and knowledge also gives a certain peace of mind”* (Interviewee 7). Some participants searched the internet for answers, sometimes finding ambiguous information. Other participants contacted the companies providing the technical supplies to report and gain details on lacking features.

Some participants purposely downplayed the negative aspects of living with T1D: *“I think it’s important to show a bright side as well, not only that it is so hard”* (Interviewee 8). Some expressed that living with T1D did not hinder them from having a good life without constraints. Living with T1D could entail a healthier diet and increased knowledge of the body and its health status. Several participants felt they could be open about having T1D and could manage diabetes in public. Participants reported that they were often treated with curiosity and interest regarding their disease.

Some participants were not concerned about complications. Several expressed that they wanted to deal with any obstacles in the future when they actually have to face them. Participants reflected on the importance of living in the moment: *“I don’t go around and worry that much, instead, I try to live when you live sort of and then take what may come in the future...”* (Interviewee 6). For some, thinking about the future could be too painful. Participants were concurrently reflecting on balancing living in the present while being mindful of their future health.

Over the years of living with T1D, the participants acquired personal knowledge and skills. Several participants had experienced personal growth since younger years facilitating their ability to cope with diabetes: *“I was ashamed [when younger]. Today... I don’t feel ashamed at all of my diabetes”* (Interviewee 9). Participants expressed a varying degree of acceptance of their condition. Several participants declared that managing diabetes was the individual’s responsibility and that you make your own choices. Many participants described insight and awareness of the causes of their elevated levels of HbA1c. The uniqueness of each person’s diabetes was also considered by noting that diabetes management works differently for others and the experiences of living with diabetes could be diverse and linked to several factors. Participants also expressed that they had gained a deeper understanding of other people living with diseases. Some participants were involved in patient organizations.

Support in Life: Feeling That the Support is There When Needed

The participants’ families provided feelings of safety. Family members take control in acute situations and knew exactly what to do: *“It was my wife who saw it... She knows what to do... milk or dextrose or something. She knows exactly everything”* (Interviewee 2). Family support could be given by acts constituting consideration and was differentiated from surveillance. Knowledgeable friends and colleagues could also provide support and security. Diabetes communities in social media and diabetes organization activities (i.e., camps) played a supportive role according to some participants. Experiences could be shared and sometimes used to solve problems, such as lack of treatment supplies. The feeling of connection was brought up as important.

The diabetes health care team had an important supportive role for many participants. Crucial items were availability, continuity, specialist knowledge, and individualized care. Participants perceived diabetes HCPs as open to discussing treatment from the perspective of the person with diabetes: *“But now I have a great diabetes team that I really feel is on my*

side and ask yeah but what do you need?... That you can come up with a solution together..." (Interviewee 11). Participants with a long duration of diabetes had experienced a decrease of a blaming approach over the years.

DISCUSSION

This study explores the experiences of living with T1D as an adult with prolonged elevated HbA1c. To the best of our knowledge, this is one of the few qualitative studies in recent times that describe the experiences of adults with high glucose levels. People with high HbA1c are at a greater risk of complications and risk of reduced mental health and well-being. The analysis revealed two main categories, constraining and manageable, forming an overarching theme—a *lifelong follower*. The main categories show two dimensions of experiences that may exist at the same time. The findings related to constraining are consistent with other reoccurring themes in previous qualitative research, based mainly on experiences of adolescents and young adults; challenges in living with diabetes and at the same time living like everybody else [13, 15, 18–21, 27], stigmatization and ignorance in the environment [13, 15, 18–21], worrying about complications and hypoglycemia [18, 19, 21]. This underlines the importance of continuing the discussion of these issues in older age groups. Stigma perceived by adults with T1D is associated with both diabetes distress and HbA1c [32]. As noted by the participants, a closely related issue is the perceived lack of knowledge about diabetes in health care outside the endocrinological sphere and in the public. In addition, this deficiency has been noted and discussed in previous qualitative studies involving adults with T1D [13, 25]. The need for measures to raise public awareness about diabetes has been addressed [32, 33]. Furthermore, Rock [34] investigated how T2D was communicated in the media and concluded that it was not done so in a fully comprehensive manner. The role of today's media and its relationship to knowledge in conveying the differences between T1D and T2D is worthy of study. Specialist knowledge in

diabetes health care was described as crucial, which aligns with the organizational division of diabetes care in Sweden, where all persons with T1D are enrolled at endocrinology clinics. The need for general knowledge about diabetes in health care is highlighted by the late admission of children with new-onset diabetes to pediatric units [35].

Meanwhile, some participants downplayed the negative aspects of living with T1D. In this regard, Carrier and Beverly [36] aimed to reframe the negative approach when diabetes is discussed and explored positive aspects of living with T1D and T2D. Some findings from their study also agreed with the current study: connection and support in the diabetes community, increased health awareness and engagement to support others in need.

The experiences of living with T1D are diverse. Consequently, the need for person-centered diabetes care is crucial, as discussed by Ruissen et al. [37]. In a study of adults reaching treatment targets, acceptance of the disease and the ability to "master" diabetes were two key elements [23]. However, these elements may be met by those who do not achieve general treatment targets. The life context of the individual, medical prerequisites, goals, and values are inseparable and impact diabetes management. In the dialogue between the person with T1D and the HCP, it may be helpful to identify constraining and manageable factors, to find the way forward.

Strengths and Limitations

The study comprised participants from nearly half of Sweden's health care regions, which may strengthen transferability. There were no connections between the interviewers and the participants. Four researchers with different clinical and qualitative experiences were involved in the analysis process.

There may have been a risk of misclassification due to self-reported diagnosis of T1D and HbA1c. We did not have access to medical records because of the recruitment strategy. However, the qualitative approach in the study directs the focus to experiences of living with

T1D and we decided to accept the risk. Furthermore, the interview comprised background questions to ensure a diagnosis of T1D and elevated HbA1c levels. Advertising on social media and through a patient organization may have led to a biased population. Thus, people not connected to social media or those with diabetes burnout may have been missed in this study.

CONCLUSION

The findings revealed the diverse experiences of adults with prolonged elevated HbA1c. Living with T1D, a lifelong non-chosen follower, could be perceived as constraining but manageable in different degrees. A person-centered care approach addressing both dimensions may be beneficial. Experiences of living with and managing diabetes are multifaceted and intertwined with life context and medical prerequisites.

An interesting aspect to consider in future research is how presence or absence of long-term complications may affect experiences of living with T1D as an adult. The sample for such a study may include participants outside and within glycemic target range.

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Supervision, Data curation, Formal analysis, Writing—review & editing. Sissel Andreassen Gleissman: Conceptualization, Supervision, Formal analysis, Writing—review & editing. Eva Toft: Conceptualization, Writing—review & editing. Therese Anderbro: Conceptualization, Writing—review & editing. Unn-Britt Johansson: Conceptualization, Supervision, Funding acquisition, Resources, Formal analysis, Writing—review & editing.

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Compliance with Ethics Guidelines. This study complies with the guidelines of the Helsinki Declaration [31]. The participants were informed that participation was voluntary, confidential, and that they could withdraw from the study anytime. Oral and written information was given about the study's aim and procedure. Written informed consent was collected from all participants. The study was approved by the Swedish Ethical Review Authority (Dnr 2022-00754-01 and 2022-02793-02).

Data Availability. The datasets generated during the current study is not publicly available due to the risk of identification of the study participants. According to Swedish and EU data legislation, the data can only be made available upon reasonable request.

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