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'Striving for freedom or remaining with what is well-known': a focus-group study of self-management among people with type 1 diabetes who have suboptimal glycaemic control despite continuous subcutaneous insulin infusion

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ABSTRACT

Introduction Continuous subcutaneous insulin infusion (CSII) treatment is beneficial for obtaining glycaemic control for many persons with type 1 diabetes mellitus (T1DM). Still, some individuals do not obtain improved HbA1C levels despite CSII treatment, and there is a lack of evidence regarding how psychosocial factors may influence glycaemic control. Thus, we aimed to explore the attitudes and experiences of self-management among people with T1DM and suboptimal glycaemic control despite CSII treatment.

Research design and methods A qualitative inductive design was applied, and four FGDs were performed with 37 adult men and women of various ages and duration of T1DM. All participants had suboptimal glycaemic control despite CSII treatment. Transcripts were analysed using qualitative manifest and latent content analysis.

Results and conclusion The themes *Searching for freedom and flexibility* and *Preferring safety and the well-known* illustrated the divergent psychosocial strategies adapted, which both resulted in suboptimal glycaemic control. The technical devices and their effects on glycaemic levels may be challenging to understand and adjust to fit people's lifestyles. The rapid advances of technology devices in diabetes care can potentially change peoples' lives, but is the educational support developing as fast? Multifaceted web-based education of high quality, including tailored support with a person-centred focus, is more important than ever before as the need for technical knowledge and understanding may put further disease burdens to patients with T1DM on CSII treatment.

Strengths and limitations of this study

► Despite the well-known benefits of continuous subcutaneous insulin infusion (CSII) treatment, some users still have suboptimal glycaemic control. Therefore, we interviewed patients with type 1 diabetes mellitus on CSII treatment, who had suboptimal glycaemic control, to gain further insight into their experiences.

► The use of focus group discussions produced rich and outspoken data that revealed diverging strategies, which may explain the suboptimal glycaemic control.

► Men were in the minority in the sample; thus, their experiences of suboptimal glycaemic control despite CSII treatment, may not have been fully explored in this study.

► Understanding how people with suboptimal glycaemic control, despite CSII treatment, reason and act on their self-management should be a research and clinical priority and assist diabetes care services to develop tailored support and problem solving for these individuals.

INTRODUCTION

Poorly controlled type 1 diabetes mellitus (T1DM) negatively influence people's health and social life.[1] Continuous subcutaneous insulin infusion (CSII) improves glycaemic control for people with T1DM,[2–5] even for more extended study periods.[6 7] Furthermore, insulin pump treatment is associated with lower cardiovascular mortality than treatment with multiple daily insulin injections.[8]

Despite the benefits of CSII treatment, there are remaining treatment problems. Unexplained hyperglycaemia may relate to mechanical problems with devices, poor knowledge of programming basal and bolus doses and catheter placement.[9] Fear of hypoglycaemia is a confining factor to tight glycaemic control.[10] Also, patients show

frustration with troublesome, time-consuming technical devices and dislike how they reveal their medical condition to others.[11] Furthermore, pump treatment is experienced as 'a shackle, and a lifeline',[12] as liberating but revealing,[13] and also challenging as the insulin pump enables social engagements, but brings distress of pump failure.[14] Attitudes to CSII technology include reduction of the disease burden and obtaining a sense of normality, but comes with needs to have access to support teams and supported self-management to obtain glycaemic control.[15] A systematic review suggests that HbA1c levels may be associated with diabetes numeracy among people with pump treatment, that is, individuals' capacity to interpret and calculate insulin doses impacts the glycaemic control. Furthermore, lower HbA1c levels relate to higher quality of life scores. The evidence regarding the associations between psychosocial factors and HbA1c levels among insulin pump users is however limited.[16]

Previous research shows that CSII treatment is beneficial for people with T1DM, but unfortunately, all users do not obtain glycaemic control. Therefore, further understanding of troublesome self-management among CSII users is needed to collaboratively support individuals to obtain treatment goals without increased disease burden. Therefore, we aimed to explore the attitudes and experiences of self-management among people with T1DM and suboptimal glycaemic control despite CSII treatment.

METHODS

Qualitative focus group discussions (FGDs) with adults with T1DM and suboptimal glycaemic control despite CSII treatment were conducted. The Regional Ethical Review Board at Linköping University, Sweden, approved the study (Dnr: 2011/457–31). By applying an FGD design, we aimed to use group dynamics to gather rich information about the topic within a relatively homogeneous group of participants.[17]

Setting and recruitment

Patients with suboptimal glycaemic control at two diabetes centres in the County Council of Östergötland, Sweden, were invited to participate in the FGDs before attending an educational intervention about CSII treatment. An information letter was sent to 108 patients registered at the centres, and who met the inclusion criteria: T1DM of various duration, age >18 years, treatment with CSII and HbA1c>165 mg/dL (57 mmol/mol). Exclusion criteria were: ongoing pregnancy, and severe mental or physical disease. A diabetes nurse contacted eligible participants by phone 2 weeks after the invitation letter to provide further study information if needed. Fifty persons accepted to participate and were assigned to the subsequent intervention groups. The FGDs were performed within the intervention group constellations for practical reasons. However, 13 withdrew their participation before the planned FGDs, resulting in a final sample of 37 participants divided into four FGDs comprising 7–12 people in each group. According to the information letter and for ethical reasons, reasons for not participating or dropping out were not questioned. The participants' recruitment procedure is presented in figure 1.

Procedure

The research team developed an interview guide based on clinical experience and literature, and covered views and beliefs related to T1DM, the daily life with T1DM and related self-management when having CSII as treatment. Before each FGD, researchers assured that all participants had received oral and written information of the study, confidentiality and their ability to withdraw their participation at any time. Participants also signed an informed consent form and approved that the FGDs were digitally recorded.

The FGDs were conducted by ÅH, JL and UR and took place in a private and undisturbed room at the local diabetes centre. The authors took turns in acting as the moderator and observers during the FGDs. In addition, researchers discussed the contents of each FGD
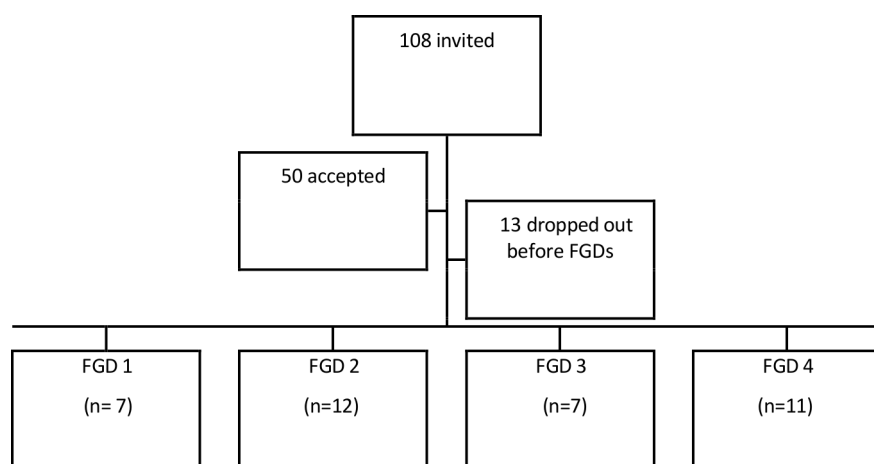

Figure 1 Flow chart illustrating recruitment process and final sample for FGDs. FGDs, focus group discussions.

to evaluate and, if needed, alter any topics in the interview guide. All FGDs were digitally recorded and lasted between 50 and 75 min.

Patient and public involvement

Patients or the public were not involved in any steps of this research procedure.

Analysis

The recordings were transcribed shortly after each FGD and checked for accuracy by researchers. An inductive qualitative content analysis approach was used to analyse the transcriptions; a suitable method to systematically explore variations in experiences and meanings.[18 19] First, the material was thoroughly read to identify content areas corresponding to the study aim. Second, meaning units addressing the aim were identified, condensed and labelled with codes. Third, the codes were compared for similarities and differences, discussed and repeatedly reviewed among researchers to form subthemes and themes representing the threads of meanings (ie, the latent content) running through the material. Three authors experienced in qualitative methodology (MP, JL and ÅH) performed this iterative review, and the preliminary findings were discussed and reformulated according to consensus between all authors to ensure credibility. Finally, two contrasting themes were identified, illustrating the strategies participants revealed about their self-management.

RESULTS

In total, 14 men and 23 women participated. The characteristics of participants are summarised in table 1. Most participants were middle-aged and had a T1DM duration of, on average, 28.5 (SD13.8) years. All had a history of suboptimal HbA1c levels at inclusion. Eighteen participants used technical devices with options to calculate carbohydrates (one man and 17 women), and 16 had devices that enabled continuos glucose monitoring (CGM) (five men and eleven women). No participant had a sensor-augmented (SAP) device.

An overview of the findings is found in table 2. The themes *Searching for freedom and flexibility* and *Preferring safety and the well known* illustrated the divergent strategies that participants adopted to manage their CSII treatment.

Table 2 A summary of the subthemes and themes

Subtheme	Theme
Life-long struggle to pass like everyone else	Searching for freedom and flexibility
Strong drive and desire to start CSII treatment	
Frequent and conscious choices to be autonomous or non-adherent	
Scepticism about technology and its opportunities	Preferring safety and the well known
CSII treatment was never requested	
Sense of security and control in old habits	

CSII, continuous subcutaneous insulin infusion.

Some participants appreciated the freedom CSII treatment provided, and frequently adjusted their treatment to suit their present living conditions, including a personal choice to be non-adherent to treatment in some situations. Others preferred the ordinary scheduled life of diabetes and predominantly used preset doses. They never or seldom used the options available within their devices and preferred to remain with their well-known habits. However, neither strategy did result in balanced glycaemic control.

SEARCHING FOR FREEDOM AND FLEXIBILITY

Some participants appreciated the freedom and the flexibility provided by the CSII treatment. After initial struggles to initiate CSII treatment, they felt that they had the freedom to live their lives as they wished and frequently adjusted their treatment to their current situation.

Life-long struggle to pass like everyone else

Several participants expressed that the initiation of CSII had meant new liberty; freedom to live life as anyone else and for example, having sleep-ins on weekends was appreciated. Before starting to use CSII, the disease and its treatment were perceived as limiting since they always had to bring the right equipment for meals and related injections. Some revealed that having diabetes during childhood/adolescence was perceived as a significant stigma. One participant said:

Table 1 Characteristics of participants

	FGD 1	FGD 2	FGD 3	FGD 4	Total
Men (n)	1	5	4	4	14
Women (n)	6	7	3	7	23
Age (SD), years	45.7 (12.6)	52.3 (13.0)	66.7 (10.5)	42.6 (12.8)	50.8 (14.7)
HbA1C (SD), mmol/mol	79 (19)	71 (9)	69 (6)	76 (12)	74 (12)
Duration of T1DM (SD), years	17.4 (11.8)	33.9 (10.8)	32.6 (15.7)	26.9 (13.6)	28.5 (13.8)

FGD, focus group discussion; T1DM, type 1 diabetes mellitus.

Who wants to sit in the lower school canteen with a syringe … to be the only one with diabetes in the whole school.

Wanting to fit in and pass as anyone else led to revolts against the scheduled life recommended by healthcare professionals (HCPs) to keep diabetes under control. Furthermore, some participants described how they had experienced work-related problems before initiation of the pump treatment, for example, the need for regular eating or the loss of their professional driving license due to the disease. Such problems diminished after starting CSII treatment and contributed to living a life like everyone else. Another relief was the social situations involving food. Eating with others had previously meant revealing their condition, a situation that often caused other people to make comments or ask questions. Several participants mentioned skipping their insulin because they were not comfortable revealing their disease when dining with others. Hence, starting CSII treatment was perceived to improve their social situation considerably. To fit in socially and choose their meals like anyone else were expressed as monumental reliefs and the flexibility of the treatment supported living a 'normal life'.

I want to be like other people. I do not want to stand out.

Strong drive and desire to start CSII treatment

Some participants described how they had read or heard about CSII treatment and quickly realised that this option would fit them. However, CSII was not always an available option, and they described how they had to argue with the HCPs several times before getting their 'permission' to initiate CSII treatment. Others chose to participate in research studies where CSII treatment was part of the trial to access the desired treatment. A few also had decided to buy their device as they thought it took too long to be equipped with the wanted treatment from the HCPs.

I have eaten, I have exercised and taken my insulin, but somehow it did not work. I could not balance (my blood glucose), and I asked for pump treatment several times. 'No, that is not for you,' they said.

After the desired CSII was initiated, participants described using many available device options to customise and adjust their treatment. A basic programme for ordinary daily life was mainly used, but they often switched to other programmes depending on the day's activities. For example, the bolus doses were frequently used depending on what food they chose to eat. Some used sensors to adjust the treatment further, and they expressed that the use of the technical devices had led to improved HbA1C from previous poorer levels, even though still suboptimal. Despite the perceived positive effects, they stressed the importance of receiving an excellent introduction to the new devices and being motivated

to learn and allocate time to test and understand all available options offered by the techniques.

I have different strategies. There are five different programs (in my device), so I can change. For example, if I am ill, I have one (programme) with a higher base level of insulin as I need that then. Or for extreme exercise, for example, when I dance all day, then I use another (programme) and then I have one (programme) that I usually use.

Frequent and conscious choices to be autonomous and non-adherent

Participants revealed making conscious choices regularly not to follow the recommended treatment, such as during driving or before going to bed. The fear of hypoglycaemia led them to disconnect the pump temporarily or eat extra without insulin adjustments.

I have had very low (blood glucose) and got scared that I would not wake up the next morning, so therefore I prefer to have high (blood glucose) in the evenings.

Situations that require social interaction could also result in conscious choices to have higher blood glucose than recommended. Conversely, risking lower blood glucose in these situations led to feelings of insecurity as mind and appearance could be affected, that is, fear of how others would perceive them in case of hypoglycaemia.

I find it (having low blood glucose) very embarrassing … It is troublesome to be in situations where you talk and meet people, and my mind does not follow. So I work on keeping it (blood glucose) higher (in these situations).

Other non-adherent situations when the pump was disconnected or the old regime of multiple daily injections was used to feel more comfortable occurred, for example, during physical activity, swimming and sexual activities. In such situations, the device was perceived as prohibitive and messy. Some women preferred to disconnect the pump when they wanted to use tighter clothes as they considered the devices too big and difficult to hide.

The pump is not practical with a summer dress; where shall I keep it? I think it is too big. My 'little black' dress does not fit properly.

PREFERRING SAFETY AND THE WELL KNOWN

As illustrated by the second theme, some participants did not appreciate nor use the flexibility of the CSII treatment. Instead, they preferred the safety and well-known aspects of the multi-insulin dose treatment. They were suspicious and uncertain of using the technology, and caregivers persuaded some to initiate the CSII treatment against their desire. These participants preferred the

safety of old habits and regimes so well embedded in their daily lives.

Scepticism about technology and its opportunities

Some participants expressed reluctance to use the options available with CSII treatment. Instead, they always used the preset basic programme settings no matter the situation. A few had tried to use the bolus doses once or twice but never regularly. The main reason for not using the technical options to individualise their treatment was the security of a familiar conservative regime. Furthermore, experiences of leakage or other technical problems had made them distrust the accuracy of the equipment. Another hesitance towards the CSII treatment was that learning to use the available options were perceived as complex and too time-consuming, and thus, no benefits of adjusting the treatment themselves were found. A sense of scepticism was revealed, that is, why change something in the treatment when it is impossible to foresee any benefits from the changes.

> I can think 'Tomorrow, I will try' [to use the options provided by the device], but I never do.

CSII treatment was never requested

When the FGD groups discussed their reasons for starting with CSII treatment, it was apparent that some participants had never had any desire for this change of treatment. The HCPs initiated the change to CSII and thus, persuaded or told the participants to change due to unstable blood glucose and poor glycaemic control as the HCPs hoped that CSII treatment could improve the situation. However, feeling 'forced' to change the treatment therapy influenced some participants' feelings and self-management. A few participants had tried CSII treatment before and were uncomfortable with the treatment and had therefore returned to the traditional multi-insulin dose regime. Still, they were once more persuaded to try CSII despite their previous negative experiences.

> They [the medical staff] have pestered me for years [to start pump treatment], but I did not want to [...], but then they persuaded me.

Sense of security and control in the well known

Some participants revealed that they had had diabetes for so long that it was hard to change their deeply ingrained habits. Over time, they adjusted to a regime that worked reasonably well and felt secure and in control of their habits; thus, they showed little acceptance for introducing the changes that came with the CSII treatment. Starting to experiment with the available options in the devices would diminish their current sense of security and control. Furthermore, some revealed that they were so accustomed to being supervised by others, leading controlled lives from the very beginning of having diabetes. Therefore, autonomy and deciding about their treatment were unfamiliar and somewhat scary. Consequently, some

participants preferred continuing along the well-beaten track even though glycaemic goals were not obtained.

> My pump treatment is very conservative and based on the treatment I had in the middle of the 80 s. Mainly the same treatment as I had before puberty [...]. It (my treatment) is so ingrained in my bones.

DISCUSSION

This study found that the participants who had suboptimal glycaemic control despite their CSII treatment predominantly used either of the strategies *Searching for freedom and flexibility* or *Preferring safety and the well known* in their self-management. Some participants appreciated the freedom and self-adjustments CSII treatment provided and revealed how they often ignored treatment adherence. On the other hand, others preferred the safety of keeping to well-known habits and regimes and consequently never or seldom used the technical options to adjust their treatment to current situations. These differing self-management strategies of T1DM and CSII treatment may shed some light on why some people with CSII treatment do not achieve glycaemic control.

Our participants revealed either a solid drive to access CSII treatment or were persuaded by HCPs to initiate the treatment; hence, HCPs appeared to impact what treatment options to use strongly. A systematic review reveals that HCP's levels of implicit bias (ie, unawareness of their negative assessments based on individual characteristics) do not differ from the general population. These biases are likely to influence all aspects of healthcare, from diagnosis to available treatment care options.[20] However, an intervention report that several individuals whom the staff did not select for CSII treatment have sufficient skills to manage education and pump treatment very well.[21] Accordingly, HCP's perceptions about people's skills may influence what treatment to offer despite the existing guidelines, perceptions that do not benefit people in need of treatment options. Furthermore, it has been shown that when patients have an option to choose their preferred treatment method (CSII or multiple daily injections, MDI), neither diabetes distress nor HbA1c levels differs between the therapy groups.[22] Thus, patients' options to choose their preferred treatment methods need to be reinforced to fight suboptimal glycaemic balance.

The stigma of diabetes negatively affects psychological well-being, self-management and clinical outcomes, as people with diabetes constantly feel monitored and judged by others.[23] Studies also report that the technical devices increase the visibility and draw unwanted attention to the disease.[13 14] Depression is also a strong predictor of non-adherence to T1DM treatment.[24] As an example, less than half (43.9%) of participants adhere to the self-monitoring blood glucose recommendations of ≥four times a day. The most commonly reported reasons for not meeting the recommendations are lack of time and

not remembering; reasons that associate significantly with lower age, shorter duration of T1DM, higher education, and full-time employment.[25]

Our participants were outspoken about their inconsistent diabetes self-management, and for some, lack of diabetes education and motivation to fully use the technical aids was expressed. Inconsistent self-management may be hazardous for people with T1DM on CSII treatment. More young adults with T1DM and CSII treatment who have hospital-treated episodes of diabetic ketoacidosis (DKA) miss premeal insulin bolus doses than those using MDI treatment. Further risk factors for DKA are pump malfunctions, social factors and lack of education.[26] Our participants were middle-aged on average. Many of our participants had a long experience living with T1DM and of suboptimal glycaemic balance, and their experiences are similar to the presented study of young adults with a shorter duration of T1DM who also struggle to find beneficial and working solutions for their self-management. Therefore, other options than standard diabetes care and support are needed to fully support people with a suboptimal glycaemic balance to find acceptable solutions to maintain their self-management without increased disease burdens, especially in social situations.

Several participants in our study revealed scepticism about the technology and its opportunities; that is, why go through troublesome and time-consuming changes without foreseeing any benefits? Frequent tensions between expectations and experiences when introducing CSII are shown in a review; on the one hand, improved flexibility and self-management but on the other hand, urges to develop skills on complex technologies that need frequent use.[27] Technical problems such as kinking and blockage of infusion sets are frequently reported and other pump malfunctions.[28] Other reported barriers to technology use are cost-related, followed by barriers related to wearing the devices, where more women than men dislike the way the devices look at their bodies.[29] Challenges using the devices when engaged in swimming and sexual activities are also reported;[30] these presented barriers and challenges may contribute to poorer outcomes and relate to the experiences our participants also made.

Some of our participants lacked diabetes education and support for their devices which may have contributed to poorer outcomes. A question to be considered—has diabetes education not kept pace with the technical development and thus, applied further burdens to users' self-management? Studies have stressed the importance of additional diabetes care support. For example, psychological support and support to find alternative strategies are emphasised for improved glycaemic control and quality of life without further increasing the treatment burden.[31] Furthermore, cognitive group therapy for depressed patients with T1DM improves depressive symptoms and HbA1c levels up to 1 year postintervention.[32] Thus, a multifaceted approach to self-management education and support may solve physical and mental problematic

situations for many patients with T1DM who show suboptimal glycaemic control. Web-based education may be an option to provide tailored education based on personal needs, group sessions and support when needed, but so far, most studies on internet-based diabetes education have focused on adolescents or parents to children with T1DM. However, a rapid decrease in HbA1C levels is reported when a customised teaching plan and web-based teaching modules are used after initiation of SAP treatment in adults, and the observed decreases in HbA1C levels remain stable over the first year.[33] Today, there is good access to internet-based services in society, and multifaceted web-based support (ie, flexible diabetes education and person-centred support) can be a possible option that suits many CSII users. In Sweden, most residents already use web-based services in their contacts with authorities and healthcare services,[34] and many have extended geographical distances to their nearest diabetes healthcare service. Therefore, a web-based educational option could be preferred. Also, group sessions provided online are more and more common, as shown during the pandemic. Person-centred diabetes education contribute to improved HbA1C levels,[35] and tailored education may fit the expectations of people with T1DM who want individualised support, provision of technological devices and adjustment of medical treatment to individual needs to obtain a good life.[36] Though, the amount of needed knowledge and understanding of the technology may challenge some pump users' hopes of a facilitated daily life and self-management.[27]

Further research in CSII treatment in T1DM should preferably explore web-based multifaceted diabetes educational interventions and their effect on diabetes self-management and glycaemic control. Another approach to the problem of suboptimal glycaemic control is to use the newer, more advanced, but also costlier insulin pumps that are sensor-augmented with low-glucose suspend, predictive low glucose suspends or automated insulin dosing. These systems need continuous glucose monitoring (CGM), which only 16 of the 37 participants in this study had. The systems are recommended today, as well as more patient education is delivered via telemedicine, especially in the era of the COVID-19 pandemic.[37]

Methodological considerations

The sample of participants strengthens the findings of this study as they represented men and women, various ages and durations of T1DM and CSII treatment, and they were cared for by different care providers. All participants had suboptimal glycaemic control, which may have contributed to a permissive discussion climate. The FGDs were moderated by experienced interviewers, which may have contributed to the open-minded discussions. However, potential limitations to the study also need to be addressed. Men were the minority in the FGDs; thus, the male perspectives of being on CSII treatment and having suboptimal glycaemic control may have been less explored. Sensitive topics, such as non-adherent

behaviour, can also be regarded as less suitable to address in FGDs.[17] There is always a risk of social desirability bias in interview studies as participants provide socially desirable and acceptable responses.[38] Despite these potential limitations, outspoken and revealing experiences were shared in the dynamic discussions; thus, we believe that such potential bias related to collecting data by using FGDs was minimised. There is also a risk in larger focus groups that fewer details may be shared as participants may feel that the available time needs to be equally distributed between partakers, but the experienced interviewers helped moderate in-depth explorations and distributions of talking time. It is suggested by Guest et al[39] that three focus groups may be enough to capture the most prevalent themes within a data collection. Thus, we believe that our four focus groups covering 37 participants were sufficient to capture a variety of experiences and address the aim of the study.

The data were initially analysed by three researchers with different professional backgrounds (MP, JL and ÅH) and discussed within the team until consensus was obtained to secure the trustworthiness of the findings. Updated medical and clinical knowledge related to the findings and the article was supplied by two of the researchers (UR and ÅE).

CONCLUSION

This study revealed diverging strategies among people with T1DM on CSII treatment which may explain their suboptimal glycaemic control. The rapid advances of technology devices in diabetes care can potentially change peoples' lives, but is the educational support developing as fast? High-quality diabetes education and tailored support with a person-centred focus are more important than ever before as the demands of technical knowledge and understanding of diabetes devices may put further disease burden on people with T1DM.

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