Beyond A1c: What outcomes matter to persons living with type 1 diabetes when it comes to adopting digital health interventions for self-management support

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Abstract

We set out to better understand what outcome measures are important to individuals living with Type 1 diabetes (T1D) in Ontario, Canada to help inform the development of the Type 1 diabetes Virtual Self-management Education and Support (T1ME) trial. To do this, we used a qualitative approach, in which we conducted six focus groups with a total of 24 adult participants living with T1D (age 18 to > 65) in Ontario. Each focus group was semi-structured in nature; participants were encouraged to talk openly about their experiences with T1D self-management and provide their perspectives on more focused topics like technology and relationships with healthcare providers. Our interpretive analysis helped us devise a framework for our results that centered around six main discussion themes: 1) adapting self-management to meet evolving needs; 2) looking 'beyond A1c' towards more personalized indicators of glycemic management; 3) the benefits and challenges of adopting new T1D technology; 4) establishing trusting relationships with diabetes care providers; 5) perceived benefits of peer support; and 6) perspectives on virtual care: pre- and post-COVID-19. Our goal is that these findings help facilitate the development of patient-oriented outcome measures that are in line with the unique needs and preferences of T1D patients in this new, more virtual landscape of clinical care, education and self-management support.

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Beyond A1c: What outcomes matter to persons living with type 1 diabetes when it comes to adopting digital health interventions for self-management support

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Abstract

We set out to better understand what outcome measures are important to individuals living with Type 1 diabetes (T1D) in Ontario, Canada to help inform the development of the Type 1 diabetes Virtual Self-management Education and Support (T1ME) trial. To do this, we used a qualitative approach, in which we conducted six focus groups with a total of 24 adult participants living with T1D (age 18 to > 65) in Ontario. Each focus group was semi-structured in nature; participants were encouraged to talk openly about their experiences with T1D self-management and provide their perspectives on more focused topics like technology and relationships with healthcare providers. Our interpretive analysis helped us devise a framework for our results that centered around six main discussion themes: 1) adapting self-management to meet evolving needs; 2) looking 'beyond A1c' towards more personalized indicators of glycemic management; 3) the benefits and challenges of adopting new T1D technology; 4) establishing trusting relationships with diabetes care providers; 5) perceived benefits of peer support; and 6) perspectives on virtual care: pre- and post-COVID-19. Our goal is that these findings help facilitate the development of patient-oriented outcome measures that are in line with the unique needs and preferences of T1D patients in this new, more virtual landscape of clinical care, education and self-management support.

Key Words

- T1D self-management, patient reported outcomes, patient reported outcome measures, virtual care

Introduction

Type 1 diabetes (T1D) is one of the most complex chronic conditions to manage on a daily basis; requiring constant vigilance through self-monitoring of glucose levels and moment-to-moment decision-making regarding insulin dosing. Until recently, T1D intervention studies focused largely on glycemic control as a primary outcome, as indicated by hemoglobin A_{1c} (HbA_{1c}) concentrations [1]. As a predictor of long-term complications, A1c levels represent a clinical indicator of the adequacy of T1D management and are used by healthcare professionals to guide management [2,3]. However, biomedical markers such as A1c can be discouraging for patients who do not achieve target glucose levels [4], which can lead to feelings of guilt [5], burnout, loss of motivation, and/or diabetes distress [6,7]. Because A1c measurement does not capture daily fluctuations in glucose levels [8], there has been a shift towards using data from continuous glucose monitors worn by patients to assess glycemic management in clinical and research settings. This includes t*ime in range*, which represents the percentage of one's time spent with normal or near-normal glucose levels. Measures such as these capture the variability in glucose levels that patients experience on a day-to-day basis and therefore may facilitate meaningful dialogue between patients and providers [9]. However, neither A1c nor time in range capture the amount of work patients invest in T1D self-management [10]. The work-load associated with T1D self-management has been compared to a 7-day a week, 24-hour a day job that involves diligent blood glucose monitoring and frequent decision-making to match insulin administration with dietary intake [11]. In addition, individuals living with T1D have to consider the impact that other aspects of daily life have on their glycemic management, including work schedules, exercise regimens, sleep, and stress [12]. Therefore, there is a need in clinical trials to move beyond clinical metrics like A1c towards outcomes that matter most to patients.

There is a growing need for interventions to improve efficacy for self-managing chronic health conditions, like T1D. Digital health interventions that promote frequent virtual communication (e.g. text messaging, emails, and videoconferencing) between patients and providers can improve both quality of care [13], and glycemic management [14]. However, there is a lack of literature to guide researchers on the outcomes that matter most to patients. Related questions include, what would make an individual living with T1D decide to use a virtual intervention? and would it actually improve their self-management experience? These questions are more relevant today than ever before given the shift towards a more virtual model for diabetes care as a result of the COVID-19 pandemic. Now, virtual care has become more commonplace in T1D care and is routinely available to patients in Canada [15], but we are still learning how to deliver virtual care in a way that best meets patients' needs.

Patient-reported experience and outcome measures (PREMS and PROMS) are being increasingly used in research studies to assess the impact of clinical interventions on patient needs [8]. Compared to traditional clinical measures, they represent outcomes that may be more meaningful to those living with chronic conditions, such as quality of life, symptoms, functionality, and physical, mental and social wellbeing [16]. Further, by capturing patients' perspectives, PREMS and PROMS provide information that cannot be otherwise assessed using classic biomedical markers and are often helpful for elucidating "why" interventions were or were not effective [17]. Beyond research, using PREMs and PROMs in clinical practice can increase shared decision-making in care [18], and improve patient experiences and outcomes [16].

We set out to establish an understanding of the lived experiences of T1D self-management, as

well as patients' education and support needs. Additionally, we aimed to assess which facets of a virtual health care intervention were important to individuals living with T1D. Finally, we aimed to identify outcomes meaningful to the T1D community that could be used to evaluate a virtual care intervention.

Methods

Context of the Study: The T1ME Trial

This qualitative study was undertaken to inform a randomized controlled trial, the Type 1 diabetes virtual self-Management Education and support Trial (T1ME Trial). The T1ME Trial aims to test a high frequency, low touch (virtual) model of care for persons with T1D. Patient partnership is a core feature of the T1ME Trial, and the Patient Advisory Committee (PAC) has been contributing to its design and implementation. Early on, the PAC members commented that the planned primary outcome for the trial (HbA1c), struck them as problematic, given that many people living with T1D dislike being 'defined' by their A1c and A1c cannot capture other, more relevant aspects of life with T1D. They asked us to explore what other outcomes might be relevant to people living with T1D, and how these inform their daily self-management practices – which was the impetus for this qualitative investigation. The goal of the study was to understand the types of outcomes that were perceived as meaningful/useful by a diverse sample of adults living with T1D in Ontario, in the context of their usual care and self-management experiences. In order for the study to inform the trial's design, we also needed to understand their education and support needs. Additionally, we aimed to identify the aspects of a digital health care intervention that were important to individuals living with T1D.

Qualitative study design

We sought to understand participants' lived experiences managing T1D along with their perspectives on self-management support, education, and outcomes, with an emphasis on virtual care. To do this, we employed an interpretive, qualitative methodology , which was exploratory in nature [19, 20], and patient-centred in its design (21). An approach of qualitative description was adopted [22].

Ethics

The study was reviewed and approved by the St. Michael's Hospital, Unity Health Toronto Research Ethics Board (# 19-201). All participants gave written informed consent.

Sampling and recruitment

Through a convenience sampling approach, we were able to include participants living with T1D from diverse sociodemographic positions, with a range of perspectives [23, 24]. Eligible participants included Ontario residents 18 years of age or over living with T1D. Participants were recruited by B.M. from multiple sources, including a diabetes clinic in Toronto, online study advertisements posted by a national diabetes organization (Diabetes Canada), and snowball sampling [24]. With the onset of the COVID-19 pandemic, participant recruitment became increasingly difficult; while we stopped at six focus groups, we feel that conceptual saturation was achieved, in that no further themes were being identified [25].

Data collection

We conducted focus groups with participants [26] either in-person (at St. Michael's Hospital, Unity Health Toronto) or virtually using video-conferencing technology (Zoom Video Communications) between January 2020 and July 2020. The shift to virtual groups was necessitated by the onset of the COVID-19 pandemic; all focus groups conducted after March 1, 2020, were conducted virtually due to COVID-19 pandemic containment measures. Focus groups lasted 60 to 120 minutes, were audio recorded and transcribed, and field notes were recorded. Participants also completed a demographic questionnaire.

We created a semi-structured focus group guide without predetermined hypotheses, rather we wanted to ground our analysis in the discussions with participants [27] and identify patient-oriented outcomes that would reflect their unique perspectives and experiences [28]. The focus group guide was developed by endocrinologists, qualitative researchers with prior experience in T1D, and individuals with lived experience of T1D (B.M, J.A.P., C.P., G.L.B., with input from the Patient Advisory Committee) (Appendix 1). The focus group guide included open-ended questions regarding participants' self-management experiences, along with questions regarding their use of various technologies, and any experiences with virtual care or incorporating technologies into their self-management. We also included a hypothetical scenario regarding a digital health (smartphone application) intervention. The objective of each focus group discussion was to encourage participants to describe their own experiences with self-management and elicit their perspectives on self-management education and support, delivered either virtually or in person. The moderators of the focus groups (B.M and J.A.P.) are individuals with expertise in qualitative research methodology, and who had previously conducted research on the topic of T1D.

Data analysis

Focus group transcripts were analyzed using an inductive, interpretivist approach [27], in which we developed a thematic framework that encapsulated our interpretations of the data set [22]. We defined themes [28], looking for patterns within and across focus group transcripts [30,31]. Building themes from the perspective of participants [22, 27], allowed us to devise a conceptual framework that reflects/portrays what life with T1D is like for them, and commonalities in their first-hand accounts.

During the course of analysis, we met periodically to discuss the evolving conceptual/coding framework and link our findings to relevant literature [32]. These analytical meetings involved input from the whole analytical team (S.D., B.M., G.L.B., J.A.P). In particular, we benefited from the guidance of our senior authors, which provided us with clinical insight from a practicing endocrinologist and health services researcher (G.L.B), along with methodological expertise in qualitative social science (J.A.P). We sought clarification of participants' responses during the focus groups (question-answer technique) [33]; additionally, we participated in discussions with our project's patient partners and we refined our interpretation of the results and our conceptual framework based on this feedback.

While our approach to analysis was inductive, interpretivist, and stayed close to participants' accounts, our analysis was also informed by theory [22]. We drew on theory as we were analyzing the first-hand participant accounts to help make sense of the evolving qualitative data set [34]. From this approach, we used theory for interpretive purposes to help build our thematic framework during analysis [22]. Our interpretations were rooted strongly in the notions of the "work" of chronic illness self-management [35], including the work entailed in managing T1D [14], and how technology

might play a role in mitigating this *work* [36]. Given our practical focus on moving beyond A1c towards (patient-centered) outcome measures that matter to people with T1D [1], theory helped us think about how a multitude of biopsychosocial factors interplay in complex narratives about life with T1D; including how factors such as "A1c," Time in Range, the T1D community and social relationships (e.g. with family, friends and health care providers) can influence one's perspective on self-management. In particular, narrative theory [37] played a prominent role throughout analysis, as we thought about how individual participant stories about the T1D experience, along with focus group dialogue, came together to illustrate broader themes related to the social context of living with T1D in Ontario. From this narrative stance [38], theory helped us think about what life with diabetes was like from the perspectives of participants and to better understand what outcomes what outcomes reflect what it means to live life with T1D.

Results

From January to July 2020, we conducted six focus groups (five virtual and one in-person) with a total of 24 participants (average of 4 participants in each focus group). Table 1 outlines the demographic and clinical characteristics of participants. In terms of age, participants ranged from emerging/young adults (aged 18 – 30) through to older adults (aged 65 and older). Time living with T1D ranged from 1 to 56 years.

Our analysis identified six main themes from participant discussions around self-management, including: 1) adapting self-management to meet evolving needs; 2) looking 'beyond A1c' towards more personalized indicators of glycemic management; 3) the benefits and challenges of adopting new T1D technology; 4) establishing trusting relationships with diabetes care providers through holistic care; 5) perceived benefits of peer support; and 6) perspectives on virtual care: pre- and post-COVID-19. Each theme is discussed in detail below.

Adapting self-management strategies to meet evolving needs

This theme relates to the learning process, in which participants described an ongoing need to adapt diabetes self-management to their evolving needs. Participants described the complex and unrelenting work of self-management. Many participants faced ongoing struggles and challenges trying to keep their blood sugar levels within a target range, *"I find it a bit of a struggle every day, to be honest… I do have low blood sugars in the early mornings, before I even wake up, pretty often."*(P11). However, as people live longer with T1D, self-management began to feel more like a "habitual" or "natural" part of everyday life. Participants explained that they achieved a sense of confidence and "control" through an active learning process guided by regular support from their health care team:

> *I feel so much more in control of what I can control, in the last six months than let's say, the first six months, cause it was [a] big, big change, at my age [mid-forties at diagnosis]… at first, I used to see the nurse and the doctor…every month …I was just learning… reading, trying to understand this new disease and how to control it. So now, I feel, I don't need them as often* (P12).

Soon after diagnosis, participants reported that they developed confidence for managing diabetes on their own, as they acquired lived experience. For example, one participant characterized people with T1D as "*ambitious people*" (P13) who have to acquire their own set of skills and

expertise for self-management, a skill set they described as being unique from the diabetes education they received from healthcare providers.

Adaptation was a key part of this skill set, as participants constantly had to adjust to new challenges associated with changing life circumstances, such as adapting to parenthood, a new job, or beginning post-secondary school in a new city:

> *One of the challenges that I'm finding is that as we age, and go through different stages of life, we have to find ways to adapt to whatever's changing. So, for instance… getting married, having children… not being able to focus solely on yourself, because you're concerned about other people now… So it's more about adapting to life as it changes.* (P14)

Participants portrayed living with T1D as a dynamic experience that occurs within a psychosocial context that fluctuates across the life course.

Looking beyond HbA_{1c} towards personally meaningful indicators of glycemic management

Looking beyond "A1c", participants spoke about the benefits of using more nuanced outcomes, such as time-in-range, to assess their glycemic management. For example, participants discussed a desire to shift the conversation with providers away from $HbA_{1c,}$ and recognized its many limitations,

> *A1c, it's an average and it's an average that doesn't necessarily tell the truth. You could be consistently at seven or you can go … up and down like a yo-yo and then, it'll still average it out to seven. It can still look like 'Oh, you're doing perfectly well.' whereas you're doing anything but well. So you can't really count on the A1c alone* (P17)

Some participants explained that they valued measures that were more relevant to their lived experience over more quantitative indicators such as HbA_{1c} or time-in-range. A key example related to the physical symptoms associated with high or low blood glucose levels (essentially how physically comfortable they felt throughout the course of a day). As one participant recounted,

> *I think a lot of it is just, I don't want to be in discomfort. When I'm high, I'm uncomfortable; when I'm low, I'm uncomfortable* (P18).

Participants also commented on how these symptoms interrupted aspects of their life such as job performance or being able to participate in hobbies.

The benefits and challenges of adopting new T1D technology

Participants reported using a range of technologies to manage their T1D, and to experience life without feeling as though diabetes was dominating their attention. One participant described how 'looping' technology saved them from having to make a "hundred thousand decisions" each day (P7). 'Looping' refers to either commercial or open-source, community developed closed-loop systems that use continuous glucose monitor (CGM) readings and algorithms to automatically adjust insulin delivery from a pump [39]. Aside from looping, participants spoke about how they used different insulin pumps, glucose monitors, and smartphone applications. Many of the participants recounted the time when they switched from insulin injections to an insulin pump as a particularly memorable moment, one that made self-management feel easier, and gave them more freedom.

I've only been on the pump for about five years. And I'm thirty years into this, and I'm kicking myself, literally. I should have been on it ten years ago. Because the impact on my hemoglobin A1c and so forth… but more, it is more convenient … and it is just a real game changer, switching over to that pump (P10).

Participants also offered their perspectives on what outcomes they would like to see if/when adopting a (new) digital health intervention. In particular, they spoke about how willing they would be to take on a new self-management support/education application. A participant characterized it this way:

If I were about to take on another intervention and you're calling it an app, I'd want to make sure that it's integrated into everyday life, and not become another task. So, I'm not adding on to the maintenance, I'm either increasing the efficiency of the maintenance or replacing some of those tasks. (P10).

This notion of *easing the burden of decision-making* was important to participants, and would factor into their willingness to adopt a new smartphone application, for example. Indeed, when talking about their 'ideal diabetes app,' many participants explained that they would love to use an application that adapted to their behavioral habits and lifestyle,

If I could have anything, in…an app or…in a dream world… it would be something …that would go 'You usually go to the gym at six pm on Tuesday. It's three pm on Tuesday. Do you want to lower your basal?' Or … 'You're often low during the night at three am, after you go to the gym… you know, stuff like that…to try and help me predict and be that little … angel on my shoulder (P18).

In addition to describing what an 'ideal' app would look like, participants reported on their experiences using a range of apps and technology, as well as accessing online information from a variety of different sources (social media, patient organizations). Although most participants described access to technology and rapid access to information as being very beneficial, some said they could feel overwhelmed at times, because of 'information overload' associated with technologies. From this perspective, a participant felt that trying to be overly precise could result in a sense of guilt or failure with glycemic management:

I think knowing your exact blood sugar can play little games with your head, I guess. You know? 'Oh crap, it's not six point seven exactly.' (P1).

Participants shared their views on using a trusted information portal or digital library that could help them find useful online resources, personalized to their individual needs. A conversation amongst participants within Focus Group 2 highlights views on the potential benefits of an information portal or technology to build community:

P7: I kind of love the idea of even like, I'm using this term really loosely, but like, an online library that has all of these resources that either our team has or other people have brought to them. … 'cause you can Google stuff, but it's nice to feel like you're getting something from a source that's a little more legitimate.

P6: The staff and the nurses at the hospital, they seemed to have a lot of knowledge,…they

> *are suggesting events, and readings and … articles, …that could benefit from being shared on such a portal.*

Throughout this discussion, responses were uniformly favorable towards the possibility of having an online portal to find trusted information, with resources that were vetted by health care professionals and T1D peers going through similar challenges. Furthermore, the potential of using an app to *build community* posits benefits for participants in this discussion group, as it can act as an outlet to share first-hand T1D information and connect people with T1D within their local community.

Establishing trusting relationships with diabetes care providers through holistic care

As participants gained experience and confidence with self-management, they said they relied less on their healthcare teams. However, most participants reported that they needed to check in periodically with their healthcare teams to keep them on track and help navigate new challenges. For instance, a participant compared their regular diabetes care visits to a "*vaccine*; (P17)" something they felt could prevent them from experiencing long-term complications. Another participant characterized their regular follow-up visits as a "*wake-up call*" (P19), which could keep them from becoming too complacent.

Participants also described the importance of building trusting relationships with their health care teams. As one participant described, their relationship with their nurses became like a "*borderline friendship* (P5)." Another participant highlighted the importance of psychosocial support given how self-management is "*entwined (P7)*" with everything else in their life,

> *The nature of being diabetic, it just gets wrapped up in everything in your life. So, I often think… my nurses … have to kind of be a therapist as well. (laugh) Because, when I go in and I say, like, you know, this week, or, 'These months have been bad, because… I lost my job.' or whatever the reasoning is. Like, it always ends up being about everything else that's going on in your life, because diabetes is so entwined in everything you do. And they are so supportive about that. And they just listen (laugh) and they let you… get your emotions out if you need to. And I find that incredibly helpful* (P7).

Although participants emphasized that frequent interactions with providers helped them stay on course with their self-care, they also noted that these interactions represented only a fraction of the time they spent self-managing and navigating through the complex social contexts of everyday life. As one participant commented,

> *When I see my endocrinologist, it's very quick…I see her for ten minutes* (P24).

Perceived benefits of peer support

Beyond the assistance offered by clinicians, participants spoke about the benefits of being involved with the T1D community and engaging with peer support. For instance, one participant explained that using social media allowed them to connect with other people living with T1D facing similar challenges,

> *And it's just more… quick, to get responses from social media, as opposed to getting appointments with specialists … Like, all these small issues that we deal with every day, not in textbooks that they [health care professionals] can't necessarily relate to. So it's good… to get different perspectives, from different people* (P8).

Connecting with others living with T1D can be helpful for patients. Indeed, participants stated that they enjoyed participating in the focus groups and talking to others about their self-management experiences as it gave them an opportunity to share views and compare knowledge,

> *This is the first time I've been invited to something like this. So thank you, … But you know, it's a pleasant surprise that there's, obviously, other [people] who are dealing with the same potential struggles. And you know… I don't know very many diabetics, so it's nice to know that there are other [people], of similar age brackets, out there, that you know, are dealing with the same things that we're dealing with* (P4).

Unlike a typical Facebook group, participants noted that our focus groups provided an opportunity for participants to interact (either virtually or in-person), and learn from one another. This positive feedback regarding the focus groups reflects the potential benefits of incorporating more peer support programs into T1D care.

Perspectives on virtual care: Pre- and post-COVID-19

A central focus of discussions was on participant perspectives and experiences related to virtual care (i.e. clinical care provided via phone or videoconference). Notably, the first four focus groups occurred before the onset of the COVID-19 pandemic and the enforcement of physical distancing measures in Canada (March 2020), which reflect a different context compared to the two later groups, when there was a far greater uptake of virtual visits for diabetes patients across Ontario. Throughout this section, we will consider virtual care across participant discussions, highlighting what may have changed due to COVID-19 or stayed the same.

Participants explained that the pandemic marked a time in which virtual visits became the new ‘normal’ , mandated by public health measures. During the pre-pandemic focus groups, participants generally agreed that a shift towards more virtual visits made sense for diabetes care, and it was already ‘*going this way in the future* (P24)’

> *I did just have, actually, a virtual appointment. It was done over the phone…and it was perfect. It saved me a very long commute. (laugh) And, we accomplished all the same things, so it was pretty great.* (P5)

Aside from physical examinations, many participants said that most diabetes care could be done virtually, and they highlighted specific advantages of virtual care, such as saving travel time and reduced time off work. However, participants questioned what might be “lost” in virtual encounters,

> *What about the human interchange factor? We're not robots…There’s always something lost in translation… I'm not sure what would be lost yet … so it's good to have the option of both [virtual and in-person visits* (P17)

Participants valued having in-person touch points with providers; physically being in the clinic made some participants feel as though they were more engaged with their care,

> *I find that when I go, I'm a hundred percent there, in mind and spirit. And you know, I feel a little bit more engaged* (P4)

However, participants noted that having trusting relationships with healthcare providers that

they have already met face-to-face in the clinic enhanced their engagement and satisfaction during virtual appointments,

> *I wouldn't mind the virtual appointments at all. Because I know my team. I've met them face to face…But, if I didn't know those people as well as I do right now, I would not be as happy doing it in a virtual environment* (P20)

Overall, participants appeared to value the ability to contact providers when urgent issues arose between clinic visits. They clarified that they did not need providers to be at their "*beck and call*" (*P4*). Rather, it was important to know that they could get a timely response from a trusted health care provider when more unanticipated situations occurred related to their self-management.

Discussion

We conducted focus groups with adults living with T1D in Ontario, Canada to better understand their self-management experiences and how they viewed virtual care (comparing perspectives both pre- and post-pandemic). Participants represented a diverse group of adults with T1D from various life stages, occupations, and duration of diabetes. Our findings illuminate some common concerns, experiences and needs of adults living with T1D at various life stages. These are important to consider, in this increasingly virtual era of diabetes care.

Looking beyond HbA1c towards more nuanced indicators of glycemic management, participants noted that using 'time in range' to identify glycemic patterns and focusing on physical symptoms associated with high or low blood glucose levels might be more valuable and practical for informing their self-management. Moreover, participants spoke about the critical role of incorporating technology within their lives to ease the burden of daily decision-making. Although participants generally spoke positively about advances in diabetes technologies (including insulin pumps, artificial pancreas/looping systems), some also expressed concern regarding information overload (e.g., CGM data). Prior research suggests that information overload can decrease sustained use of CGM devices [40]. More research needs to be done to highlight ways in which diabetes technology can decrease the workload associated with T1D self-management rather than add to it.

Participants spoke about the benefits of peer support, and leveraging the knowledge and skills of the T1D community, to learn how to adapt self-management education to evolving needs. While we acknowledge that individuals who participate in focus groups may be more likely to find benefits in peer support, this finding was similar to other studies. In their systematic review, Elnaggar et al., (2020) found that while people with diabetes primarily use social media platforms to seek information, support received through virtual communities has hidden benefits. The sharing of experiences and knowledge can serve as a catalyst for motivation and self-efficacy [41]. Similarly, in our focus groups there was also a general consensus that leveraging the support of the diabetes community (either online or in-person) was beneficial to participants by allowing them to connect with other people living with T1D who were going through similar life circumstances. Sharing experiential knowledge [42], together with motivation and support [43], could contribute to the improved glycemic management, as was observed by Liu et al. (2022) among those engaged with mobile peer support [44]. Therefore, diabetes care teams should leverage the key components of lived experience and peer interactions to enhance self-management.

Mobile self-management interventions for people with T1D, have potential to improve glycemic control when paired with input from clinicians (e.g. via text messaging or other communication modalities that promote frequent patient-provider interactions) [45]. Our results suggest that patients want self-management education to "meet them where they are at" in their specific life stage, taking into account their social context. Participants recounted that in order to establish trusting relationships with healthcare teams, diabetes care providers must individualize self-management education to the person. Currently, the recognition of the need for patient-centered care has become an integral part of the organization of diabetes care within Canada, the United States and other countries [46, 47]. However, as our study findings indicate, personalized approaches to diabetes care can be tough to implement in everyday clinical practice, and mobile and/or virtual care may be the tool providers need to better connect with people with T1D and learn what their needs are outside of the clinic.

In contrast to the generally positive accounts from participants regarding virtual care, some voiced concern that virtual care could lead to less personalized care. These participants questioned whether the 'human factor' would be lost in virtual visits. However, most participants, especially those in the final focus groups (who had experienced more virtual care) saw the benefits of virtual care and thought that it was the direction in which diabetes care was moving. This is similar to T1D patient feedback during the pandemic from the United States [48] and British [49] where 82% and 72% of participants respectively wanted to use virtual care in the future.

Participants in our study spoke at length about constantly trying to find ways to adapt their diabetes self-management practices to their evolving needs, which they described as an ongoing learning process. In doing so, they often used the language of "control". Specifically, participants spoke about how the concept of being "in control" of their blood sugars can feel burdensome, especially during challenging life periods. As the term "glycemic control" is extremely popular in the diabetes literature and in clinical practice, we have reflected on the use of this terminology throughout our qualitative analysis and the writing of this manuscript after hearing from our patient partners. Using words such as "control" can leave individuals with feelings of guilt and being a "bad" patient when they are not reaching their target ranges or personal diabetes goals [50]. Moreover, the word "control" can invoke ideas of power struggles; for example, between parents and emerging adults, or people living with diabetes and health professionals. Our discussions with our patient partners about the language used reflects a greater movement in diabetes care and education towards being sensitive to issues of judgement (or even stigma) that can negatively influence clinical care interactions [51]. All healthcare interactions, virtual or otherwise, must consider that language can have significant impacts on patient well-being and outcomes [52]

One of the key strengths of this project was using a patient engagement approach in all aspects of the study. The conception, planning, design, analysis, and drafting of the manuscript was guided by people with lived experience of T1D. The collaboration with people with lived experience can improve the quality and relevance of research by focusing on the priorities set by patients [53]. Furthermore, the present qualitative study is informing the design of the broader T1ME trial. With our patient partners, we have used the qualitative results presented here to identify patient reported outcomes and experience measures to be used in the T1ME trial. Engaging patients in the study design and selection of outcomes can lead to increased recruitment and retention in trials, because study measures will be meaningful and applicable to the lived experience of the target population [54]. Aside from our patient engagement approach, conducting our research during the COVID-19 pandemic also strengthened our work. Our last two focus groups, conducted after social distancing policies were implemented, were particularly illuminating because they provided insight into patient experiences with virtual care.

Conducting our study during the COVID-19 pandemic also posed some limitations. We had to cease data collection after the sixth focus group as we were unable to continue recruiting in person at diabetes clinics. While studies have shown that virtual recruitment has benefits such as inclusion of a more diverse population [55], we found that it was much more difficult to recruit participants through advertisements and flyers compared to approaching them in clinic. We also acknowledge that there may have been an accessibility barrier for some individuals with T1D in Ontario (who may have trouble accessing technology) and these individuals may have different views compared to the perspectives shared within this study. Another limitation was that all but one of our participants lived in urban settings. Thus, our results may not fully reflect the experiences of those living in rural areas. Furthermore, our sample may be missing key perspectives from individuals who have differing views and experiences related to their socioeconomic status, ethnicity or literacy level [56]. Finally, while we recommend a holistic and patient-centered virtual care model, we understand that using virtual care has been reported to increase workload for nurse educators in some telehealth programs [57]. Therefore, effective support needs to be offered to healthcare providers in addition to patients for a virtual care model to be successfully implemented [58].

Conclusion

The COVID-19 pandemic has accelerated the move towards a more virtual model of T1D care. This move is in line with the unique needs of a diverse T1D patient population who require personalized education and timely support to help manage a relentless and complex chronic condition. In our study, we have highlighted the perspectives of people with T1D in Ontario who are trying to adapt to this more virtual landscape of diabetes care in Canada. Our findings help explore the ways in which people with T1D want technology to meet them 'where they are at' in their unique T1D journey, and provide an opportunity to think about more patient-centric outcome measures that go beyond HbA_{1c}, such as symptom control (alleviating fluctuations in highs or lows) and the patient perceived benefits associated with time-in-range. Although participants generally spoke positively about technological advancements in CGM and insulin delivery systems (CSII), there were contrasting perspectives related to the issue of *information overload*, which sheds light on the need for additional support to navigate the increasingly data-driven nature of T1D self-management. Our findings indicate that finding ways to use technology to leverage the provision of personalized support of peers, as well as providers, can help build a sense of community, and bridge the gap between the clinical care needs of individuals with T1D and the complex social context that surrounds their daily glycemic management.

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Conflicts of Interest

Dr. Shulman has received speaking and advisory board fees from Dexcom Canada

Author Contributions

BM, AN, CP, DG, MG, CMC, GL, GLB, JAP, and the T1ME PAC were integral in planning the study. BM, CP, CMC, GL, GLB, and JAP created the interview guide. BM and JAP conducted the focus groups. GM, RS, HW, CHY, and GLB provided guidance throughout the data collection process. SD and JAP conducted initial qualitative analysis. BM, SD, AN, DG, MG, SJ, GLB, and JAP conducted secondary qualitative analysis. BM, SD, and AN drafted the manuscript. BM, SD, AN, CP, DG, MG, CMC, GL, SJ, GM, RS, HW, CHY, GLB, and JAP edited and approved the final version of the manuscript. GM, RS, HW, CHY, GLB, and JAP obtained funding for this study

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Abbreviations

CGM: Continuous glucose monitor
$HbA1_c$: Hemoglobin $A1_c$
PAC: Patient Advisory Committee
PREMS and PROMS: Patient-reported experience and outcome measures
T1D: Type 1 Diabetes
T1ME Trial: Type 1 diabetes virtual self-Management Education and support Trial

Table 1. Demographic and clinical characteristics of the participants

Characteristic	**No. (%)**
Participants	24
Men	9 (38)
Women	15 (62.5)
Age ranges* of participants:	
18 to 24 years; emerging adults	2 (8)
25 to 44 years; young adults	12 (50)
45 to 64 years; middle-aged adults	7 (29)
≥ 65 years; older adults	3 (13)
Duration of diabetes at focus group	
1 to 10 years	6 (25)
11 to 20 years	4 (17)
21 to 30 years	3 (12)
31 to 40 years	4 (17)
≥ 41 years	7 (29)
Insulin administration	
Continuous subcutaneous insulin infusion	17 (71)
Open artificial pancreas system (Closed Loop)	1 (4)
Multiple daily injections	7 (29)
Continuous glucose monitoring technology	21 (88)
Occupation	

Full-time student	2 (8)
Full-time work	14 (58)
Part-time work	2 (8)
Unemployed	2 (8)
Retired	3 (13)
Place of residence in Ontario	
Urban	23 (96)
Rural	1 (4)

Notes: *Age ranges were classified based on literature looking at Type 1 diabetes throughout distinct periods of adulthood [McCarthy MM, Grey M. Type 1 diabetes self-management from emerging adulthood through older adulthood. Diabetes Care. 2018; https://doi.org/10.2337/dc17-2597]

Appendix 1 - Focus Group Guide

Introduction/Icebreaker

I would like you to introduce yourselves. Can each of you tell the group how long you have been living with Type 1 diabetes and what made you decide to join this discussion group today?

Personal experiences managing Type 1 diabetes

1. What do you think about related to your Type 1 diabetes self-management during the course of a typical day?
    - Probes: changing insulin pump sites, hypoglycemia or hyperglycemia, etc.
        - Does anything bother you about self-managing Type 1 diabetes?
        - Does your diabetes management ever interfere or intrude with other areas of your life (e.g. work, family, education)?
2. When you are self-managing your diabetes, what are you hoping to achieve? What goal(s) do you have?
    - Why are these important for you?
    - Do you have difficulty attaining these goals? Can you tell me about that?
    - What is or would be helpful in assisting you to achieve these goals?
3. What is your relationship like with your health care providers?
    - How do they help with self-management?
    - Are there any specific types of health care providers you feel closer or less close with? Why?

- How do you communicate with your health care team between visits? (e.g. email, text, phone, etc.).
- What would be an ideal way of communicating with your health care team?
- What would the ideal frequency of communication be with your health care team? Probes: daily, weekly, as needed (for example, when crises arise or you encounter a new challenge in your life).
- What are your thoughts on virtual care visits? Do you think these would be helpful for your self-management needs?
- Are there any health care supports that you are not currently receiving, but think would be helpful in managing your diabetes?

4. Outside of the clinic, are there people or other information resources you use to support your self-management?
    - Where do you go to find trusted information related to your management? Do you ever find you need more support or guidance for this?
    - What role, if any, do friends and family play?
    - Do you ever feel like you need more support outside of the clinic context? Can you tell me about that? Can you provide an example?

We are about to transition into a discussion about your use of apps generally, and health management/diabetes management apps specifically. Before doing so, is there anything else that you would like to discuss about your experiences with diabetes management?

5. I wanted to get a sense of the group's experiences with apps. Perhaps we could begin by discussing if you use apps and if so, which apps you tend to use most?
   Probes:
    - Why do you use that app? What features of the app do you find helpful? Are any features unhelpful?
    - Does anyone use health management apps? Which ones? Can you tell me about that? Do you use any diabetes related smartphone applications to help with self-management? Tell me about your experiences with these.
    - If you do not use health management or diabetes management apps, can you tell me why?

We would now like you to apply these discussions to a hypothetical situation: Technology Company wants to know if they improved a patient's quality of life

6. We would like to present a hypothetical situation to you. In this situation, a technology company has created a new smartphone application that intends to help improve the lives of people with Type 1 diabetes. However, none of the app developers has experience self-managing Type 1 diabetes and they need advice from those that do. One of the primary questions they have for you is, *if you were to use this application for a prolonged period of time, what would make you feel as though self-management became easier for you?*

Potential probes:

- What functions would you like to see in the app? Can you tell me about why those would be important for you? What impact would this have on your diabetes self-management?
- What changes in your life would you like to see and why?
- What would make you feel as though this self-management support tool was a success? What would make you feel as though it failed to make improvements?
- How could an app that allows videoconferencing with your healthcare providers address patients' self-management needs?

7. We are coming to the end of our discussion today. However, before we conclude, is there anything else that you wish to add? Anything we haven't discussed that you think is important for us to know?

Supplementary Files

CONSORT (or other) checklists

COREQ checklist for qualitative research.
URL: http://asset.jmir.pub/assets/ad25427325f68c39ca8c9e4005b57c3b.pdf