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Original Paper

Exploring the Needs and Preferences of Users and Parents to Design a Mobile App to Deliver Mental Health Peer Support to Adolescents With Type 1 Diabetes: Qualitative Study

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Abstract

Background: Beyond physical health, managing type 1 diabetes (T1D) also encompasses a psychological component, including diabetes distress, that is, the worries, fears, and frustrations associated with meeting self-care demands over the lifetime. While digital health solutions have been increasingly used to address emotional health in diabetes, these technologies may not uniformly meet the unique concerns and technological savvy across all age groups.

Objective: This study aimed to explore the mental health needs of adolescents with T1D, determine their preferred modalities for app-based mental health support, and identify desirable design features for peer-delivered mental health support modeled on an app designed for adults with T1D.

Methods: A semistructured qualitative focus group study was conducted with adolescents with T1D and parents of adolescents with T1D. Data were collected through pre–focus group surveys, including sociodemographic background, diabetes status, health care experiences, and focus group sessions, including their opinions on peer support and technology. A thematic analysis following an inductive and iterative process was performed to develop themes and subthemes from the collected information.

Results: Focus group participants included 10 adolescents (mean 16, SD 1 years; 8/10, 80% female; who had been living with diabetes for an average of 9, SD 5 years) and 10 parents (mean age 51, SD 7 years; 9/10, 90% female). Four core themes emerged: (1) experience: navigating adolescence with T1D, (2) empowerment: support systems that enabled better management of their T1D, (3) obstacles: societal barriers that affect adolescents' T1D management, and (4) innovation: adolescent-driven preferences for digital peer support platforms.

Conclusions: App-based peer support offers a promising avenue for addressing the mental health needs of adolescents with T1D. Understanding the unique support needs of these adolescents and using this information to suggest design considerations for a mental health peer support app is an important step toward addressing their complex emotional and social challenges.

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KEYWORDS

peer support; type 1 diabetes; digital interventions; diabetes distress; depression; mental health; focus groups; disease management; adolescent; parent; mobile app; mHealth; type 1; diabetes; qualitative study; physical health; psychological; emotional health; mental health support; thematic analysis; data collection; mobile health

Introduction

Managing type 1 diabetes (T1D) extends beyond physical health to include a significant psychological component [1]. This psychological aspect is often due to diabetes distress (DD), a state of emotional burden directly related to the demands of living with diabetes [2]. DD is influenced by various factors, including the complexity of diabetes management, social dynamics, and puberty-related changes (both physical and psychosocial) that occur during adolescence [3]. For example, adolescents may feel shame and stigma from visible self-care tasks, which are sometimes mistaken for illicit drug use, leading to questioning by authority figures and reluctance to engage in public self-care needs [4].

In Canada, accessing psychological support is inconsistent across provinces [5]; therefore, obtaining treatment for DD may pose a significant challenge. Barriers include uncertainties about where to seek help [6], long waiting times [7], a shortage of mental health care professionals [6], concerns about stigma [8], geographic or demographic disparities (impacting youth, rural communities, and Indigenous populations) [6], and the financial burden of services not covered by private insurance plans [5].

Peer support may present a potential solution for adolescents with T1D, especially when facilitated through digital platforms [9]. This age group is highly attuned to technology, often preferring digital interactions over in-person ones [10]. Digital platforms offer the privacy and flexibility that adolescents value, allowing them to seek support without the discomfort or stigma of face-to-face encounters. In addition, these platforms provide the convenience of accessing support at any time and from any location, which is particularly important given the financial and geographic barriers to accessing traditional mental health services [10]. These platforms also allow adolescents with T1D to tailor support to their specific needs and preferences, providing a space to share experiences, express empathy, and exchange bidirectional assistance in managing their condition [9]. However, these digital platforms should be codesigned with the target population to be effective [11].

T1D REACHOUT (The University of British Columbia) is a peer-led mobile app to support mental health, cocreated by researchers and adults with T1D living in British Columbia, Canada [12]. It offers support mechanisms, including (1) one-on-one support through a self-selected peer supporter, (2) group texting support through a 24/7 chat room, and (3) face-to-face group sessions through video huddles. The app is developed using a participatory approach, ensuring that the target population's preferences and unique challenges were at the forefront of its design. While the direct impact of this participatory approach on the app's effectiveness requires further empirical validation, the literature on digital health suggests that user engagement in design processes can enhance the relevance and usability of interventions [11,13,14].

Tailoring the T1D REACHOUT app's functionalities to adolescents with T1D may address some of the dimensions of DD. Focus groups were selected as the primary method for user engagement because they provide a dynamic environment for participants to discuss shared experiences and preferences [15]. The group setting encourages interaction, allowing adolescents to build on each other's ideas and reveal insights that might not emerge in one-on-one interviews.

Therefore, the aims of this study were three-fold: (1) to explore the mental health needs of adolescents with T1D in British Columbia; (2) to determine their preferred modalities for app-based mental health support delivery; and (3) to identify the desirable design features for a peer-delivered mental health support app for adolescents, using the existing T1D REACHOUT app as a model.

Methods

Study Design

We conducted a semistructured qualitative study involving focus groups with a convenience sample comprising either adolescents living with T1D or parents of adolescents with T1D from families receiving care at BC Children's Hospital (BCCH) or in the Interior Health. Our findings are reported following the COREQ (Consolidated Criteria for Reporting Qualitative Research) checklist [16], given in Multimedia Appendix 1.

Ethical Considerations

Ethical approval for this study was obtained from the University of British Columbia–Children's & Women's Health Centre of British Columbia Research Ethics Board (H21-01806; approval date: January 25, 2022; principal investigator: MG). Additional approvals were secured from the Interior Health Authority (IHA) and Vancouver Island Health Authority (VIHA) research ethics boards.

All participants provided informed consent (some adolescents provided assent with their parent or guardian providing consent, while others consented directly) before participating in the study. Initial consent discussions were conducted through Zoom videoconferencing software (Zoom Video Communications) or telephone to explain the study objectives and address participants' questions. Informed consent and assent were documented electronically using the REDCap (Research Electronic Data Capture; Vanderbilt University) eConsent [17,18].

All focus group recordings were automatically transcribed by the Zoom videoconferencing software and deidentified before analysis by replacing identifiable information, such as names, with participant IDs. Study data were stored securely, and only study team members could access them.

Participants received a CAD $25 (approximately US $18) e-gift card as a token of appreciation for their time and participation in the focus groups.

Sampling and Recruitment

Recruitment began in March 2022 and concluded in February 2023. To be eligible, adolescent participants had to meet the following inclusion criteria: (1) being aged 15-18 years; (2) having physician-diagnosed T1D; (3) having access to a smart device or computer; and (4) residing in the IHA region, VIHA region, or receiving care at BCCH. The decision to include diverse locations was made to capture a broader range of perspectives, with the aim of achieving a more comprehensive representation of our participants. For parents or guardians, inclusion criteria were as follows: (1) having a child with T1D aged 15-18 years; (2) having access to a smart device or computer; and (3) residing in British Columbia.

We used diverse recruitment methods: invitation emails were sent from the BCCH Diabetes Clinic to families who had authorized contact for research, and families attending the BCCH Diabetes Clinic were recruited in person; invitation letters were sent from Diabetes Educational Centers in IHA and VIHA to eligible families; and promotional flyers at diabetes clinics, social media posts on T1D-specific Facebook groups, and referrals from pediatric endocrinologists who identified participants likely to benefit from the study were also used.

Data Collection

Prestudy Survey

Participants completed a prestudy survey using the REDCap platform [17,18], administered after the informed consent process. The surveys captured the demographic and care context and the T1D challenges to contextualize the focus group results; the survey data were not analyzed thematically but served as background information only to facilitate focus group stratification and contextualize discussions. These pre–focus group surveys (given in Multimedia Appendices 2 and 3) assessed sociodemographic background, diabetes status, health care experiences, opinions and experiences with peer support, and technological preferences. Parent surveys assessed sociodemographic background, their child's treatment-related information, and health care coverage.

Focus Groups

Subsequently, participants were scheduled for focus group sessions with peers from the same health region and age group (parents, adolescents aged 15-16 years, or adolescents aged 17-18 years). Focus group sessions were conducted between May 2022 and February 2023. Each focus group session lasted approximately 90 minutes and was conducted with 2-8 participants. The focus groups were facilitated by 2 female researchers with complementary expertise (more details are provided in the *Ensuring Rigor and Trustworthiness* section). The facilitators (TST or TIY) led groups using a focus group guide (Table 1), which was designed based on the study's goals and existing literature on similar populations [4,14]. The focus group guide underwent a walk-through with the research team before data collection to ensure its clarity and relevance. This process allowed us to refine the questions, ensuring they were appropriate and aligned with the objectives of the study.

Table 1. Focus group guide: questions used to guide the adolescent and parent focus groups.

Focus groups	Questions
Adolescents	• As someone living with T1D[a], what kind of emotional or mental health support do you need? • When you are frustrated with having T1D, who do you turn to for support? • What topics or situations do you find yourself needing the most support for? • How receptive would you be to getting support from other people with TID your own age? • What are your thoughts about seeking support from slightly older people with T1D (ages 19-30 years)? • What T1D-specific social media networks have you used before (Connected in Motion, JDRF[b], Facebook groups, or any online communities)? • Demo the REACHOUT App—then ask "What did you like about the REACHOUT App?"[c] • How important would it be to have health care professionals (ie, nurses, dieticians, psychologists) involved in REACHOUT NexGEN?
Parents	• What do you worry about the most raising an adolescent with T1D? • What kind of support do you need with regard to being a parent of an adolescent with T1D? • When you are frustrated with T1D-related issues, who do you turn to for support? • What topics or situations do you find you need the most support around? • What are the issues or situations that you and your daughter/son have the most conflict about (related to T1D management)? • What T1D-specific social media networks have you used before (Connected in Motion, JDRF, Facebook groups, or any online communities)?

[a]T1D: type 1 diabetes.

[b]JDRF: Juvenile Diabetes Research Foundation.

[c]We showed participants a video of the app. Afterward, we asked the questions "What did you like about the app?" and "How important would it be to include certain features?"

Adolescent and parent focus group questions differed slightly but focused on similar topics, with the adolescent focus groups viewing a demonstration of the existing REACHOUT app. While focus groups were structured with core and follow-up questions, organic discussions were encouraged to gain further insights and clarity on specific ideas. Focus groups were conducted online through Zoom videoconferencing software, and at the beginning of the session, the facilitator discussed the session rules and privacy and confidentiality.

The focus group size was designed to allow for diverse input while maintaining a manageable and comfortable setting. The target size was 4-6 participants per group, which is generally recommended in the literature to promote rich discussion while allowing everyone to participate [15]. However, due to logistical constraints, some groups were smaller than anticipated. While smaller groups may limit diversity of opinion, they may foster a more intimate and open environment, encouraging participants to share more personal insights. Combining groups from the same age range might have enhanced the diversity of viewpoints; however, separate groups were maintained based on scheduling and participant preferences, with the smaller groups offering a more personalized discussion.

The focus groups are intended to identify key user preferences and insights that will inform future redesign efforts. The insights from the focus group will form part of the revised requirements for the app redesign based on the adult app [12].

Data Processing and Analysis

Survey responses were analyzed using descriptive statistics using SPSS Statistics for MacBook (version 29.0; 2023; IBM Corp), with frequency data expressed as count (%) and continuous data expressed as mean (SD).

To ensure the accuracy of the focus group data, audio recordings of the focus groups were automatically transcribed by Zoom, deidentified by removing names, and then further verified by TIY. A thematic analysis of the resulting transcripts followed an inductive and iterative process to develop themes and subthemes [19]. Two coders, TIY and PJ, independently coded each of the transcripts using NVivo 12 (Lumivero). The coders compared their results throughout the coding process, ensuring consistency and accuracy. In cases of disagreement, coders reviewed the relevant data together and reassessed their coding decisions. If a consensus could not be reached, TST or MG made the final decision after reviewing the codes in the context of the research questions and focus group guide. After completing the first round of coding from the last focus group, we determined that thematic saturation had been reached and decided to end the recruitment and data collection process [20]. Finally, the study team convened to discuss and establish a unified codebook, organizing the identified themes and subthemes.

Ensuring Rigor and Trustworthiness

We ensured the rigor and trustworthiness of our research through triangulation, combining prestudy surveys and focus groups to capture diverse perspectives. Peer debriefing by 2 independent coders (TIY and PJ) validated themes, ensuring consistency and accuracy. Thematic saturation confirmed no new significant themes emerged.

We documented each research step to maintain transparency and reduce bias, enhancing credibility. The team's positionality also strengthened the process: TT, with over 25 years of experience in qualitative methodologies, provided theoretical expertise; TIY, an MSc student with an MBBS, contributed clinical insights and methodological knowledge; and SP and PJ, a medical student and graduate, respectively, added relevant academic and practical experience.

Results

Participants

Out of 48 adolescents with T1D and 26 parents of adolescents living with T1D who expressed initial interest in the study, 16 of the former and 17 of the latter consented, and 10 of both groups participated in the focus group discussions. Reasons for nonparticipation (n=54) included the inability to reestablish contact after initial consent (28/54, 52%), loss of interest (7/54, 13%), scheduling conflicts (11/54, 20%), and "no show" to focus group session despite previous confirmation (8/54, 15%). Participants included parent-child dyads, parents without their children, and children without their parents.

Prefocus Group Survey

The mean age of adolescent participants was 16 (SD 1) years and they had been living with diabetes for an average of 9 (SD 5) years (Table 2). Parent participants had a mean age of 51 (SD 7) years and were mostly (9/10, 90%) female (Table 3).

Table 2. Characteristics of adolescent participants (n=10).

Variables	Values
Age (years), mean (SD)	16 (1)
Age at diagnosis (years), mean (SD)	9 (5)
Sex, n (%)	
Male	2 (20)
Female	8 (80)
Racial background, n (%)	
White	8 (80)
East Asian	1 (10)
Other	1 (10)
Insulin delivery system, n (%)	
Multiple daily injections	5 (50)
Insulin pump	5 (50)
Blood glucose monitoring device, n (%)	
Continuous glucose monitor	6 (60)
Flash glucose monitor	2 (20)
CGM[a]+lancets and strips	2 (20)
Continuous or flash glucose monitor type, n (%)	
Dexcom G6	8 (80)
Freestyle libre	2 (20)
Diabetes care provider, n (%)	
Endocrinologist	6 (60)
Family physician	2 (20)
Diabetes nurse	1 (10)
Other	1 (10)

[a]CGM: continuous glucose monitoring.

Table 3. Characteristics of parent participants (n=10).

Variables	Values
Age (years), mean (SD)	51 (7)
Sex, n (%)	
Male	1 (10)
Female	9 (90)
Racial background, n (%)	
Arab	1 (10)
White	9 (90)
Education, n (%)	
High school graduate	1 (10)
Some college or technical graduate	5 (50)
College graduate	1 (10)
Graduate or professional degree	3 (30)
Total household income (CAD $)[a], n (%)	
$20,000-$29,999	1 (10)
>$90,000	9 (90)
Child's insulin delivery system, n (%)	
Multiple daily injections	2 (20)
Insulin pump	8 (80)
Child's blood glucose monitoring device, n (%)	
CGM[b]	6 (60)
Flash glucose monitor	2 (20)
CGM+Lancets and strips	2 (20)
Extended health care coverage, n (%)	
Yes	8 (80)
No	2 (20)
Counseling services coverage[c], n (%)	
Child only	1 (13)
Family	2 (25)
No coverage	2 (25)
I don't know	3 (38)

[a]CAD $1 = US $0.76.

[b]CGM: continuous glucose monitoring.

[c]Only participants with extended health coverage (n=8) were asked this question.

Focus Groups

We conducted 5 focus groups: 2 groups consisted of parents, with 1 group comprising 6 participants, and the other having 4 participants; the remaining 3 groups were composed of adolescents, with 1 group of 3 participants aged 15-16 years, another group of 5 participants aged 17-18 years, and the final group including 2 participants aged 15-16 years.

Four overarching themes were identified, with 3 themes exploring the support needs of adolescents living with T1D and 1 theme exploring their preferences for a peer-led mental health support app. These themes were (1) experience: navigating adolescence with T1D, (2) empowerment: support systems that enabled better management of their T1D, (3) obstacles: societal barriers that affect adolescent's T1D management, and (4) innovation: adolescent-driven preferences for digital peer support platforms. These 4 themes were then further categorized into subthemes.

Theme 1: Experience—Navigating Adolescence With T1D

Subthemes included (1a) challenges beyond physical health, (1b) balancing T1D management and independence in adolescent-parent relationships, and (1c) transitioning toward managing diabetes independently.

Subtheme 1a: Challenges Beyond Physical Health

Most adolescents described diabetes as a "lonely" condition and reported difficulty finding peers with the same emotional struggles. Adolescent concerns included fear of hypoglycemia in unfamiliar situations, anxiety about long-term complications, and challenges of everyday activities such as driving or writing exams. Even when feeling anxious, some adolescents were still reluctant to discuss these worries with health care professionals, family, and friends.

> *I don't have anyone to talk to, and I just like to go through it, which probably adds a lot more stress to me having to be all alone going through that.* [Adolescent 1]

Adolescents also described specific instances where they felt isolated, such as during school trips or exams, when managing diabetes became a visible and misunderstood challenge among peers.

> *My friends don't get why I always carry snacks or why I sometimes leave during class—it makes me feel different and not in a good way.* [Adolescent 3]

Parents expressed different concerns, such as shielding their children from worry while encouraging responsible diabetes management.

> *I don't want to scare her into worrying about, you know, potential problems with losing limbs or heart attacks or strokes, or the absolute worst possible things.* [Parent 4]

Subtheme 1b: Balancing T1D Management and Independence in Adolescent-Parent Relationships

Encouraging adolescents to prioritize diabetes care created a complicated dynamic between adolescents and parents. While parents wanted to instill a sense of responsibility in their children, they did not want to be perceived as overbearing (ie, "helicopter parents").

> *I find that there was a period where my son would systematically forget to bolus for his meals, and as a parent, I just had to nag him and nag him, and I think that hurt our relationship.* [Parent 3]

Communication with parents was particularly challenging when adolescents felt overwhelmed by constant reminders and pressure regarding management.

> *I don't want to bring up my care and then have them like be more stressed and be on me more because their way of supporting me is like bugging me.* [Adolescent 9]

However, parents also mentioned that when they engaged in constructive communication, they improved their relationship with their children.

Subtheme 1c: Transitioning Toward Managing Diabetes Independently

As adolescents approached adulthood, some parents recognized the need to relinquish some diabetes-related responsibilities and shift them onto their children.

> *There definitely was a transition period where I had to let him take over, and it wasn't perfect. In fact, it was a scary thing to do, but I find that eventually, by backing away and letting him take charge, he did take charge, and he's much, much better today.* [Parent 5]

This sentiment was echoed by several adolescents, particularly those traveling far from home to attend university.

> *I'm going away for university next year, and I feel like it's because my parents—I've kind of been able to prove to my parents that I can be independent, but I was doing that by kind of like trial and error.* [Adolescent 1]

In contrast, other adolescents were not ready to assume complete management control and chose to remain at home close to their parents.

Theme 2: Empowerment—Support Systems That Enable Better Management of Their T1D

Subthemes included (2a) the role of online support systems, (2b) family and community support as foundational support systems, and (2c) interest in peer connections.

Subtheme 2a: Role of Online Support Systems

Both adolescents and parents discussed the value of online support systems for connecting with others living with T1D or caring for a child with T1D. These platforms helped reduce isolation and foster companionship with individuals who understood their experience. Adolescents highlighted the importance of online communities to share experiences with peers managing T1D, while parents appreciated the role of these communities in providing access to advice from other caregivers.

> *I find that if I look online, and I see discussion of other people and their struggles with diabetes, I feel a little bit less lonely, but it still isn't quite the same as having someone to talk to and relate to.* [Adolescent 10]

> *I have found some Facebook support groups, and I've been looking at them, and in many ways, some of them I have vented on there, and I have learned a lot.* [Parent 4]

While these digital environments offered the space to exchange thoughts and frustrations about T1D, some adolescents found these online groups overwhelming, primarily when discussions evolved into emotion-heavy topics such as long-term complications.

Subtheme 2b: Family and Community as Foundational Support Systems

Family members were described as the cornerstone of support. Adolescents noted that siblings often stepped in to help with reminders or provided companionship during health care appointments. Parents, on the other hand, saw themselves as "safety nets," providing structure to daily management tasks.

> *If I have any new issues that I realized have come up that I need help Problem Solving, my mom is definitely my go-to person since she knows the situation well.* [Adolescent 8]

Although many adolescents leaned on parents and friends for support, talking about diabetes with loved ones was not always satisfying. Instead, some adolescents valued connecting with other T1D peers who could offer empathy and understanding and exchange practical information.

Parents accessed community support by connecting with other parents of children with T1D and exchanging tips and information.

> *It's super important to feel supported and just be able to have another mom say to you, oh, this is where you get this, this is where you get the small juice boxes that, you know, all the little tips and tricks that.* [Parent 3]

Subtheme 2c: Interest in Peer Connections

Adolescents expressed a strong desire to connect with young adults with T1D (ie, near-peers) who have successfully achieved independence in managing their diabetes, while parents echoed this need from their perspective, hoping to reduce adolescents' feelings of loneliness.

> *It would be nice to talk to someone my age who gets it—like what it's like to have T1D during a school trip or stuff like that.* [Adolescent 5]

> *I want to know how older diabetics are achieving independence and what role diabetes plays in their life.* [Parent 8]

They sought insights on managing diabetes in the work and school setting. Parents were equally eager to help their children link up with relatable peers to reduce feelings of loneliness and isolation during a challenging period in life.

> *I'm looking also for her to find peers who have a similar medical condition so that she doesn't feel like she's so alone as a teenager.* [Parent 7]

Theme 3: Obstacles—Societal Barriers That Affect T1D Management

Subthemes included (3a) insurance-related obstacles, (3b) stigma and discrimination surrounding diagnosis, and (3c) lack of understanding by the public.

Subtheme 3a: Stigma and Discrimination Surrounding Diagnosis

Adolescents recounted situations where they felt unfairly scrutinized by authority figures, such as being accused of using illicit drugs (use of needles for insulin administration). Stigma and discrimination often originated from individuals outside the immediate family and peer group; however, these negative comments sometimes also came from friends. Anticipating these situations, many patients and families guarded their diagnosis from others. Those who disclosed their condition often found themselves mistaken for having type 2 diabetes and were targets of pejorative stereotypes (eg, poor lifestyle habits).

> *You've probably seen like hundreds of jokes that are like, oh, if you eat that, you're gonna get diabetes and then, of course, that makes you feel bad because there's that stigma, and that's just so not true.* [Adolescent 9]

Some parents reported concealing their child's diagnosis until it was essential to disclose it, such as when starting a new job.

> *It wasn't easy for my son to get a job because of, you know, the circumstances around his health.* [Parent 3]

Because of the stigma around diabetes, parents needed to advocate for their children in the school and work setting and encourage them to advocate for themselves.

Subtheme 3b: Insurance Coverage Obstacles

Participants also expressed frustrations with navigating insurance coverage.

> *I don't understand how insurance works. I don't know how they're going to cover the cost of my diabetes supplies. I don't know what they cover; I don't have that information.* [Adolescent 9]

For many parents, securing lifesaving supplies for their children was an arduous process that involved hours on the phone.

> *It takes two hours and three hours of my day to stay on top of things and get updates from insurance companies and stay on hold, and all of this, and I feel like if there's a shortcut of information, that would be amazing.* [Parent 3]

They also invested considerable time on the internet searching for pertinent information. Adolescents reported a general lack of knowledge regarding the policies and procedures of medical insurance and the costs of diabetes supplies. Not surprisingly, these frustrations were noted by participants preparing to leave home to attend university.

Subtheme 3c: Lack of Understanding by the Public

Both adolescents and parents reported negative experiences when talking to the general public about diabetes. Not only did individuals without T1D make inaccurate assumptions and demonstrate a lack of knowledge and sensitivity, but also these conversations often required exhausting explanations and effort.

> *Explaining it to somebody creates more work for the diabetic than it does to help them because, first, you need to explain it before, and you can tell them what's bothering you about it, so they understand how everything works. So, it creates more work, so sometimes it's easier just to not open up the conversation.* [Adolescent 1]

Consequently, participants avoided situations or interactions where the topic of diabetes could emerge.

> *It's pointless to go to others because I would have to teach them, so my daughter and I just talk about it amongst ourselves.* [Parent 4]

Theme 4: Innovation—Adolescent-Driven Preferences for Digital Peer Support Platforms

Subthemes included (4a) information security and accuracy, (4b) enhancing user interface and user experience, and (4c) add-ons for optimizing interactions.

Subtheme 4a: Information Security and Accuracy

Many participants expressed concern about exchanging inaccurate and potentially harmful medical advice about insulin pumps, dosages, dietary restrictions, and so on.

> *Information about managing your pump and insulin, bolusing, and how you will lose a dress size in a matter of two weeks, there's a lot of curiosity around that, so I'm concerned about that.* [Parent 4]

One suggestion to reduce this risk was to have health care professionals moderate group chats.

> *I think there could be some privacy issues, and what can be talked about. I don't know if it's kind of overkill but there could be like mediators, especially on chats that might be covering more sensitive topics.* [Adolescent 9]

Subtheme 4b: Enhancing the User Interface and User Experience

Participants expressed positive feedback about the planned REACHOUT NexGen platform, appreciating its concept, components (group chat, personal messaging, and access to trained near-peer mentors), and potential benefits for peer discussions. Parents wanted the platform to be user-friendly, straightforward, and enjoyable for adolescents, while adolescents focused more on aesthetics, user experience, and navigation assistance. Specifically, they suggested a more welcoming color palette and an introductory tutorial guiding users through its various components.

> *For the like homepage sort of thing, it looks kind of like intense, like it looks like Microsoft teams, which is kind of like intimidating.* [Adolescent 1]

> *Just like the design of the homepage a little bit maybe. I don't know, I'm not good with design, but maybe it could change a little bit just to make it look more visually appealing.* [Adolescent 2]

Subtheme 4c: Add-ons for Optimizing Interactions

Participants recommended features to incorporate into an ideal digital support platform, such as the ability to pin messages or chats on the platform's home screen and complete phone calls or video calls on the platform. These features, currently absent in the adult version of REACHOUT, were proposed to enrich user interactions and connectivity.

> You know in iMessage, for example, you are able to pin a certain conversation, so it becomes like a bubble at the top of your list, so it's like a priority almost. [Adolescent 7]

> If there could be video calls or even phone calls, it would be nice, so you don't have to get off the app if you want to speak to someone on the phone. [Adolescent 1]

Discussion

Principal Findings

This study explored the support needs of adolescents with T1D, focusing on the psychosocial challenges they face during an already demanding stage of life characterized by puberty-related changes, academic pressures, peer dynamics, and increased conflict with parents. In doing so, it provided specific design insights for app-based peer support, including features such as moderated chats for safety and video calls to foster emotional connection. These findings address gaps in the literature by demonstrating how technology can be tailored to meet adolescents' unique support needs and highlight ways to adapt an existing app (T1D REACHOUT), initially designed for adults, to better serve the adolescent population with T1D.

Comparison With Previous Work

Other studies [4,21,22] have also observed concerns about diabetes management, fear of long-term complications, strained relationships with parents, and transition into adulthood. For example, Castensøe-Seidenfaden et al [21] identified key worries among 9 adolescents aged 15-19 years and 13 parents, including safety in managing diabetes, independence, and apprehensions about future health complications.

Our results also revealed the pivotal role of support systems. Over and above family support, which has been shown to have a positive impact on mental health in adolescents with T1D [23,24], our participants voiced a clear desire to connect with peers with T1D. As adolescents approach adulthood, they gravitate more strongly toward their friends for support rather than their parents [25], as noted in subtheme 1b, where adolescent participants expressed being overwhelmed by their parents. In the context of T1D, peer support offers a space to exchange viewpoints and experiences regarding specific challenges, foster mutual understanding, and encourage collaborative problem-solving [26,27].

Furthermore, engaging in peer activities bolsters adolescents' capacity for empathy and support [28]. It can play a significant role in alleviating stress and anxiety during times of transition, as noted in subtheme 2c, where adolescent participants expressed desires to connect with peers and near-peers. Previous research among adolescents with T1D has found a link between peer support and improved diabetes outcomes. For example, Doe [29], in a study of 90 adolescents aged 15-18 years, observed a significant association between peer support and better glycemic control. Similarly, in a study by Raymaekers et al [30] involving a large cohort of 467 individuals, including adolescents (14-17 years) and emerging adults (18-25 years), it was found that increased emotional support from peers predicted lower levels of diabetes-related distress.

Our findings also highlight the specific ways adolescents wish to connect with peers with T1D, such as through moderated digital platforms that enable both group and one-on-one interactions. This expands upon previous work by Doe [29], which linked peer support with better glycemic control but did not explore the exact mechanisms or features adolescents preferred for peer interactions. Finally, our data provide insights that inform the design and implementation of a peer-delivered mental health support mobile app for adolescents. Using the principles of human-centered design [31], we were able to transform insights from theme 4 into actionable design strategies for our app; this included refining the app through a streamlined interface, clear color schemes, clutter reduction, user tutorials, message pinning, enhanced connectivity through calls, and moderated chats for safety. Although the integration of features such as phone and video calls has predominantly been used to provide support between scheduled visits with the diabetes care team and to facilitate online clinic appointments with health care providers [32], our findings suggest that these modes of communication may also foster a sense of companionship and emotional connection with peers. Similarly, other studies have identified app-related preferences for this T1D age cohort, such as user-friendliness, ease of navigation, and safe participation by moderating peer discussions [13,14,33]. For example, the self-compassion chatbot (called "COMPASS") app [33], designed for adolescents aged 12-16 years with T1D, demonstrated improvements in psychosocial well-being among adolescents with T1D, but participants in our study advocated for safe discussions with their peers and features that can assist in easy navigation, such as a search bar function.

While there are existing platforms that adolescents with T1D have already leveraged to obtain peer support (eg, Reddit, Discord, and TikTok), these online environments lack two core features: (1) access to focused one-on-one support delivered by a trained near-peer and (2) health care professional–monitored chat rooms and discussion boards [34]. Over and above same-age peers, adolescents have expressed a desire for support from young adults with T1D who have more years of life experience to share [4]. Furthermore, adolescents seek security in knowing safeguards are in place to prevent the exchange of medically contraindicated information [35]. In response to this gap, our platform, REACHOUT NexGEN, will incorporate these critically important features. For example, T1D REACHOUT, the adult version of the app, uses trained moderators and health care professionals to oversee chat rooms and discussion boards, ensuring that the information exchanged is accurate and safe [12]. This moderation system helps protect users from receiving inaccurate advice, a concern that was echoed in our study by adolescent participants who emphasized the importance of safeguards. By adopting these practices, REACHOUT NexGEN will offer a safe and secure space for adolescents with T1D to connect with both peers and near-peers, therefore addressing their need for support while safeguarding their well-being.

Limitations

This study has limitations. First, one of our focus groups (adolescents aged 15-16 years) had only 2 participants, which may have hindered in-depth discussion; however, we obtained some useful points from the discussion, and we ran another focus group with more participants from this age group. Second, most of our participants were female and may have been more inclined to openly discuss health issues [36] and engage in research studies [37]. The majority of the participants were female, which may have influenced the support needs emphasized in our findings. Female adolescents are often more likely to articulate psychosocial challenges and emotional well-being, which may have led to a stronger focus on these areas [36]. Female adolescents with T1D often experience higher levels of DD due to a combination of hormonal fluctuations once they reach menarche, which complicates blood glucose management and psychosocial factors, including body image concerns and increased risk of eating disorders [38]. Conversely, the lack of male representation may mean that certain challenges, such as stigma around discussing diabetes among male peers or unique preferences for technological interactions, were underrepresented. A more gender-diverse sample could provide a more balanced perspective on the support needs of the broader adolescent population with T1D. Also, our focus group participants lacked sociodemographic diversity and may not reflect the larger adolescent population with T1D [39]. Finally, the variation in focus group sizes, influenced by participant preferences and scheduling constraints, may have limited broader discussions and diversity of perspectives. While smaller groups fostered personalized interactions, future studies should aim to balance participant preferences with recommended group sizes to enhance discussion dynamics.

These factors all potentially limit the generalizability of our findings. Future studies should explore strategies to engage a more heterogeneous sample by actively collaborating with community organizations, advocacy groups, or cultural associations representing various demographic groups, as this could contribute to a more nuanced understanding of the complexities within different demographic groups.

Conclusions

This study confirmed the existing and compelling evidence of the need for mental health support for adolescents with T1D. It also showed that adolescents are interested in the potential benefits of app-based peer support for providing emotional assistance. Further research is required to evaluate the platform's feasibility and effectiveness to uncover potential challenges, refine design features based on user feedback, assess user engagement and satisfaction, and evaluate the app's sustained impact over time.

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Data Availability

The datasets generated and analyzed during this study are not publicly available due to the privacy and confidentiality requirements of the research ethics board.

Authors' Contributions

TIY contributed to investigation, formal analysis, writing–original draft. PJ contributed to formal analysis, writing–review & editing. SP contributed to investigation, writing–review & editing. NCW contributed to methodology, project administration, writing–review & editing. SA contributed to funding acquisition, methodology, writing–review & editing. TST contributed to conceptualization, funding acquisition, methodology, supervision, writing–review & editing. MG contributed to conceptualization, funding acquisition, methodology, supervision, writing–review & editing.

Conflicts of Interest

SA participated on advisory boards for Dexcom, Abbott, Novo Nordisk, Eli Lilly, Sanofi, and Insulet.

Multimedia Appendix 1
COREQ (Consolidated Criteria for Reporting Qualitative Research) checklist.
[DOCX File , 25 KB - diabetes_v10i1e64267_app1.docx]

Multimedia Appendix 2
T1D REACHOUT NexGEN Study: adolescent focus group participant questionnaire.
[DOCX File , 44 KB - diabetes_v10i1e64267_app2.docx]

Multimedia Appendix 3
T1D REACHOUT NexGEN Study: focus group parent questionnaire.
[DOCX File , 28 KB - diabetes_v10i1e64267_app3.docx]

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Abbreviations

BCCH: BC Children's Hospital
CGM: continuous glucose monitor
COREQ: Consolidated Criteria for Reporting Qualitative Research
DD: diabetes distress
IHA: Interior Health Authority
REDCap: Research Electronic Data Capture
T1D: type 1 diabetes
VIHA: Vancouver Island Health Authority

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Original Paper

Examining How Adults With Diabetes Use Technologies to Support Diabetes Self-Management: Mixed Methods Study

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Abstract

Background: Technologies such as mobile apps, continuous glucose monitors (CGMs), and activity trackers are available to support adults with diabetes, but it is not clear how they are used together for diabetes self-management.

Objective: This study aims to understand how adults with diabetes with differing clinical profiles and digital health literacy levels integrate data from multiple behavior tracking technologies for diabetes self-management.

Methods: Adults with type 1 or 2 diabetes who used ≥1 diabetes medications responded to a web-based survey about health app and activity tracker use in 6 categories: blood glucose level, diet, exercise and activity, weight, sleep, and stress. Digital health literacy was assessed using the Digital Health Care Literacy Scale, and general health literacy was assessed using the Brief Health Literacy Screen. We analyzed descriptive statistics among respondents and compared health technology use using independent 2-tailed *t* tests for continuous variables, chi-square for categorical variables, and Fisher exact tests for digital health literacy levels. Semistructured interviews examined how these technologies were and could be used to support daily diabetes self-management. We summarized interview themes using content analysis.

Results: Of the 61 survey respondents, 21 (34%) were Black, 23 (38%) were female, and 29 (48%) were aged ≥45 years; moreover, 44 (72%) had type 2 diabetes, 36 (59%) used insulin, and 34 (56%) currently or previously used a CGM. Respondents had high levels of digital and general health literacy: 87% (46/53) used at least 1 health app, 59% (36/61) had used an activity tracker, and 62% (33/53) used apps to track ≥1 health behaviors. CGM users and nonusers used non-CGM health apps at similar rates (16/28, 57% vs 12/20, 60%; *P*=.84). Activity tracker use was also similar between CGM users and nonusers (20/33, 61% vs 14/22, 64%; *P*=.82). Respondents reported sharing self-monitor data with health care providers at similar rates across age groups (17/32, 53% for those aged 18-44 y vs 16/29, 55% for those aged 45-70 y; *P*=.87). Combined activity tracker and health app use was higher among those with higher Digital Health Care Literacy Scale scores, but this difference was not statistically significant (*P*=.09). Interviewees (18/61, 30%) described using blood glucose level tracking apps to personalize dietary choices but less frequently used data from apps or activity trackers to meet other self-management goals. Interviewees desired data that were passively collected, easily integrated across data sources, visually presented, and tailorable to self-management priorities.

Conclusions: Adults with diabetes commonly used apps and activity trackers, often alongside CGMs, to track multiple behaviors that impact diabetes self-management but found it challenging to link tracked behaviors to glycemic and diabetes self-management goals. The findings indicate that there are untapped opportunities to integrate data from apps and activity trackers to support patient-centered diabetes self-management.

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KEYWORDS

diabetes; self-management; mobile health; health technology; continuous glucose monitors; digital health literacy

Introduction

Background

Adults with diabetes can significantly lower their risk of diabetes complications such as nerve damage, kidney failure, blindness, myocardial infarction, and stroke by maintaining healthy daily diabetes self-management behaviors [1-3]. Diabetes self-management behaviors span multiple domains, including taking medications on a consistent schedule, engaging in regular physical activity, maintaining a healthy diet, self-monitoring blood glucose levels and blood pressure, practicing good sleep hygiene, and managing stress [4,5]. Adults with diabetes navigate these self-management behaviors to make daily decisions unique to their treatment regimens—such as adjusting medication doses and food intake after exercising. Successfully changing and sticking with healthy self-management routines is challenging for many people [6,7]. These demanding tasks can also lead to overwhelming diabetes distress, which can result in less motivation to stick to healthy regimens as well as higher blood glucose levels [8].

Technologies such as mobile apps, wearable activity trackers, and wearable continuous glucose monitors (CGMs) are available to support adults with diabetes; however, little is known about how adults with diabetes use CGMs in combination with mobile apps and activity trackers for other diabetes self-management domains. With 1 in 5 Americans reporting that they use a smartwatch or fitness tracker [9], there are increasing opportunities for adults with diabetes to use these devices for diabetes management, as evidenced by their incorporation into diabetes treatment guidelines [10]. While CGM use has been linked to lower glycated hemoglobin levels among people with type 2 diabetes who use insulin [11,12], available evidence is not clear on whether using CGMs enables patients to improve medication taking or other diabetes self-management behaviors [13,14]. There is mixed evidence on whether using activity trackers results in lower blood glucose levels for adults with diabetes [15-17]. It remains unclear whether and how adults with diabetes connect data from these apps with information from their CGMs to guide daily behavioral routines. Other domains, including stress and sleep—increased stress has been linked to higher blood glucose levels among adults with type 1 and 2 diabetes [18]—are included as behaviors that are important to address in treatment guidelines [5], but we do not know whether adults with diabetes use technologies to track these behaviors and link them with their diabetes information.

Objectives

In this mixed methods study, we aimed to assess how adults with diabetes use and combine blood glucose level and self-management behavior tracking technologies to inform their day-to-day diabetes self-management and reach their personal health goals. Our research question focuses on understanding how adults with diabetes with differing clinical profiles and digital health literacy use and integrate data from multiple behavior tracking technologies for diabetes self-management.

Methods

Study Population

Individuals aged 18 to 75 years with diabetes (type 1 or 2) who were prescribed at least 1 diabetes medication were eligible for this study. The age cutoff for the study was set at 75 years because diabetes management goals change once individuals are beyond a certain age, including more liberal blood glucose level targets that emphasize safety. This could affect the appropriateness of certain technologies, such as CGMs, and how individuals use them.

The exclusion criteria included a diagnosis of gestational diabetes without another diabetes diagnosis, a diagnosis of schizophrenia or any other kind of “serious mental illness,” and diagnoses of “serious medical illnesses” (eg, cancer, chronic obstructive pulmonary disease, and end-stage kidney disease).

Recruitment

Potentially eligible participants were either referred by health care providers (n=2) or recruited via a posting on the University of Pittsburgh Pitt+Me research registry, which was available from March to November 2023. The posting contained information about the purpose of the study; eligibility criteria; and what participation involved, including with regard to completing the survey on the internet and potentially being invited for an interview. The target audience included individuals diagnosed with diabetes who are currently prescribed at least 1 diabetes medication. Potential participants who had responded to the posting were contacted via telephone by a study team member to confirm eligibility and obtain verbal consent (refer to the *Ethical Considerations* subsection for details). The study team member then administered the survey over the telephone or via a web-based Qualtrics (Qualtrics International Inc) form. After completing the survey, potential interview participants were purposefully recruited to represent a variety of experiences with technology and diabetes-related factors such as diabetes type, diabetes medication use (insulin

or oral), and CGM use (current or prior), as well as demographic factors, including age, sex, and racial identity and ethnicity.

Closed-Ended Survey Questions

The web-based survey (Multimedia Appendix 1 [19,20]) included 46 questions about sociodemographic characteristics; functional challenges to using apps (vision or dexterity problems); and diabetes management, including blood glucose level monitoring patterns. The survey took approximately 10 (median 9.31, IQR 11.85-18.66) minutes to complete; included free-text, multiple-choice, and Likert-scale response options; and was developed internally by the research team through multiple versions. We assessed current or previous participant experience with 6 types of mobile apps for diabetes self-management behaviors that correspond to key self-management domains in American Diabetes Association diabetes management guidelines [5]: blood glucose level monitoring, diet, exercise, weight loss, sleep, and stress and mindfulness. While current and previous technology use represent different use patterns, we decided to group these patterns together because these data could be used to craft interventions that incorporate different domains that adults with diabetes have demonstrated interest in tracking. We also asked about current and former use of wearable blood glucose level and activity trackers. We used questions from previously validated surveys, including the Brief Health Literacy Screen [19,21] for general health literacy, which is scored on a scale ranging from 3 to 15, with scores of ≤9 reflecting marginal or inadequate health literacy [22,23]; and the Digital Health Care Literacy Scale (DHLS) [20] reflecting the ability to use mobile apps (scored from 0 to 12, with higher scores indicating higher digital health literacy).

Interviews

Semistructured interviews were conducted using a secure videoconferencing platform (Zoom; Zoom Video Communications, Inc) from May to November 2023. All interviews were conducted by a study team member with a doctorate degree in nutritional sciences, subject matter expertise, and training and experience in conducting interviews. Another study team member who is a primary care physician and expert in health literacy also participated and asked follow-up questions ad hoc. A trained research assistant took notes during the interviews and wrote reflexive memos summarizing each interview afterward. The interview guide (Multimedia Appendix 2) included questions for participants about their experiences using health technology to track data and make diabetes-related behavior changes. The guide was developed by study team members, pretested with 3 adults (who were not included in the data analysis), and revised based on their responses. In the final guide, participants were first asked to describe how they tracked information during a typical day and their experiences with diabetes-related mobile apps (6 types: blood glucose level monitoring, diet, exercise, weight loss, sleep, and stress and mindfulness) and wearable blood glucose level and activity trackers. We then asked participants to describe how they learned to use these apps and trackers; what features helped them manage diabetes; what aspects of the tools or training could have been more helpful; whether they combined information if they used >1 tool; and why they stopped using the tool, if applicable. In addition, participants were asked whether they shared blood glucose level data with members of their health care team or others (eg, family members); and to describe these experiences and how, if at all, they could be enhanced. The interviews took 45 to 60 minutes to complete and were recorded and transcribed. Transcripts were reviewed for accuracy by the research assistant.

Data Analysis

Survey

Descriptive statistics—frequency (percentage) for categorical variables and mean (SD) for continuous variables—were used to assess patient characteristics and summarize other data (eg, health technology use, general health literacy, and digital health literacy). Participant use of each of the 6 types of apps and 2 types of wearables was tallied by category. We then categorized participants as 0, 1, or >1 app and wearable used. Health technology use was compared among participant groups (eg, age and insulin use) using independent 2-tailed *t* tests for continuous variables and chi-square for categorical variables. Data are presented as frequency (percentage) or mean (SD), unless otherwise noted. To capture as many aspects of technology use among adults with diabetes as possible, we did not exclude participant responses if they did not complete all questions in a particular section. Data were analyzed using SPSS (version 28.0; IBM Corp) and Stata (version 18.0 for Mac; StataCorp LLC).

To analyze the association between health literacy and app use, we used a cutoff score of ≤9 as a marginal or inadequate score based on prior literature [22,23]. As there are no defined tiers for low, marginal, or high levels of digital health literacy in the DHLS, we created categories for this score, including ≤9 (marginal or inadequate digital health literacy) and ≥10 (adequate digital health literacy) based on the distribution of scores among the survey respondents. We tested the association between digital health literacy and total app use using Fisher exact tests with an assigned α of .05.

Interviews

We used content analysis to summarize themes by interview topic [24,25]. An initial inductive codebook was developed based on the anticipated categories of information that would be gathered during the interviews. Members of the research team separately coded 3 transcripts, compared results as a group, and then adjusted the codebook to include deductive emerging themes. After reaching sufficient agreement on the dually coded transcripts, single-user coding was applied to the remaining transcripts. Team members separately reviewed coded passages and potential themes, which were then presented and discussed as a group until consensus was reached. Analysis was conducted using NVivo software (version 14 for Mac and Windows; Lumivero).

Ethical Considerations

This study was deemed exempt by the University of Pittsburgh Institutional Review Board (22120073-001).

For the survey consent process, a study team member contacted interested individuals and confirmed their eligibility. The team member then outlined the goals of the study, the processes for completing the survey, the possibility of being contacted for a postsurvey interview, the potential risks and benefits of participation, the processes for protecting confidentiality and data safety, and the option of declining participation at any time. These parameters were reviewed with interview participants, who were selected from the survey respondents, at the beginning of their interviews.

Study data—including survey responses and interview quotes—were deidentified, labeled with a study ID number, and stored on Health Insurance Portability and Accountability Act–compliant servers. All personally identifying information was removed from transcripts.

Participants received US $10 in compensation for completing the survey and US $30 in compensation for completing the interview.

Results

Survey

A total of 61 adults with diabetes completed the survey. Of the 61 respondents, 60 (98%) owned a smartphone, and 54 (94%) used web-based resources to look up health information. As shown in Table 1, of the 61 respondents, 21 (34%) were Black, and 23 (38%) were female. Approximately half (29/61, 48%) were aged 45 to 70 years, and most (50/61, 82%) had some college education. A majority (44/61, 72%) had type 2 diabetes, 59% (36/61) used insulin, and 56% (34/61) reported having current or prior experience with using a CGM. Respondents had overall high levels of general health literacy (mean 13.1, SD 2.6; possible scores: 3-15) and digital health literacy (mean 10.6, SD 2.1; possible scores: 0-12). The characteristics of the interview participants are presented in Table 2.

Table 1. Survey respondent characteristics.

Characteristics	Values
Age group (y; n=61), n (%)	
18-44	32 (52)
45-70	29 (48)
Female sex (n=61), n (%)	23 (38)
Race and ethnicity (n=61), n (%)	
Asian	4 (7)
Black or African American, non-Hispanic	21 (34)
White, non-Hispanic	35 (57)
Multiple	1 (2)
Education (n=61), n (%)	
High school graduate or GED[a]	11 (18)
Some college	23 (38)
College graduate or higher	27 (44)
Time since diabetes diagnosis (y; n=61), n (%)	
≤1	3 (5)
1-3	11 (18)
3-5	10 (16)
>5	37 (61)
Diabetes type (n=59), n (%)	
Type 1	15 (25)
Type 2	44 (75)
Insulin frequency (among those who used insulin; n=36), n (%)	
Once daily	7 (19)
Twice daily	7 (19)
≥3 injections daily	15 (42)
Insulin pump	7 (19)
Take noninsulin diabetes medications (n=61), n (%)	43 (70)
CGM[b] use (n=56), n (%)	
Currently	32 (57)
Previously	2 (4)
Never	22 (39)
Brief Health Literacy Screen (possible scores: 3-15; n=60)	
Score, mean (SD; range)	13.1 (2.6; 6-15)
Inadequate health literacy (score: ≤9), n (%)	6 (10)
Adequate health literacy (score: ≥10), n (%)	54 (90)
Digital Health Care Literacy Scale (possible scores: 0-12; n=61)	
Score, mean (SD; range)	10.6 (2.1; 2-12)
Marginal digital health literacy (score: ≤9), n (%)	11 (18)
Adequate digital health literacy (score: ≥10), n (%)	50 (82)

[a]GED: General Educational Development Test.

[b]CGM: continuous glucose monitor.

Table 2. Interview participant characteristics.

Characteristics	Values
Age group (y; n=18), n (%)	
18-44	6 (33)
45-70	12 (67)
Female sex, n (%)	9 (50)
Race and ethnicity (n=18), n (%)	
Asian	2 (11)
Black or African American, non-Hispanic	7 (39)
White, non-Hispanic	9 (50)
Multiple	0 (0)
Education (n=18), n (%)	
High school graduate or GED[a]	4 (22)
Some college	7 (39)
College graduate or higher	7 (39)
Time since diabetes diagnosis (y; n=18), n (%)	
≤1	1 (6)
1-3	2 (11)
3-5	0 (0)
>5	15 (83)
Diabetes type (n=18), n (%)	
Type 1	2 (11)
Type 2	16 (89)
Insulin frequency (among those who used insulin; n=11), n (%)	
Once daily	5 (45)
Twice daily	1 (9)
≥3 injections daily	5 (45)
Insulin pump	0 (0)
Take non–insulin diabetes medications (n=18), n (%)	16 (89)
CGM[b] use (n=13), n (%)	
Currently	9 (69)
Previously	0 (0)
Never	4 (31)
Brief Health Literacy Screen (possible scores: 3-15; n=18)	
Score, mean (SD; range)	12.0 (2.5; 7-15)
Inadequate health literacy (score: ≤9), n (%)	2 (11)
Adequate health literacy (score: ≥10), n (%)	16 (89)
Digital Health Care Literacy Scale (possible scores: 0-12; n=18)	
Score, mean (SD; range)	10.6 (2.5; 2-12)
Marginal digital health literacy (score: ≤9), n (%)	4 (22)
Adequate digital health literacy (score: ≥10), n (%)	14 (78)

[a]GED: General Educational Development Test.

[b]CGM: continuous glucose monitor.

As shown in Table 3, of 53 survey respondents, 43 (87%) reported currently or previously using health apps in 1 of 6 categories or wearable activity trackers. There was variability in completing survey items on specific types of apps or wearable activity trackers (combined app and wearable activity tracker use: n=53; wearable activity tracker use: n=60). Of the 6 types of health apps plus wearable activity trackers surveyed, on average, 2.6 (SD 2.0; range 0-7) types were used. Nearly half (25/53, 47%) of the respondents used ≥3 types of apps and wearable activity trackers. The most frequently used apps were those related to blood glucose level monitoring (37/61, 61%), followed by those related to food (23/61, 38%) and weight (18/61, 30%). Nearly three-fifths (36/61, 59%) of the respondents reported using a wearable activity tracker, including 28% (17/61) who used an exercise app. A similar percentage of CGM users (20/33, 61%) and nonusers (14/22, 64%) used wearable activity trackers. The use of blood glucose level monitoring apps was more common among CGM users than nonusers (28/34, 82% vs 5/22, 23%; $P<.001$) as well as more common among insulin users than nonusers (27/36, 75% vs 10/25, 40%; $P=.006$). However, non-glucose monitoring app use (39/61, 74%) was similar among CGM users and nonusers (16/28, 57% vs 12/20, 60%) as well as among insulin users and nonusers (20/33, 61% vs 12/20, 60%), but there was a trend toward lower use among those aged 45 to 70 years compared to those aged 18 to 44 years (14/27, 52% vs 18/26, 69%); however, these results were not statistically significant ($P=.20$). Participants also reported sharing self-monitored data with their health care providers at similar rates across age groups (17/32, 53% for those aged 18-44 y vs 16/29, 55% for those aged 45-70 y; $P=.87$). Details of health technology use (current or previous) among interview participants are presented in Table 4.

Table 3. Health technology use (current or previous) among survey respondents.

	Respondents, n (%)
Blood glucose level monitoring apps (n=61)	
CGM[a] or glucometer app	31 (51)
Another website or app	6 (10)
Food tracking app (n=61)	23 (38)
Weight tracking app (n=61)	18 (30)
Exercise app (n=61)	17 (28)
Stress-related, mindfulness, or meditation app (n=61)	14 (23)
Sleep app (n=61)	13 (21)
Wearable activity tracker (n=61)	36 (59)
Combined total app types and wearable activity tracker use (n=53)	
0	7 (13)
1	13 (25)
>1	33 (62)
Have tried to share information from apps with health care provider (n=61)	33 (54)
A health care provider recommended health app or wearable activity tracker (n=49)	18 (37)
“Have you ever completed a telehealth video visit?” (n=54)	42 (78)
“Do you use online resources (websites, search engines) to look up health information?” (n=54)	51 (94)
“I own a personal computer, laptop computer, or tablet” (n=54)	52 (96)

[a]CGM: continuous glucose monitor.

Table 4. Health technology use (current or previous) among interview participants.

	Participants, n (%)
Blood glucose level monitoring apps (n=18)	
CGM[a] or glucometer app	9 (50)
Another website or app	4 (22)
Food tracking app (n=18)	9 (50)
Weight tracking app (n=18)	6 (33)
Exercise app (n=18)	3 (17)
Stress-related, mindfulness, or meditation app (n=18)	6 (33)
Sleep app (n=18)	6 (33)
Wearable activity tracker (n=18)	11 (61)
Combined total app types and wearable activity tracker use (n=17)	
0	0 (0)
1	5 (29)
>1	12 (71)
Have tried to share information from apps with health care provider (n=18)	12 (67)
A health care provider recommended health app or wearable activity tracker (n=10)	4 (40)
“Have you ever completed a telehealth video visit?” (n=11)	8 (73)
“Do you use online resources (websites, search engines) to look up health information?” (n=11)	10 (91)
“I own a personal computer, laptop computer, or tablet” (n=11)	11 (100)

[a]CGM: continuous glucose monitor.

As seen in Table 5, combined wearable activity tracker and app use was higher among those with DHLS scores of ≥10, particularly for those using >1 tracker or app, but this did not reach statistical significance (*P*=.09).

Table 5. Digital Health Care Literacy Scale (DHLS) scores and app use among survey respondents.

	Respondents with DHLS scores of ≤9, n (%)	Respondents with DHLS scores of ≥10, n (%)	*P* value
Total app types used (range 0-6)	11 (100)	42[a] (100)	.35[b]
0	4 (36)	6 (14)	
1	3 (27)	14 (33)	
>1	4 (36)	22 (52)	
Wearable activity tracker use	11 (100)	49 (100)	.1[c]
No	7 (64)	17 (35)	
Yes	4 (36)	32 (65)	
Combined total app type and wearable activity tracker use (range 0-7)	11 (100)	42 (100)[a]	.09[b]
0	3 (27)	4 (10)	
1	4 (36)	9 (21)	
>1	4 (36)	29 (69)	

[a]Not all participants completed all app use survey questions; hence, the total number of respondents for total app type and wearable activity tracker use are different.

[b]Fisher exact test.

[c]Fisher exact test for 2 × 2 contingency tables (2-sided).

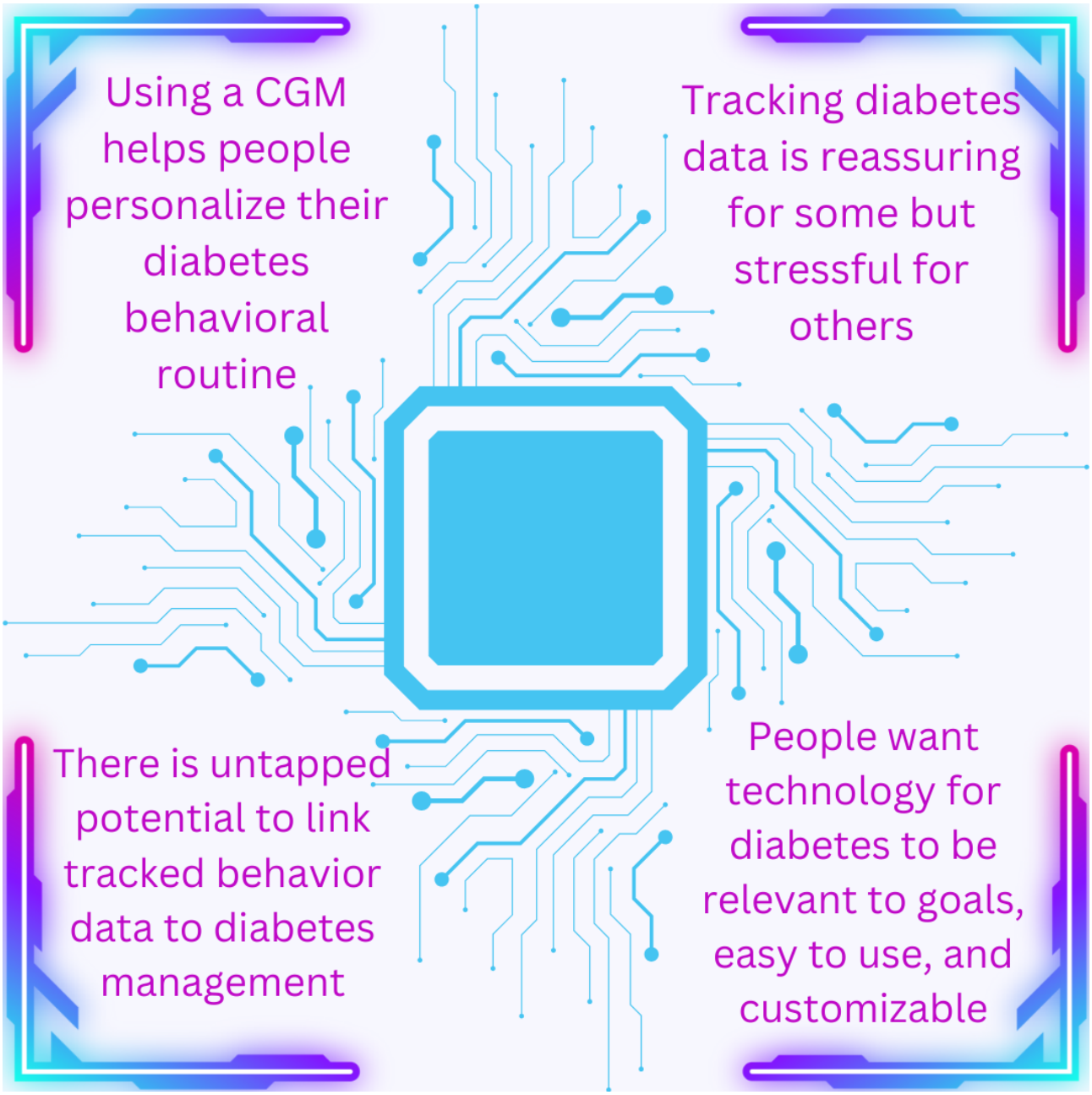
Interviews

Overview

Of the 61 survey respondents, 18 (30%) were invited to complete semistructured interviews examining how technologies were and could be used in daily diabetes self-management. As shown in Table 2, most interviewees (16/18, 89%) had type 2 diabetes, with 45% (5/11) of the interviewees who used insulin requiring ≥3 injections daily. They had high levels of digital health literacy on the DHLS as well as high levels of overall health literacy on the Brief Health Literacy Screen. Half (9/18, 50%) of the interviewees used a CGM or glucometer app, 67% (12/18) shared data with a health care provider, 73% (11/18) had used telehealth, and 91% (10/11) used web-based resources.

Four major themes emerged from the interviews, as shown in Figure 1 and described in the following subsections.

Figure 1. Main themes from semistructured interviews. CGM: continuous glucose monitor.



Theme 1: Using a CGM Helps People Personalize Their Diabetes Self-Management Behavioral Routine

Despite the fact that CGM apps are focused on guiding insulin dose adjustments, many interviewees described using CGM data to guide day-to-day diabetes health behaviors such as eating choices and physical activity patterns:

> *So I get to choose what to eat knowing what my blood sugar is...When I see my blood sugar's closer to 200 then I will eat less fruits or sugary food in the morning and really more eggs or something like that.* [Male, aged 45-59 y, with type 2 diabetes]

> *Yes, like when I was going to the gym and I was working with this workout group and we were weightlifting, my sugar would go up even though I*

> *didn't eat anything. Like I could start at 90. And by the end of the workout, my sugar was like at 145-150. And I was noticing that happen[ing]...then like on my drive home it was start[ing] to go down but after we worked out with the weights my glucose would always go up.* [Female, aged 26-44 y, with type 1 diabetes]

Others with type 2 diabetes discussed how the use of their CGM allowed them to be more flexible in terms of when and how often they checked their blood glucose levels:

> *My doctor absolutely would prefer that I'm, you know, pricking 4 times a day. That's just not feasible with the lifestyle that I live. It's just not possible. So the [continuous] glucose monitor helps in that...Sometimes like if I'm feeling weird, I'll do it [check the app] more times. Sometimes, I'll do it less times.* [Female, aged 26-44 y, with type 2 diabetes]

Notably, many participants discussed tailoring the more generic lifestyle behavior advice they receive from clinicians to identify what personally impacts their blood glucose levels. Interviewees described how using CGMs allowed for personalized understanding of the extent to which certain eating patterns impacted their blood glucose levels, which was "better than a dietitian." They described CGM data as liberating because these data gave them insights into their body's responses to foods that they previously felt were "off-limits":

> *It's the dietitians I think, are very, to some extent they're helpful. But I actually found the CGM much more helpful...I like Chinese food. And what I was told was at the beginning, that probably you can't eat that anymore, in that you have to decrease that. But that's not entirely true...actually I'm able to actually eat certain types of foods. And I got that information more from my CGM than dietitians.* [Male, aged 45-59 y, with type 2 diabetes]

> *It [the CGM] tells me, depending on what I'm going to eat, what I have a taste for, what my taste buds are, yes, no. The numbers will help me and let me know. Okay, I can have this, but not too much of it.* [Female, aged 26-44 y, with type 2 diabetes]

Theme 2: Tracking Additional Data for Diabetes Management Is Reassuring for Some, While Others Feel That It Increases Stress

Interviewees expressed an array of views on how increasing the amount of data available affects their confidence managing diabetes. Some found it reassuring to have extra data:

> *I told you I was a numbers guy. I'm also kind of a fanatic on schedule, and it was nice, because [the CGM] kind of put you into a schedule.* [Male, aged 60-70 y, with type 2 diabetes]

> *Even though the days and the moments I use it [the CGM] fluctuate, I still use it way more than I took the time out to finger stick myself. So even in the days that I've only, you know, scanned 3 times. That still gives me a good idea of you know where I stand with my numbers and was able to keep me, you know, mentally aware that, hey? You're still, you know, you're still on track. It's still on track.* [Female, aged 26-44 y, with type 2 diabetes]

Others who tried tracking health data described feeling stressed or overwhelmed by the additional data:

> *Each one of us have obsessive compulsive things. And one of the things that bothers me is when I look at the green area in that [CGM app] graph, and I see myself go outside of the green area, it kind of bothers me so I always want to stay within that green area or close to it. I like to see it all green, when I see some yellow I don't like that. I'll accept it. And they say yep, that's because of this food that I ate. But usually I don't like it.* [Male, aged 45-59 y, with type 2 diabetes]

> *So I wait to put my new [CGM on], and getting that first number, I get anxious to see what it is, what it's going to be. And you know, did I wonder? Like, oh, did I? You know, did I do good today with eating? You know I took my medicine, and you know it should be this, but what if it's that?* [Female, aged 26-44 y, with type 2 diabetes]

> *I think it's obsessive to be looking at that [activity tracker] all day...I'm not one of those people that wants to count their steps. You know, I might want to count them one day, and then the next day I don't. So, you know, so I don't want to be focused on a watch...it's just too much for me.* [Female, aged 49-59 y, with type 2 diabetes]

Some people described having extra data from wearable monitors as relieving stress because they were better able to share their data with others:

> *Every time I scan...my wife gets to see what my blood sugars are. She has the app...So as soon as I scan, it shows up on her phone. It's one of the alerts in her phone, and then she sees the range as well. So she sees all of the information. So she does remind me and then sometimes she'll text me and say your sugar's really high or something and I say "Yeah I just had this type of meal."* [Male, aged 45-59 y, with type 2 diabetes]

The ability to share wearable activity tracker and app data with health care providers was also described as stress relieving because interviewees felt that this made it easier for health care providers to understand how diabetes management was going at home:

> *When I come in for an appointment, [the physician will] download 2 weeks' worth of data. So she's connected to my system all the time. And her reaction was, "Wow, you're 90 plus percent compliant."* [Male, aged 60-70 y, with type 2 diabetes]

> *So the conversations we would have when I go to my appointments...is basically them asking me, okay, what are you doing differently? Your levels are like, really good. There's no adjustments that need to be made...And then, if they see anything real low on a specific day, they'll ask me, okay, well, what was*

> *going on this day, you were really low. And so there, if there's any adjustments need to be made, they'll tell me right then and there.* [Female, aged 26-44 y, with type 2 diabetes]

Theme 3: There Is Untapped Potential to Link Data on Commonly Tracked Lifestyle Behaviors to Diabetes Self-Management

Interviewees mentioned using wearable activity trackers and mobile apps to track multiple aspects of their lifestyle, including healthy eating, physical activity, sleep, and stress levels. While they often discussed links between stress or sleep and blood glucose levels, they rarely discussed linking or comparing tracker data on these behaviors with blood glucose level monitor data:

> *So I'm one of those people who, you know, who may eat more chips because I'm just feeling down, or I'm just having a stressful day, something like that. And so when that happens when I'm stressed a lot, that's what messes with my eating, and then it messes with my blood sugar, and then my readings are very high, because I ate the wrong thing all day, or I've eaten a wrong...I've eaten a candy bar before I went to bed.* [Female, aged 45-59 y, with type 2 diabetes and no CGM experience]

> *I do see it [sleep] in my app, my health app, and it shows up that once in a while. That's a once every four weeks my phone tells me that "oh you reached your goal for tonight." But it does make me more mindful that yeah, I'm not sleeping as much as I need to be.* [Male, aged 45-59 y, with type 2 diabetes]

> *There was a lot of good information [in] there of "Try this or do this, or make sure you're..." I mean, everything from what you're eating to socializing. So, I think...what can I, what can I do to sleep better? And how does how does that sleep really affect my diabetes?* [Male, aged 60-70 y, with type 2 diabetes discussing a subscription-based lifestyle and weight management app]

Theme 4: People Prefer to Use Diabetes Management Apps and Wearables When It Is Relevant and Customizable to Their Self-Management Priorities With Data That Are Easily Collected and Integrated in One Place

Interviewees preferred customizing whether, when, and how they tracked certain diabetes lifestyle data based on their personal goals or situation at the time:

> *It came to a point where I was no longer interested or cared about how many steps I took because, you know, again, most of my day is spent in the car. So like, I wasn't really stepping. If that makes sense, it wasn't, you know, you would see different friends and stuff on social media. And, "Oh, I had 10,000 steps," and it's like, yeah, I barely made a thousand a day. So like, yeah, bump this.* [Female, aged 26-44 y, with type 2 diabetes]

> *I think they [specific app] probably try to do too much with exercise logging. So I don't even, I just ignore that feature. 'Cause doctors really want me to focus on caloric intake.* [Male, aged 60-70 y, with type 2 diabetes]

> *I'll use it [a food and activity tracking app] for myself sometimes to track what I'm eating, and when I was focused on losing weight. And I haven't really been focused on it because I'm focused on something else right now.* [Female, aged 45-59 y, with type 2 diabetes]

If they did use trackable data, interviewees wanted to control how frequently they were prompted to track data and what types of prompts they received:

> *So again, you know I'm technical, technically savvy, whatever you want to call it. And I thought that the app would be perfect for me, thinking, by my lifestyle being on the go and stuff like that. But, it really wasn't. So one of one of the biggest things that I didn't like about it, is it overrides. It was overriding anything [settings] that I had on my phone at the time...It was just like, you know, bust through...I didn't know about the alarms and things so it's going off, you know, during times where it's inappropriate.* [Female, aged 26-44 y, with type 2 diabetes discussing the mobile app that accompanies the CGM]

Interviewees preferred that their data were easy to visualize and interpret:

> *The application that [the CGM company] provides does provide a graphing capability. So I can graph or print the numbers out for the 3 months time period, and take those along with me for [the physician] to look at...It'll tell you what your actual numbers were, for the average ones for the day, what the average was for the last 30 days, the last 90 days. And it'll do a trend line for you. Tell you the time in within range. So all that information is there, and we do share it.* [Male, aged 60-70 y, with type 2 diabetes]

> *Yeah. I love [the CGM]. Yeah, I love, It makes things so much easier to put in perspective, like with the graphs and stuff.* [Male, aged 45-59 y, with type 2 diabetes]

Interviewees felt that the lower the burden of tracking, the better. They expressed a preference for passive collection of data. Manual data entry was viewed as a difficult habit to maintain:

> *I don't [track] anymore with the [manual entry] activity trackers because they're more cumbersome than anything, and like I said, that's why the [watch with activity tracker capability] is working, because it's just tracking without me being actively needing to work it out. I used the [food and activity tracking app] more for the, for the nutritional information...but then after a month it's just too cumbersome to log every single thing over there.* [Male, aged 45-59 y, with type 2 diabetes]

Interviewees preferred seeing data from multiple behaviors in one place, which was described as reducing the burden of data use and, in some cases, helping them make connections between health behaviors and blood glucose levels:

> *So everything is very integrated in my phone, [the health app] even brings my medications, even brings my labs [and] tests. You know, I look at my sleep and go through the sleep. I look at my steps but because I'm not actively physically active, it's more of "okay, here's the information." It's nice to see.* [Male, aged 45-59 y, with type 2 diabetes]

> *Yes, I have [the CGM] connected to the [CGM] app, and then [other app] is connected to the watch. I just noticed when I was putting in my weight on the [wearable activity tracker] it has the glucose readings on that as well. I guess they're connecting...it is helpful because they have like the charts. So it's just nice to see like it's all in range or it's going up and down.* [Female, aged 26-44 y, with type 1 diabetes]

Discussion

Principal Findings

In this web-based survey of diverse adults with diabetes and moderate to high digital health literacy, we found that nearly two-thirds (33/53, 62%) used technology to track >1 lifestyle factor impacting their daily diabetes self-management. This included individuals who did not use CGMs and those with varying levels of digital health literacy. It is important to note that participants self-selected to participate in the survey, which was posted on the web, and this may have skewed the sample toward those with higher digital health literacy. Wearable activity trackers were equally used among CGM users and nonusers. Mobile apps used to track blood glucose levels and eating were more common than those used for stress or sleep; however, approximately a quarter of the respondents tracked their stress (13/61, 21%) and sleep (14/61, 23%) levels using apps. In the sample of interviewees with overall higher digital health literacy, we found that current technology offers adults with diabetes an opportunity to customize general diabetes lifestyle advice to their needs and, for some, reduces stress around diabetes management. Given that these adults with diabetes who were able to respond to a web posting to participate in a research study were tracking multiple behaviors, there may be untapped potential, at least among technology-savvy adults with diabetes, to link data from tracking sources to diabetes self-management. Participants desired that apps and wearable activity trackers passively collect, integrate, and graphically display data from various sources in one place and allow customization to their changing personal goals over time.

Comparison to Prior Work

Our results echo those of prior qualitative studies that identified factors impacting the use of specific individual apps or activity trackers among adults with diabetes. These factors include ease of use, customizable user experiences, health care provider perceptions and guidance, and seamless connectivity. They impacted app and activity tracker use among diverse groups of adults with diabetes (including those on insulin) [26-30]. Our study uniquely focused on how adults with diabetes combined multiple types of diabetes self-management technologies rather than using a particular app or activity tracker. In particular, we were interested in how many people used >1 app because that could present an opportunity to understand how they integrate data from these different sources, particularly because some trackable behaviors (eg, sleep) can impact trackable blood glucose levels or other trackable behaviors (eg, physical activity).

In addition, while some prior studies addressed factors that affect CGM app use [30], our study examined the interface between CGM data, which are more voluminous than those generated by other apps, and diabetes self-management behavior data, which are often tracked on a daily basis. CGM data can be used for overviews, beyond minute-to-minute readings, which could make CGMs and behavior tracking apps easier to use together. There is untapped potential to connect these data sources and, particularly, to help adults with diabetes link data that they are tracking on stress and sleep to their tracked blood glucose levels.

Our results highlight the highly individualized impact of trackable lifestyle data on diabetes self-management behaviors beyond just tracking blood glucose levels. Interviewees who used CGMs described many uses beyond insulin dose adjustments, including using CGMs to guide and personalize their diabetes self-management routines. In this way, additional lifestyle data from novel trackers that cover other domains of diabetes self-management could add more insights and personalization to an individual's daily diabetes management. In particular, a better understanding of the relationship between personal data patterns and blood glucose levels could increase the sense of ownership of adults with diabetes over their diabetes self-management [31-33] and enhance intrinsic motivation for change [33-35].

Future Directions

Our study has important implications for how adults with diabetes can use and integrate multiple technologies for diabetes self-management. Participants in our study used apps for tracking multiple behaviors across different age groups and treatment regimens; therefore, technologically focused diabetes self-management education programs could be expanded to accommodate the growing number of non–insulin users who integrate wearable activity tracker, CGM, and app data to manage their condition. These programs could be focused on addressing known barriers among adults with diabetes to using technology for diabetes self-management, including a lack of understanding of how to use personal health data, low digital health literacy, and a lack of knowledge and overall awareness of digital tools used for diabetes [36,37]. Newer platforms that allow users to combine inputs from multiple sources of health data and understand the relationships between these domains have been shown to be acceptable to users [38] and effective in some cases for short-term treatment outcomes in people with type 1 [39,40] and type 2 [41-45] diabetes, although there was heterogeneity in the types of data and interventions included. Taken together, these findings demonstrate the opportunity to incorporate multiple data sources more deliberately in

personalized diabetes self-management education and diabetes self-management apps.

Strengths and Limitations

Our study has several strengths, such as the inclusion of a diverse cohort of adults with diabetes, including people who did not use insulin—especially because more individuals (including those not on insulin) are qualifying for wearable devices such as CGMs and are using health tracking apps.

Our study also has multiple limitations. First, it relies on a convenience sample that is not necessarily representative of the general population of adults with diabetes. In particular, participation was self-selected by people who could use the internet to respond to the study invitation, which could have led to the higher levels of digital health literacy in this sample and may have contributed to higher app and activity tracker use than the general population of adults with diabetes. Second, the experiences of adults with type 1 diabetes and low health literacy are not well represented in the qualitative interview data. Third, because our main goal in this exploratory study was to describe emergent patterns and not quantify associations at this level, we did not collect information about other comorbidities, employment status, geographic location, current blood glucose control, or other factors that might confound technology use. Fourth, the low numbers of participants in the low health literacy and digital health literacy categories limited our power to assess the associations between literacy and technology use. Finally, most of the respondents (58/61, 95%) were aged >25 years; therefore, the results may not be generalizable to teenagers or emerging young adults. The results of this study could guide topics and sampling strategies for future studies that include a wider population-based sample.

Conclusions

We found that a diverse cohort of adults with diabetes used several wearable and mobile app technologies to track multiple aspects of their daily routines relevant to diabetes self-management. They were interested in digital tools that were easy to use, integrated data across multiple platforms, and aligned with their personal priorities in customizable ways. Our findings have important implications for the ways in which adults with diabetes can be empowered to manage their health successfully and experience the benefits of health technologies.

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Data Availability

The datasets generated and analyzed during this study are not publicly available because the small sample size and detailed qualitative responses could make participants identifiable. Requests for deidentified survey data can be sent to the corresponding author and will be considered on a case-by-case basis.

Authors' Contributions

All authors contributed to the conceptualization, methodology, formal analysis, and writing (original draft as well as review and editing) of this paper. TB, SG, JK, and AMR were responsible for data curation. SG, JK, CL, and AMR were responsible for funding acquisition. TB, SG, and JK were responsible for investigation. TB and JK were responsible for software. SG, JK, MZ, CL, and AMR were responsible for resources. CL and AMR were responsible for supervision. TB, SG, JK, MZ, CL, and AMR were responsible for visualization.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Key survey items.
[DOCX File , 23 KB - diabetes_v10i1e64505_app1.docx]

Multimedia Appendix 2
Interview guide.
[DOCX File , 21 KB - diabetes_v10i1e64505_app2.docx]

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Abbreviations

CGM: continuous glucose monitor
DHLS: Digital Health Care Literacy Scale

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eHealth Literacy and Its Association With Demographic Factors, Disease-Specific Factors, and Well-Being Among Adults With Type 1 Diabetes: Cross-Sectional Survey Study

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Abstract

Background: The use of digital health technology in diabetes self-care is increasing, making eHealth literacy an important factor to consider among people with type 1 diabetes. There are very few studies investigating eHealth literacy among adults with type 1 diabetes, highlighting the need to explore this area further.

Objective: The aim of this study was to explore associations between eHealth literacy and demographic factors, disease-specific factors, and well-being among adults with type 1 diabetes.

Methods: The study used data from a larger cross-sectional survey conducted among adults with type 1 diabetes in Sweden (N=301). Participants were recruited using a convenience sampling method primarily through advertisements on social media. Data were collected between September and November 2022 primarily through a web-based survey, although participants could opt to answer a paper-based survey. Screening questions at the beginning of the survey determined eligibility to participate. In this study, eHealth literacy was assessed using the Swedish version of the eHealth Literacy Scale (Sw-eHEALS). The predictor variables, well-being was assessed using the World Health Organization-5 Well-Being Index and psychosocial self-efficacy using the Swedish version of the Diabetes Empowerment Scale. The survey also included research group–developed questions on demographic and disease-specific variables as well as digital health technology use. Data were analyzed using multiple linear regression presented as nested models. A sample size of 270 participants was required in order to detect an association between the dependent and predictor variables using a regression model based on an *F* test. The final sample size included in the nested regression model was 285.

Results: The mean Sw-eHEALS score was 33.42 (SD 5.32; range 8‐40). The model involving both demographic and disease-specific variables explained 31.5% of the total variation in eHealth literacy and was deemed the best-fitting model. Younger age (*P*=.01; B=–0.07, SE=0.03;95% CI –0.12 to –0.02), lower self-reported glycated hemoglobin levels (*P*=.04; B=–0.06, SE=0.03; 95% CI –0.12 to 0.00), and higher psychosocial self-efficacy (*P*<.001; B=3.72, SE=0.53; 95% CI 2.68-4.75) were found associated with higher Sw-eHEALS scores when adjusted for demographic and disease-specific variables in this model. Well-being was not associated with eHealth literacy in this study.

Conclusions: The demographic and disease-specific factors explained the variation in eHealth literacy in this sample. Further studies in this area using newer eHealth literacy tools are important to validate our findings. The study highlights the importance of development and testing of interventions to improve eHealth literacy in this population for better glucose control. These eHealth literacy interventions should be tailored to meet the needs of people in varying age groups and with differing levels of psychosocial self-efficacy.

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KEYWORDS

cross-sectional studies; diabetes mellitus, type 1; digital technology; eHealth literacy; health literacy

Introduction

Self-care in type 1 diabetes imposes considerable challenges on the individual due to the complexities of insulin therapy and the lifestyle management it requires [1]. It is described as a constraining disease that is manageable through various approaches and support [2]. Advancements in digital devices and software applications designed to aid in diabetes self-care—digital health technology (DHT)—have helped ease these self-care challenges and people's management of diabetes in their daily lives [1,3]. DHT includes devices and applications that support lifestyle modifications, monitor glucose levels, and adjust therapy. They include blood glucose meters, continuous glucose monitoring (CGM), continuous subcutaneous insulin infusion (CSII) pumps, automated insulin dosing (AID) or hybrid closed loop systems, smart insulin pens, and associated mobile health (mHealth) apps [3]. These have been found to improve glucose outcomes in people with diabetes [3-5]. Research shows an increase in the use of CGM [4], CSII [5], and AID [4] in recent years. As per the data available in the Swedish National Diabetes Register, 93.5% of adults with type 1 diabetes use CGM, and 33.1% use insulin pumps, including AID [6]. However, each DHT's features and functionalities may pose challenges, such as learning to use a new device and the time required to get it to work, fatigue induced by frequent alarms, calibration requirements, the need to manage multiple devices, and possible signal loss. These factors can impact DHT uptake and use [7]. Additionally, negative attitudes toward DHTs have been associated with poor glucose control [8]. Education and awareness play an important role in fostering understanding and the effective use of advanced DHTs for diabetes [9]. Studies have found higher levels of health literacy being associated with better understanding and comfort in using CGM [10]. Therefore, when introducing various DHTs for diabetes, it is important to consider people's readiness for health technology, which includes their level of eHealth literacy [11].

eHealth literacy encompasses the ability to search, find, understand, and evaluate health-related information through electronic platforms to address or solve health issues. eHealth literacy is influenced by 6 core skills, namely, traditional literacy, health literacy, information literacy, scientific literacy, media literacy, and computer literacy. It is also influenced by people's current health conditions, educational background, health status during the time of the eHealth encounter, reason for seeking information, and the digital technologies used. This skill set evolves over time alongside the introduction of new technologies and changes in personal, social, and environmental contexts [12]. An awareness of a DHT user's eHealth literacy is important for reducing health inequalities stemming from modifiable social factors [13]. Previous studies have found that eHealth literacy is significantly associated with age [14], education [15,16], gender [14,16], income [16], employment status [17], well-being, living alone [17], psychological distress [14], quality of life, self-efficacy [18], using the internet for health-related purposes, technology readiness [15], and mHealth use [19]. High eHealth literacy has been linked to smart device use [20] and less stress while using computers [21]. Among people with diabetes, higher eHealth literacy is associated with better self-care behaviors [22,23], moderated through digital diabetes information seeking [23]. Among this population, eHealth literacy scores are significantly higher among those who are women [23], younger than 65 years, with a university education [22,23], are employed, living with others [22], and using mHealth apps [24].

The management of type 1 diabetes is complex, and DHT use for self-care and disease management is on the rise. Despite the positive impact of DHT on people's glucose outcomes [3], the changing features and functionalities related to various DHTs may pose challenges in their use. Therefore, eHealth literacy may play an important role in mastering the effective use of DHT for type 1 diabetes self-care. Studies have found that higher eHealth literacy is associated with improved digital device use. However, there are limited studies examining eHealth literacy among adults with type 1 diabetes. Exploring the associations between eHealth literacy and various predictors may help us understand the eHealth literacy needs of this population and the factors influencing it. This knowledge may help health care practitioners to develop targeted interventions to improve eHealth literacy among vulnerable groups and thereby promote effective DHT use for self-care. This is also important in promoting equity in DHT use in type 1 diabetes, which is a social responsibility [9]. Therefore, the aim of this study was to explore the associations between eHealth literacy and demographic factors, disease-specific factors, and well-being among adults with type 1 diabetes.

Methods

This paper is part of a larger cross-sectional survey study conducted in autumn 2022 and is reported here in accordance with the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) guidelines [25].

Population

The study used a convenience sampling method and included adults (≥18 years) with type 1 diabetes who could understand Swedish. Women with type 1 diabetes were excluded if pregnant due to changes in maternal insulin sensitivity during pregnancy, as this may require alterations in their treatment plan [26]. This could indirectly influence other predictor variables like well-being and psychosocial self-efficacy [27,28].

Recruitment

Participants were recruited primarily through advertisements on social media, particularly Facebook (using the marketing feature as well as posting in private groups for people with diabetes in Sweden). In addition, advertisements were placed on the websites of various associations for people with diabetes in Sweden and at a diabetes center in a regional hospital. More details on recruitment methods are available in a previously published paper [29].

Sample Size Calculation

The sample size was calculated using SPSS (version 28; IBM Corp). A sample size of 270 participants was required in order to detect an association between the dependent and predictor variables using a regression model. This calculation was based

on an *F* test with 20% predictability using 25 predictors in the full model and 15% predictability with 10 predictors in the nested model at 80% power and a .05 level of significance. To account for potential missing values, we decided to include 300 participants in the study.

Data Collection

Data were collected between September and November 2022 (approximately 2 months) until the desired sample size was reached, primarily through a web-based survey (Survey&Report platform by Artisans Media). The survey could be accessed via a website link or QR code provided in the advertisement flyer. Three screening questions (age, diabetes type, and pregnancy status) at the beginning of the survey helped determine eligibility to participate. The survey closed automatically if any of the exclusion criteria were met. Alternatively, participants could opt to answer a paper-based survey, which was sent to the address they provided (n=6). The survey was in Swedish and was part of a larger study. It had 64 questions in total, and data from 55 questions have been included in this paper. Certain questions were marked as mandatory, requiring participants to answer them before proceeding to the next page. Additionally, questions that were not applicable were hidden based on the participant's responses to the preceding question. Thus, the number of questions each participant answered varied from 53 to 64. Participants had the option to partially complete the survey and save their progress to finish it at a later time. Therefore, the duration taken to answer the web-based survey varied highly from 5 minutes to 1.5 days. The majority (273/295, 92.5%) answered the web-based survey in 60 minutes, with 15.2% (45/295) answering it in less than 8 minutes.

Ethical Considerations

This study was conducted in accordance with the World Medical Association's Helsinki Declaration. The study plan was reviewed by the Swedish Ethical Review Authority, and ethics approval (Dnr: 2021-05337-01 and Dnr: 2022-04079-02) was received for this paper before the commencement of data collection. Participation in the survey was voluntary, and informed consent was obtained from all participants either via the survey tool or in written form. The participants did not receive any remuneration or compensation for their participation in the study. To deidentify the data and protect participant privacy, the raw data were pseudonymized either using the web survey tool or using codes and keys (for paper surveys). In addition, the survey tool, cloud storage (Sunet Drive), laptops, and software used in the analysis were procured by Karlstad University, ensuring the European Union's General Data Protection Regulation.

Variables and Measurement Tools

Outcome Variable

eHealth literacy was measured using the 8-item Swedish version of the eHealth Literacy Scale (Sw-eHEALS). No additional contextual questions were used. Each item is rated on a 5-point Likert scale, ranging from 1=strongly disagree to 5=strongly agree, with a higher score indicating higher eHealth literacy. The scale has a good internal consistency (Cronbach α=0.94). The total Sw-eHEALS score is obtained by calculating the sum of the scores of each item, with possible scores ranging from 8 to 40 [30,31]. In this paper, the eHealth literacy score was treated as a continuous variable.

Predictor Variables

The predictor variables included in this study were identified from previous research in eHealth literacy as well as diabetes self-care. Psychosocial self-efficacy, which is a measure of psychosocial adjustment to diabetes, was measured using the 23-item Swedish version of the Diabetes Empowerment Scale (Swe-DES-23). A higher Swe-DES-23 score indicates greater psychosocial self-efficacy [32,33]. The total Swe-DES-23 score (ranging from 1 to 5) was calculated by adding the scores of individual items together and dividing by the number of items. Well-being was assessed using the World Health Organization-5 Well-Being Index [34]. The total World Health Organization-5 Well-Being Index score ranges from 0 to 100, with higher scores indicating higher levels of well-being [35].

The survey also contained questions related to demographic variables, disease-specific variables, and DHT use. These questions were developed by the research group and were pilot-tested among adults with type 1 diabetes (n=9) and diabetes nurses (n=4) to validate the content. The suggestions received from the pilot test were incorporated into the main survey questionnaire. See Multimedia Appendix 1 for outline of questionnaire.

Data Analysis

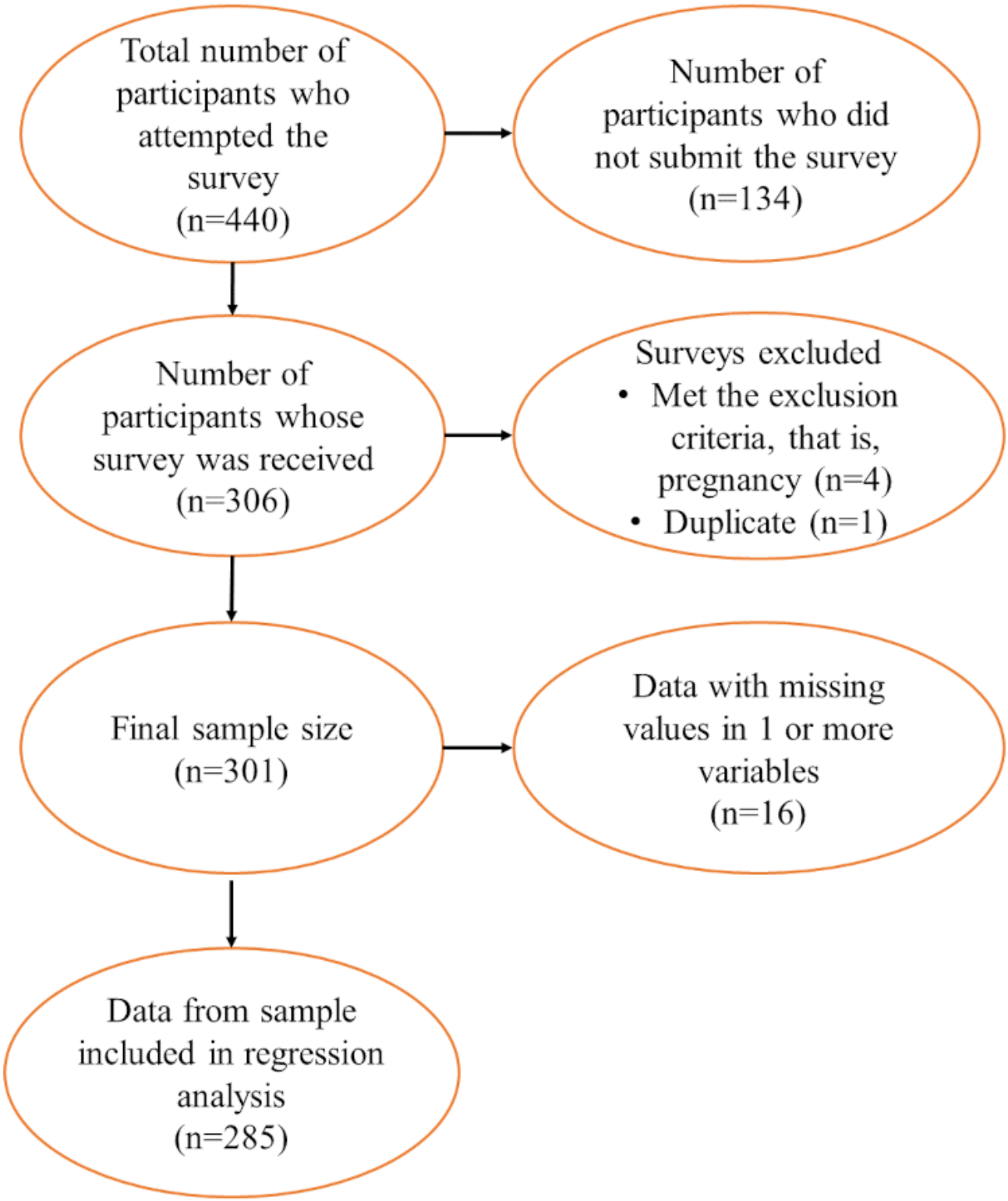
Data analysis was conducted using SPSS (version 28; IBM Corp). Mean and SD or frequency and percentages were used to describe the characteristics of the included participants. In these data, residuals were found to be normally distributed, homoscedastic, and free from multicollinearity. Nested linear regression models were used to identify the best-fitting model. Predictor variables were grouped into 3 blocks. Block 1 consisted of demographic variables, block 2 comprised disease-specific variables, and block 3 involved well-being. Model 1 included variables from block 1, model 2 included variables from block 1 and block 2, and model 3 encompassed variables from all 3 blocks. Multiple linear regression was run using the enter method to identify the best-fitting model. A *P* value of <.05 was considered to be statistically significant. No imputations were performed for missing values.

Results

Characteristics of the Study Sample

The final sample size achieved was 301. Data from participants with missing values in 1 or more of the predictor variables were excluded from the regression analysis (n=16), resulting in a sample size of 285 participants for analysis. A survey completion rate of 68.4% (301/440) was achieved for the web-based survey. This was calculated by dividing the number of participants who completed the survey and was included in the final sample by the total number of participants who initiated answering the survey (see Figure 1 for more details).

Figure 1. Flowchart of participants included in the study and in regression analysis.



The mean Sw-eHEALS score among this sample was 33.42 (SD 5.32; range 8 - 40). A ceiling effect in the Sw-eHEALS score (with the maximum score of 40 achieved by 56/301, 18.6% of participants) was found in this sample (see Figure 2 for more details). The majority of participants completed the survey digitally (295/301, 98%). Participants had a mean age of 43 (SD 16) years, with the majority being women (215/301, 71.4%). See Table 1 for descriptive statistics on variables included in the regression analysis. All participants (301/301, 100%) reported using 1 or more forms of digital device for their diabetes self-care. Digital device use by participants consisted of blood glucose meters (146/301, 48.5%), intermittent scanning CGM (119/301, 39.5%), real-time CGM (156/301, 51.8%), CSII (102/301, 33.9%) pumps, AID (71/301, 23.6%), and smart insulin pens (28/301, 9.3%). See Table 2 for details on the Sw-eHEALS score in relation to DHTs used by the participants.

Figure 2. Scatter plot depicting ceiling effect in Sw-eHEALS total score. Sw-eHEALS: Swedish version of the eHealth Literacy Scale.

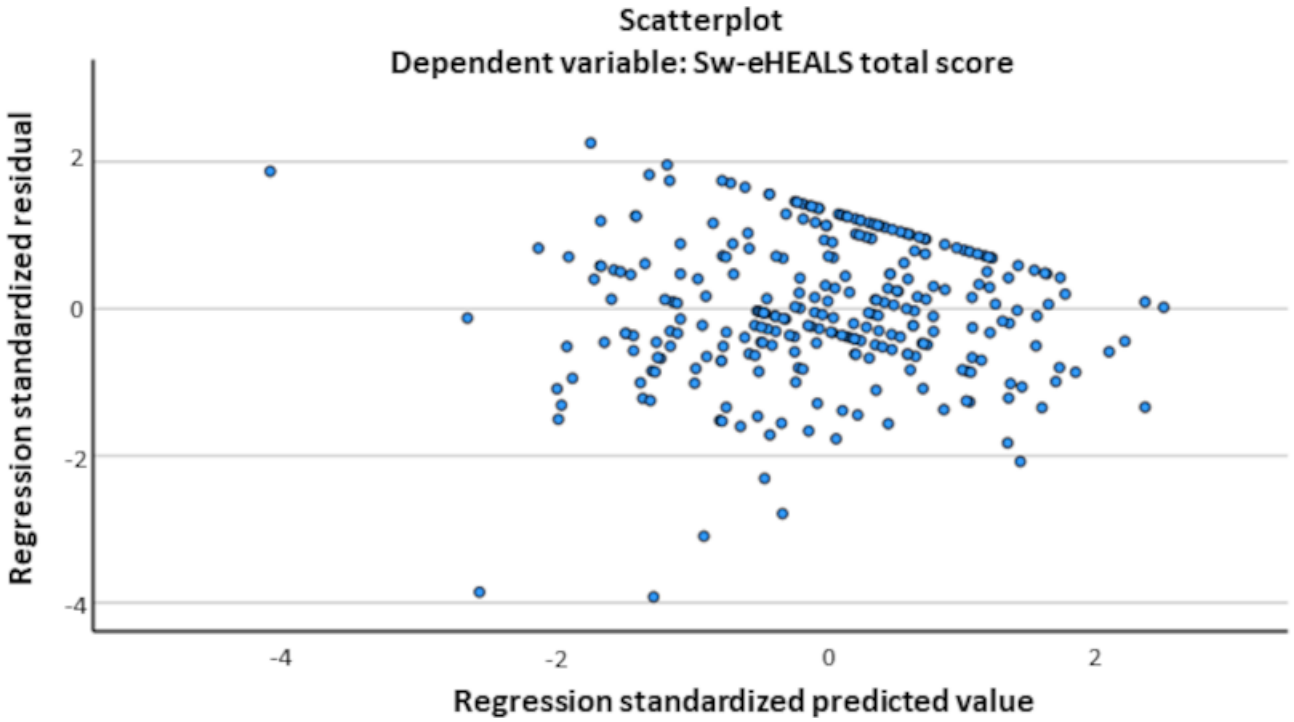


Table . Descriptive statistics of variables included in the regression analysis.

Predictor variables	Values
Demographic variables	
Age (years) (N=301)	
Mean (SD)	42.7 (15.8)
Range	18 - 86
Gender (N=301), n (%)	
Women	215 (71.4)
Men	86 (28.6)
Education level (n=299)[a], n (%)	
University level education	167 (55.9)
Primary or secondary school	132 (44.1)
Employment status (N=301), n (%)	
Studying	47 (15.6)
Employed full or part time	191 (63.5)
Unemployed or sick or retired	63 (20.9)
Living condition (N=301), n (%)	
Living alone	73 (24.3)
Living with a spouse or partner or another adult	131 (43.5)
Living with a spouse or partner or another adult or with children	97 (32.2)
Income level[b] (SEK[c]) (n=300)[a], n (%)	
≤24,999	114 (38)
25,000 - 34,999	76 (25.4)
35,000 - 44,999	64 (21.3)
≥45,000	46 (15.3)
Disease-specific variables	
Chronic diabetes complications (N=301), n (%)	
No chronic complication	214 (71.1)
1 chronic complication	56 (18.6)
2 or more chronic complications	31 (10.3)
Multimorbidity (n=300)[a], n (%)	
No other illness	166 (55.3)
1 other illness	78 (26)
≥2 other illness	56 (18.7)
Duration of diabetes (years) (N=301)	
Mean (SD)	21.7 (16.8)
Range	<1 - 75
HbA_{1c}[d] (mmol/mol) (n=290)[a]	
Mean (SD)	51.4 (11)
Range	30 - 107
Swe-DES-23[e] total (N=301)	
Mean (SD)	3.8 (0.6)
Range	2.0 - 5.0

Predictor variables	Values
BMI (kg/m^2) (n=300)[a]	
Mean (SD)	26.7 (5.1)
Range	16.8 - 46.3
Well-being	
WHO-5[f] total (n=300)[a]	
Mean (SD)	56 (19.9)
Range	4.0 - 100

[a]Total number of cases is not 301 for all variables due to missing values.

[b]Income level refers to monthly income before tax deductions.

[c]SEK: Swedish Kronor. A currency exchange rate of 1 SEK=US $0.10 is applicable.

[d]HbA_{1c}: glycated hemoglobin.

[e]Swe-DES-23: Swedish version of Diabetes Empowerment Scale.

[f]WHO-5: World Health Organization-5 Well-Being Index.

Table . Swedish version of the eHealth Literacy Scale (Sw-eHEALS) score in relation to digital health technology (DHT) used by the participants.

DHT used	Values, n (%)	Sw-eHEALS score, mean (SD)
Digital device use (n=300)		
3 or more digital device	73 (24.3)	34.2 (4.9)
2 digital device	160 (53.4)	33.2 (5.8)
1 digital device	67 (22.3)	33.1 (4.4)
mHealth[a] app use (n=301)		
Users	241 (80.1)	33.6 (5.3)
Nonusers	60 (19.9)	32.7 (5.5)
mHealth app feature type (n=241)		
Automatic data transfer from devices to mHealth app		
Users	224 (92.9)	33.8 (5.2)
Nonusers	17 (7.1)	31.4 (5.9)
Glucose entry		
Users	220 (91.3)	33.7 (5.3)
Nonusers	21 (8.7)	32.9 (4.6)
Warning alarm for high or low glucose levels		
Users	203 (84.2)	33.7 (5.4)
Nonusers	38 (15.8)	32.8 (4.6)
Graphical features		
Users	162 (67.2)	34.3 (4.5)
Nonusers	79 (32.8)	32.1 (6.4)
Insulin dose registration		
Users	116 (48.1)	34.1 (4.9)
Nonusers	125 (51.9)	33.1 (5.5)
Reminder		
Users	105 (43.6)	34.4 (4.9)
Nonusers	136 (56.4)	33.0 (5.5)
Carbohydrate calculator		
Users	86 (35.7)	34.0 (4.9)
Nonusers	155 (64.3)	33.4 (5.5)
Physical activity monitoring		
Users	78 (32.4)	34.1 (4.9)
Nonusers	163 (67.6)	33.4 (5.4)
Diet monitoring		
Users	68 (28.2)	34.6 (4.9)
Nonusers	173 (71.8)	33.2 (5.3)
Contacting or data sharing with health care personnel or relatives		
Users	56 (23.2)	34.5 (4.3)
Nonusers	185 (76.8)	33.3 (5.5)
Insulin bolus calculator		
Users	46 (19.1)	33.9 (5.4)
Nonusers	195 (80.9)	33.5 (5.2)

[a]mHealth: mobile health.

Predictors of eHealth Literacy

Nested linear regression models were used to explore the associations between the outcome variable, eHealth literacy, and predictor variables. Model 1, comprising demographic variables alone, accounted for 12.9% of the total variation in eHealth literacy, with age, education level, and income level showing associations with the Sw-eHEALS score. Model 2, involving both demographic and disease-specific variables, explained 31.5% of the total variation in eHealth literacy and was deemed the best-fitting model. In model 2, the predictors' age, glycated hemoglobin (HbA_{1c}), and psychosocial self-efficacy showed associations with the Sw-eHEALS score after adjusting for demographic and disease-specific variables. Model 3, involving all predictors (ie, demographic and disease-specific variables and well-being), explained 31.6% of the variance in eHealth literacy. However, the *F* change for this model was not significant and therefore is not presented here. See Table 3 for detailed results of the regression analyses.

Table . Nested multiple linear regression models on the association between eHealth literacy (Swedish version of the eHealth Literacy Scale) and potential predictive variables (n=285).

Potential predictive variables	Model 1: demographic variables[a]			Model 2: demographic and disease-specific variables[b]		
	B[c] (SE)	95% CI	*P* value	B[c] (SE)	95% CI	*P* value
Constant	30.24 (2.18)	25.94 to 34.53	<.001	18.50 (3.69)	11.24 to 25.76	<.001
Age (years)	–0.06 (0.03)	–0.11 to 0.00	.04	–0.07 (0.03)	–0.12 to –0.02	.01
Gender (reference=men)						
Women	0.25 (0.71)	–1.15 to 1.66	.72	0.74 (0.65)	–0.54 to 2.02	.26
Living condition (reference=living alone)						
Living with a spouse or partner or another adult	0.67 (0.78)	–0.87 to 2.21	.39	0.22 (0.71)	–1.18 to 1.62	.76
Living with a spouse or partner or another adult or with children	0.62 (0.85)	–1.06 to 2.30	.47	0.31 (0.78)	–1.23 to 1.85	.69
Education level (reference=primary or secondary school)						
University level education	1.91 (0.66)	0.61 to 3.22	.004	1.19 (0.61)	–0.01 to 2.40	.053
Employment status (reference=employed full or half time)						
Unemployed or sick or retired	0.18 (1.06)	–1.91 to 2.27	.87	–0.24 (1.03)	–2.27 to 1.80	.82
Studying	1.41 (1.19)	–0.93 to 3.75	.24	0.62 (1.10)	–1.55 to 2.78	.58
Income level[d] (SEK[e]) (reference is ≤24,999)						
25,000 - 34,999	1.71 (1.02)	–0.30 to 3.71	.09	1.03 (0.95)	–0.85 to 2.91	.28
35,000 - 44,999	2.65 (1.11)	0.47 to 4.83	.02	1.53 (1.03)	–0.50 to 3.57	.14
≥45,000	2.91 (1.23)[d]	0.49 to 5.33	.02	1.67 (1.13)	–0.55 to 3.89	.14
Diabetes complication (reference=no complication)						
1 complication	—[f]	—	—	1.10 (0.75)	–0.39 to 2.58	.15
2 or more complications	—	—	—	1.34 (1.08)	–0.80 to 3.47	.22
Multimorbidity (reference=no other illness)						
1 other illness	—	—	—	–0.33 (0.66)	–1.62 to 0.97	.62
2 or more other illness	—	—	—	–1.02 (0.78)	–2.56 to 0.51	.19
BMI (kg/m^2)	—	—	—	0.08 (0.06)	–0.03 to 0.19	.15
HbA_{1c}[g] (mmol/mol)	—	—	—	–0.06 (0.03)	–0.12 to 0.00	.04
Duration of diabetes (in years)	—	—	—	0.00 (0.02)	–0.04 to 0.04	.93
Swe-DES-23[h] total score	—	—	—	3.72 (0.53)	2.68 to 4.75	<.001

[a]Multiple R^2=0.129; R^2 change=0.129; F_{10} change=4.07; significance of *F* change <.001 (statistically significant at *P*<.05).

[b]Multiple R^2=0.31; R^2 change=0.19; F_8 change=9.04; significance of *F* change <.001 (statistically significant at *P*<.05).

[c]Unstandardized β value.

[d]Income level refers to monthly income before tax deductions.

[e]SEK: Swedish Kronor. A currency exchange rate of 1 SEK=US $0.10 is applicable.

[f]Not applicable.

[g]HbA_{1c}: glycated hemoglobin.

[h]Swedish version of Diabetes Empowerment Scale.

Discussion

Principal Findings and Comparison to Prior Work

This study explored associations between eHealth literacy and demographic factors, disease-specific factors, and well-being among adults with type 1 diabetes. The sample in this study was slightly younger, predominantly women, and had a shorter duration of diabetes compared to the statistics on adults with type 1 diabetes published by the Swedish National Diabetes Register [6]. The majority of the participants in this study had a university-level education, which is not in line with studies reporting on type 1 diabetes population from Sweden [36] or other countries [37]. The mean Sw-eHEALS score among this sample was higher than that found in other studies among people with type 2 diabetes [38], the general population [30], and older adults [14] in Sweden and in other cultural and language settings [39]. Comparable empirical studies on eHealth literacy among adults with type 1 diabetes were not found. The mean Sw-eHEALS score is slightly higher among participants who use 3 or more digital devices, mHealth app users, and users of various features. However, this difference is too minor to draw a conclusion.

Similar to our results, other studies have found that younger age [14,22] and self-efficacy [18,40] are associated with higher eHealth literacy scores. However, in contrast to our findings, some studies found no association between eHealth literacy scores and age [17,39]. Additionally, some studies did not find any association between eHealth literacy and gender [15,17], education, or income [17], which aligns with this study's findings when adjusted for disease-specific factors. Conversely, some studies found significant associations of eHealth literacy with gender [14], education level [15], employment status, well-being, and living status [17]. In this study, higher eHealth literacy was associated with lower HbA_{1c} levels, but similar studies to compare our results were not found. Similar to our findings, studies have found a relationship between HbA_{1c} levels and health literacy [41,42] or functional health literacy [43]. In contrast, other studies found no association between HbA_{1c} levels and mobile eHealth literacy [44] or functional health literacy [45]. However, the finding on the association between higher eHealth literacy and lower HbA_{1c} levels needs to be read with caution, considering the near normal range mean HbA_{1c} levels, self-reported HbA_{1c}, ceiling effect in Sw-eHEALS, and various other uncontrolled factors that could influence HbA_{1c} levels in this sample. Therefore, further studies are needed to determine the clinical relevance of this finding.

Strengths and Limitations

eHealth literacy and its association with various factors among people with type 1 diabetes is a less studied area. This study utilized widely used and validated questionnaires to measure eHealth literacy [30,31], psychosocial self-efficacy [32,33], and well-being [46]. Other questions in the survey were pilot-tested to validate their content among the targeted population and health professionals. We achieved a sufficient sample size to perform regression analysis with adequate power. The study also had higher than average completion rates for a web-based survey [47]. The total survey response time of less than 8 minutes, which may indicate insufficient effort responding, was seen in 15.2% (45/295) of the sample who answered the web-based survey, reducing the risk of inflated correlations [48]. However, we have not done an in-depth analysis to detect and eliminate insufficient effort responding. The majority of participants were recruited via social media, allowing for recruitment from all over Sweden, which strengthens the study's transferability. Additionally, the higher rate of digital survey responses compared to paper format responses may imply that participants with higher eHealth literacy were more likely to volunteer, potentially leading to selection bias. We may also have missed participants who do not use social media. The sample in this study consisted entirely of DHT users, which is not surprising, given that CGM and CSII use is high in Sweden [6], as it is financed through a publicly funded high-cost protection scheme [49].

The outcome variable, the eHealth Literacy Scale (eHEALS) score, is a valid and reliable measure of self-reported eHealth literacy among people with chronic diseases [50]. This instrument has been widely tested, used in diverse populations, and has sufficient moderate quality evidence for comprehensibility [51]. However, the eHEALS instrument has its weaknesses. The original eHEALS measures people's perceived skills with eHealth and is an indirect measure of eHealth literacy [31]. It is a single-factor scale, which was developed before the time of social media and mHealth, prioritizing ease of administration [52]. Therefore, it is not updated to account for the current dynamicity, interactivity, and multifaceted nature of the internet, social media, and mobile web [51-53]. This has led to the development of newer, more relevant instruments to measure eHealth literacy [53-55]. Findings from this study, therefore, call for further research in this field using newer measures that account for the dynamicity and evolving nature of eHealth literacy.

The ceiling effect in the eHEALS score seen in this study (Figure 2) may have led to an inability to capture true differences between participants achieving the highest possible score, thus reducing the reliability of the results [56]. It may also point toward the outdated content validity of this instrument [56] in the current digital era. However, this ceiling effect has not been previously reported in other studies using the same instrument [30,38,39]. The results of this study, therefore, should be generalized with caution, considering the advanced DHTs currently used by people with type 1 diabetes.

Conclusions

In this study, associations were found between eHealth literacy and age, psychosocial self-efficacy, and HbA_{1c} levels. People with lower HbA_{1c} levels had higher eHealth literacy scores,

which may indicate their ability to effectively use electronic information and DHT to manage their glucose levels. Interventions to improve eHealth literacy in this population are therefore important for better glucose control. Therefore, further studies focusing on the development and testing of eHealth literacy interventions are recommended. Our results highlight the importance of considering people's age and psychosocial self-efficacy in acquiring appropriate eHealth literacy. Therefore, eHealth literacy interventions should be tailored to meet the needs of people in varying age groups and with different levels of psychosocial self-efficacy. Further studies in this area are therefore recommended.

The use of nested regression models is a strength of this study, improving data generalizability. However, the results of this paper are to be interpreted with caution, especially due to the ceiling effect observed in the eHealth literacy scores. Further studies in this area using newer eHealth literacy tools are important to validate our findings.

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Data Availability

The datasets generated or analyzed during this study are available from the authors on reasonable request.

Authors' Contributions

DAS, AN, UBJ, and JN were involved in designing the study and the questionnaire. Data were collected by DAS. Additionally, DAS performed the data analysis with support from the statistician, which was critically reviewed by AN, UBJ, and JN and amended as needed. DAS drafted the first version of the manuscript, and along with AN, UBJ, and JN, critically reviewed and modified it. All 4 authors approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Questionnaire outline.
[DOCX File, 117 KB - diabetes_v10i1e66117_app1.docx]

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Abbreviations

AID: automated insulin dosing
CGM: continuous glucose monitoring
CSII: continuous subcutaneous insulin infusion
DHT: digital health technology
eHEALS: eHealth Literacy Scale
HbA_{1c}: glycated hemoglobin
mHealth: mobile health
STROBE: Strengthening the Reporting of Observational Studies in Epidemiology
Sw-eHEALS: Swedish version of eHealth Literacy Scale
Swe-DES-23: Swedish version of the Diabetes Empowerment Scale

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Original Paper

Patient and Clinician Perspectives on the Effectiveness of Current Telemedicine Approaches in Endocrinology Care for Type 2 Diabetes: Qualitative Study

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Abstract

Background: Since the rapid widespread uptake in 2020, the use of telemedicine to deliver diabetes specialty care has persisted. However, evidence evaluating patient and clinician perspectives on benefits, shortcomings, and approaches to improve telemedicine care for type 2 diabetes is limited.

Objective: This study aims to assess clinician and patient perspectives on specific benefits and limitations of current telemedicine care delivery for type 2 diabetes and views on approaches to enhance telemedicine effectiveness for patients who rely on it.

Methods: We conducted semistructured qualitative interviews with diabetes specialty clinicians and adults with type 2 diabetes. We used a qualitative description approach to characterize participant perspectives on care delivery for type 2 diabetes via telemedicine.

Results: Both clinicians (n=15) and patients (n=13) identify significant benefits of telemedicine in overcoming both physical (geographic and transportation) and scheduling (work commitments and wait times) barriers to specialty care for type 2 diabetes. In addition, telemedicine may enhance communication around diabetes care by improving information sharing between patients and clinicians. However, clinicians identify limited availability of home blood glucose data and vital signs as factors, which impair the optimal management of type 2 diabetes and related comorbid conditions via telemedicine. Previsit preparation, involvement of multidisciplinary providers, and frequent brief check-ins were identified by patients and clinicians as potential strategies to improve the quality of telemedicine care for adults with type 2 diabetes.

Conclusions: Patients and clinicians identify key strengths of telemedicine in enhancing access to diabetes specialty care for adults with type 2 diabetes and describe approaches to ensure that telemedicine delivers high-quality diabetes care to patients who rely on it.

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KEYWORDS

diabetes; telemedicine; video visit; endocrinology; effectiveness; type 2 diabetes mellitus; patient; perspectives; qualitative interviews; clinicians

Introduction

The use of telemedicine—synchronous, audiovisual, internet-based communication between patients and clinicians—to provide endocrinology care expanded rapidly in 2020 [1,2]. While many patients have since resumed in-person care, a significant proportion of patients continue to use telemedicine: more than 11% of endocrinology visits in a national sample from January 2022 to March 2023 were conducted via telemedicine [3]. Telemedicine can expand access to endocrinology care for patients in rural areas of the United States, where there are long-standing shortages of endocrinologists [4], and for patients who face transportation, mobility, or other barriers to in-person care. The use of telemedicine to increase access to specialty diabetes care is supported by national guidelines, which also support the need for additional research assessing components of successful implementation of telemedicine programs [5,6]. Evidence from randomized trials of telemedicine interventions for type 2 diabetes (T2D) demonstrates that remote review of blood glucose by care teams [7,8]; active remote medication adjustment [8,9]; patient engagement between visits via phone, text message, or portals [9]; multidisciplinary team involvement in virtual care [8]; and remote diabetes self-management education and support services [10-12] are associated with the greatest hemoglobin A_{1c} improvement and may support diabetes care quality. However, evidence on the benefits and limitations of real-world telemedicine approaches to provide endocrinology care to adults with T2D outside of trial settings is limited.

Retrospective analyses of real-world telemedicine outcomes for adults with T2D in primary care settings have had mixed results, with some studies finding equivalent or superior glycemic outcomes to in-person care [13-16], while others demonstrate inferior care quality [15,17,18]. However, evidence suggests that patients using telemedicine alone to access endocrinology care for T2D may not experience the same glycemic improvements as patients using in-person care [19]. We previously completed a survey study of diabetes specialists on factors impacting the quality of diabetes care delivered via telemedicine, in which clinicians cited clinical complexity, as well as limited clinical resources to support telemedicine, as factors that reduce effectiveness [20]. However, clinician and patient perspectives on the benefits and limitations of current telemedicine care delivery and approaches to improve this care have not been explored. As a result, in this study, we aimed to gain a deeper understanding of the perspectives of both diabetes specialty clinicians and patients on specific benefits and limitations of current telemedicine approaches for T2D and ways to enhance telemedicine effectiveness for patients who rely on it.

Methods

Study Design

In this qualitative study, we used a qualitative description approach to data collection and analysis. Qualitative description research studies aim to understand the perspectives or worldviews of participants with the goal of finding actionable insight; qualitative description is a common theoretical orientation for qualitative studies in the health sciences [21]. This theoretical orientation informed our study design, from participant selection to the development of the interview guide and data analysis [21]. Our goals of analysis were to describe the content of the interviews from the perspectives of study participants, without abstracting to the level of social theory [22]. Semistructured qualitative interviews were conducted with diabetes specialty clinicians from endocrinology clinics across the United States and patients from a single academic endocrinology center. The study team included an adult endocrinologist, a primary care provider, a qualitative methodologist, and two qualitative research analysts (one with a Master of Arts degree and one with a Juris Doctor degree, both male). We report our results based on the COREQ (Consolidated Criteria for Reporting Qualitative Research) framework [23].

Interview guides were developed by the study endocrinologist, primary care provider, and qualitative methodologist, based on findings of a previous mixed methods survey study of endocrinology patient and clinician experiences with telemedicine, specifically synchronous audiovisual communication or “video visits” for T2D, and were not pilot-tested [20]. Guides addressed patient and clinician perspectives on the current use of telemedicine to deliver or receive care for T2D, the benefits and shortcomings of telemedicine, and approaches to improve the quality of telemedicine care.

Recruitment

Diabetes specialty care clinicians were recruited via direct email outreach in June 2023. All 44 clinicians targeted for recruitment worked in adult endocrinology clinics. Patient participants were recruited from respondents to a previous survey study about telemedicine for T2D conducted between August 2022 and March 2023. All 24 patient participants contacted for recruitment were adults aged >18 years with T2D who had used telemedicine in the past year to access endocrinology care at 1 of 7 clinical sites associated with a single large academic medical center.

Data Collection and Analysis

Interviews with clinicians were conducted between June and August 2023. Interviews with patients were conducted between June and July 2023. Semistructured interviews were conducted by two trained qualitative research analysts via a secure videoconferencing platform and lasted 45-60 minutes. Audio-only transcripts generated via videoconferencing software were reviewed and corrected using notes recorded by each analyst during interviews. Interviews continued until each interviewer determined, through a review of transcripts and notes, that thematic saturation had been reached [24]. Participants did not have previous relationships with interviewers and did not receive any information about interviewers during this study. No one was present at the interviews except for the participant and interviewer. Transcripts were not returned to participants and participants did not provide feedback on the findings.

Initial codebooks were inductively developed by experienced qualitative research specialists for each dataset based on the content of the interviews. In this process, researchers reviewed transcript data for both patient and clinician interviews, respectively, to identify key concepts within the raw data that could produce a system of codes for categorizing the data. These codebooks were then reviewed and approved by the qualitative methodologist. For both sets of interviews, two coders trained in the codebook co-coded the initial transcripts (3 patient and 4 clinician transcripts, respectively), then met to adjudicate their coding and refine the codebook based on any coding disagreements or discrepancies that arose. Finalized codebooks are included as Multimedia Appendix 1 (patient) and Multimedia Appendix 2 (provider). They then applied the codebook to the remaining transcripts and assessed intercoder reliability via kappa statistics provided by MAXQDA (VERBI Software) coding software. The overall κ score for the provider coding was 0.77, indicating "substantial" agreement, and the overall κ score for the patient coding was 0.92, indicating "near perfect" agreement [25]. All coding differences were adjudicated to full agreement. This finalized coding was used to assist in both conventional content [26] and thematic analysis [27] of the transcripts. Both conventional content analysis and thematic analysis rely on familiarization with and organization of the data through coding. Following coding, a systematic review of all text segments associated with particular codes can yield additional insight. Conventional content analysis was used to summarize and describe what participants said. Thematic analysis, following the steps described by Braun and Clark [27], was then used to identify overarching themes or recurring patterns within the data that might not be identified by the summarization of content alone in the conventional content analysis. Themes were then reviewed and refined to ensure they accurately represented the data in the original context.

Ethical Considerations

This study was approved by the University of Pittsburgh Institutional Review Board (study number STUDY23030092). All participants provided verbal informed consent before the interview. Audio-only transcripts generated via videoconferencing software were reviewed and corrected using notes recorded by each analyst during interviews, with identifying details redacted. Interviews continued until each interviewer determined, through a review of transcripts and notes, that thematic saturation had been reached [24]. Participants did not have previous relationships with interviewers and did not receive any information about interviewers during this study. No one was present at the interviews except for the participant and interviewer. Transcripts were deidentified and were not returned to participants, and participants did not provide feedback on the findings. Interviews with clinicians were conducted between June and August 2023. Interviews with patients were conducted between June and July 2023. Semistructured interviews were conducted by two trained qualitative research analysts via a secure videoconferencing platform and lasted 45-60 minutes. Participants were compensated with a US $50 cash card.

Results

Participants

Diabetes specialty clinicians (n=15) who completed interviews practiced in 12 unique institutions across 8 states (California, Florida, Maryland, Massachusetts, New York, Pennsylvania, Oregon, and Texas). In total, 14 clinicians were endocrinologists, and 1 was a nurse practitioner; 14 practiced at academic medical centers, with 1 in private practice.

Patients (n=13) who completed interviews all received care within a single academic endocrinology division, including 7 clinics across both urban and rural counties, and reported duration of T2D from 3 to 20 years. There were 29 clinicians and 14 patients who did not respond to recruitment emails or phone calls or reported they did not have time to participate.

Many clinician and patient participants reported using telemedicine for the first time during the COVID-19 pandemic. Clinicians described attenuation in use over time with a declining perceived need for social distancing due to patient and institutional preferences. On the other hand, many patient participants described a desire to continue to use telemedicine due to convenience, although some reported a preference for returning to in-person care.

Findings

We identified 4 major themes around patient and clinician perspectives on key benefits of telemedicine for specialty care of T2D, limitations of current telemedicine practice, and approaches to improve the quality of diabetes care delivered via telemedicine.

Theme 1: Telemedicine Enhances Access to Diabetes Specialty Care by Overcoming Multiple Barriers to In-Person Care

Clinicians and patients generally agreed that one major benefit of telemedicine is improved access to care. Many clinicians described increasing access to endocrinology care for patients who face barriers to traditional office visits as a main reason for ongoing use. Clinicians cited multiple types of barriers faced by patients that telemedicine can help overcome: long travel times for patients who live at a significant distance from the clinic, transportation availability, and cost of transportation. Additional barriers including scheduling conflicts between in-person visits and work, as well as childcare or eldercare commitments, were also mentioned. Clinicians also perceived telemedicine to be beneficial in specific situations that require increased visit frequency, such as diabetes in pregnancy. In addition, clinicians noted that telemedicine may make it easier for patients with mental health conditions, such as depression, to access care by reducing the burden of attending visits. Importantly, clinicians noted that these factors which reduce barriers to care resulted in significantly lower no-show rates for telemedicine visits (Textbox 1).

Many patients also reported that telemedicine increased access to diabetes specialty care and made that care more convenient. Patients reported that telemedicine allows them to overcome

the lack of transportation, as well as avoid costs for parking and gas. For example, one patient stated:

> *The pros are…travel time, wait time, you know I'm not using gas, I'm not using a vehicle, I'm not traveling.*

In addition, patients reported significant benefits in saving time, both in traveling to the clinic and waiting to see their clinician, with telemedicine compared to in-person care (Textbox 1).

Textbox 1. Select quotes for theme 1: telemedicine enhances access to diabetes care in many ways.

Clinician perspectives

- They come in from two, three hours away, and in those cases we'll do telemedicine, just so that they're not having to drive back and forth like five hours.
- We're not in a wealthy area: a lot of people are having transportation issues, having trouble affording gas, um, have other issues like childcare or elder care, or, you know, can't get off from work, so it makes it difficult for them to come to in-person visits.
- Lot of times people cancelled because, for a variety of personal reasons, they can't get into the clinic, and it takes so much time to get into clinic or it costs money. But with telemedicine, I had almost a zero no-show rate.

Patient perspectives

- I think is much easier, because sometimes you can do all this money spending to get there, and they say the same thing they say every time.
- It's just more convenient. I got work and I don't have to take, like, a whole day of work off I can just schedule, you know, my lunch break.
- Telemedicine works a lot for me, being that I don't always have transportation to get to my appointments.

Theme 2: Telemedicine Can Facilitate Information Sharing in Diabetes Visits

Clinicians and patients generally agreed that telemedicine can allow for more information-sharing diabetes visits, but had differing views on the specific ways telemedicine was most helpful. Clinicians reported that the ability to have caregivers engaged in visits is one major way telemedicine enhances information sharing, especially with regard to self-management of diabetes including diet and medication regimen (Textbox 2).

Immediate access to medications in the home was cited as another benefit of telemedicine, especially for patients on complex medication regimens:

> *When they are at home, I'm actually able to tell them, why don't you go show me what exactly you're taking, show me the color of the pen…so I think that helps me from a standpoint that if they are on a very complex regimen, I have a better way of assessing.*

On the other hand, many patients focused on improved communication with their clinicians via telemedicine:

> *I think the communication just has improved. I mean [my clinician] can focus on being prepared…for the visit, where we can spend more time just discussing my goals and where I'm at.*

Screen sharing to review glucose trends and other data was also discussed as one benefit of telemedicine visits for diabetes care, which enhances communication and information sharing. In addition, patients described reduced stress associated with telemedicine compared to coming into the clinic, including feeling more at ease and avoiding the hassle associated with navigating health care facilities and procedures. This reduced stress further improved their rapport and communication with their clinician via telemedicine (Textbox 2).

Textbox 2. Select quotes for theme 2: telemedicine can facilitate information sharing in diabetes visits.

Clinician perspectives

- Having the family member there, knowing that the family member will encourage the patient to do what we've discussed when they leave the visit is very helpful.
- I'll be like, "Hey, can I speak to your spouse or your children? Can they get on the phone? We can go over the plan." That saves me time because it happens synchronously during that same visit, I don't have to call the family member after the patient has left the clinic to update about the plan.
- I exactly know what the patient is taking because they are able to show me the bottles.

Patient perspectives

- I'm able to talk with the doctors more; you know…talking, we can get a little more things discussed; she can pull things up and show 'em to me. I guess you can do that in person too, but, you know, it's just really just convenient.
- I was very comfortable talking to her about the things I needed to talk to her about…I like the telemedicine because it's, you know, I'm not like getting judged.
- I just seem more relaxed on the phone…There's no office, you know, office mumbo jumbo, you know, waiting…vital signs at all that, I just don't like any of that.

Theme 3: Clinicians and Patients Perceive Different Limitations of Current Telemedicine in Supporting Successful Diabetes Management

Clinicians and patients differed in their perspectives on the limitations of current telemedicine approaches for diabetes management. Clinicians described multiple drawbacks of telemedicine, which limit their ability to help patients manage diabetes during routine visits. The lack of glucose data, both from glucometers or when continuous glucose monitor device data are not automatically shared, was commonly cited as a major limitation. In addition, clinicians discussed increased difficulty in delivering care through telemedicine for patients with limited English proficiency due to challenges using interpretation services. For example, one clinician stated:

> *If the interpreter can't log on via the video platform, then I have to…call the patient via the telephone with interpreter…not as seamless as doing an interpreter visit in clinic.*

Clinicians also noted that telemedicine may be less effective for medically complex patients due to the limited ability to obtain vital signs and conduct a physical examination to inform management of comorbid conditions, such as hypertension. In addition, clinicians described how it can be challenging to leverage multidisciplinary care resources, such as diabetes self-management education and support, with current telemedicine protocols compared to in-person office visits (Textbox 3). As these services are often available on a drop-in basis in clinics, current telemedicine approaches may limit the ability of clinicians to provide these resources in an unscheduled manner as needs arise during video visits.

Textbox 3. Select quotes for theme 3: clinicians and patients perceive different limitations of current telemedicine in successful diabetes management.

Clinician perspectives

- Most of my patients…do not keep a separate glucose log outside of their glucometer, and so it's really challenging to try and understand…if someone's on any, you know, agent that has a potential for hypoglycemia…how can I titrate that safely in the absence of data?
- Hypertension management is trickier via telemedicine unless someone has a blood pressure cuff at home and is checking their blood pressure…so I would say I have very seldom made adjustments to antihypertensives in a telemedicine-only visit.
- A lot of type two diabetes management also focuses on lifestyle, right? Like it focuses on things like you know, their diet, what their regular lifestyle is, the level of activity, etc. So, many times if it's over telemedicine, I can't use the other services that we can offer in person in clinic right then and there when the patient is there.

Patient perspectives

- Really is no big difference. The same conversation we would have, in-office, face-to-face, will be the same conversation we would have in, you know, telecommunication.
- I really wish I could have, you know, had my blood work and my blood pressure and everything done.
- Not being able to… get my A1C in person… that's probably one of the…only other hardships that I didn't like about it.

On the other hand, many patients perceived that telemedicine overall delivered a very similar quality of care to in-person visits. For example, one patient stated:

> *The telecommunication visit was good for me…there was nothing that I really needed to see my physician with in-person, that I needed to go over her that I couldn't go over with her on the phone.*

However, some patients described the drawbacks of not receiving in-person diabetes care, including the inability to have a physical exam, vital signs, and lab work done in the office (Textbox 3).

Theme 4: Strategies to Enhance the Effectiveness of Telemedicine Diabetes Care in the Future

Clinicians and patients also had differing, but complementary, perspectives on approaches to improve the current delivery of diabetes care through telemedicine to better help patients successfully manage T2D. Clinicians described two main strategies. The first centered around preparation before telemedicine visits to ensure that all information that would routinely be available in office visits is similarly available to clinicians during telemedicine visits. This could include the collection of glucose data and home-measured vital signs, as well as addressing any potential technological barriers to the successful completion of the visit. The second main approach included the engagement of interdisciplinary team members during visits and ensuring postvisit follow-up. As one clinician stated when asked about the ideal telemedicine visit:

> *I would finish my visit and send patient back to the Zoom waiting room, and then the… CDE or nutrition will join that visit or a psychologist…and… a nurse…to kind of reiterate the instructions that or the plan that we discussed during the visit, and then schedule the follow-up, obviously. That's sort of the, the dream flow of the televisit.*

However, clinicians reported that inadequate staffing is the major barrier that prevents the implementation of these strategies in current practice (Textbox 4). Finally, some clinicians also emphasized the importance of changing policies regarding reimbursement to the future of telemedicine for diabetes care; as one clinician put it, "[if reimbursement rates go down] it's a concern because then we won't be able to do it. And I think care will suffer."

Textbox 4. Select quotes for theme 4: strategies identified to enhance diabetes care through telemedicine in future use.

Clinician perspectives

- So before the visit, would have CGM download or glucometer data for like two weeks, an updated list of their medications, episodes of hypoglycemia—that'd be very helpful to have ahead of time—and if they did have vitals from home, so if they were checking their blood pressure or weight if they had that information ahead of time, and then actually checking your blood sugar at the visit if that was part of the protocol, you know, getting…labs they were due for ahead of visit, that would be fantastic.
- So, optimal before the visit, every single person has uploaded data to a cloud… every single person has had necessary labs in order, and everyone has ensured that they can log into the app and have good internet...After the visit, you know, I think in an ideal world is that there would be some system that can prompt patients, remind patients, and then also alert me if they have not completed the next steps.
- I mean, so much of telemedicine success is based on the previsit work that's done, and that's all, you know, non-provider based. So, staffing is the biggest challenge that most practices have with trying to ensure to do the previsit calls, confirmation calls, ensuring all this stuff is done…that's the biggest barrier I think, in ensuring that practices are adequately staffed to support the in-person volume, plus do all of this [telemedicine] stuff.

Patient perspectives

- Well, I'd kind of like to have more education, you know, cause I've never seen the diabetes educator through a video visit, and I'd really like to get more education. I think that the education is key to diabetes, And the more you know about it, the better you can control it.
- Once a month check-ins or checkups… or…me being able to send my results to them, like once monthly..., like weight or… things like that.
- I mean, just if there were any, you know, specific follow-up items, that I needed, you know, to do…being, sent a reminder or whatever, electronically, or something along those lines.

While most patients felt that current telemedicine practices worked well for them, some identified additional support that could complement clinicians' approaches above to improve telemedicine care. Some patients reported desiring more of an opportunity to access diabetes education and meet with interdisciplinary team members through video visits (Textbox 4). Others felt that using telemedicine to complete more frequent check-ins on their diabetes or offer reminders between visits could improve their diabetes management by helping them stay on track:

> *A 10-minute checkup maybe once a month, once every other month. 'Hi…What are your numbers? What's your glucose? How are you feeling?'…Especially for those who haven't, you know, been consistent.*

Discussion

Principal Findings

This study provides an updated assessment of clinician and patient perspectives on the current use of telemedicine to deliver endocrinology care to adults with T2D more than 3 years after initial widespread uptake in the United States. Our findings add to previous literature by gathering perspectives from patients and endocrinology clinicians practicing in diverse clinics across the country on optimal practices to address the limitations to effective routine clinical diabetes care via synchronous telemedicine. Clinicians emphasized the importance of access to home blood glucose data and discussed how telemedicine can make it difficult to manage common comorbid conditions due to a lack of vital signs or other home monitoring data. These findings align with previous studies in which clinicians report that telemedicine is appropriate for less complex conditions and patients [20,28,29]. As a result, clinicians identify previsit preparation, including the collection of home health data as a key to promoting successful diabetes telemedicine visits, which has also been underscored in previous literature describing telemedicine practices in the United States [30]. In addition, our findings align with existing evidence from other countries, including Australia and the United Kingdom, which supports the importance of multidisciplinary care and access to education in leveraging technology for diabetes care, as well as the benefits of synchronous video visits in improving access, reducing the patient's burden of treatment, and improving clinician-patient communication [31,32]. Clinicians also identified the shortcomings of current telemedicine approaches in integrating allied professionals, including translators, diabetes care and education specialists, and nutritionists, into visits. Both clinicians and patients identified engagement of the multidisciplinary care team as one approach to ensure the delivery of high-quality care remotely, which may be especially important for patients who are clinically complex. Finally, patients also identified that enhanced follow-up after visits and the use of telemedicine for more frequent, brief check-up visits would improve the diabetes care they receive virtually.

In this study, patients generally reported satisfaction with the communication, information sharing, and overall care received through telemedicine. In addition, patients emphasized increased convenience and reduced costs associated with transportation as major benefits. These findings align with and add to previous literature in which patients with diabetes identify time and cost savings as benefits of telemedicine, while generally being satisfied with quality of care [29,33-35]. However, previous literature also underscores patient concerns about the lack of physical examination, vital signs, and in-office laboratory work potentially reducing the quality of diabetes care accessible through telemedicine, issues which were also identified in this study [29,34,35]. Our findings that patients report telemedicine is less stressful and potentially enhances communication around diabetes care contrasts with other studies of adults with T2D [34] and other chronic conditions [36] in the primary care setting, in which inferior communication and rapport building were noted. This may be due to an emphasis on the review of

home glucose data and increased use of continuous glucose monitoring in the endocrinology setting relative to primary care, which has been emphasized in previous studies as one key component to successful telemedicine visits [29].

Both clinicians and patients describe how telemedicine enhances access to care by removing barriers to in-person visits, consistent with previous literature [28,37]. Clinicians in our study also emphasized that telemedicine results in lower no-show rates than in-person care, a finding seen in previous studies in both diabetes and primary care clinics [37-39]. Adults with T2D who have geographic or transportation barriers to accessing specialty diabetes care already experience worse care quality [40-42] and higher diabetes-related mortality [43-45]. Thus, ensuring that telemedicine delivers care that is at least as high-quality as in-person is crucial to promoting equitable access to care. Policies that preserve reimbursement for telemedicine care and promote improvement of care delivery through telemedicine will be critical to continuing access to diabetes specialty care for underresourced populations.

Limitations

Strengths of this study include providing an updated assessment of the perspectives of patients and clinicians on the current use of telemedicine for diabetes care more than 3 years after initial use when many centers have refined their virtual care delivery process. Importantly, this study includes diabetes specialty clinicians from across the United States; while most practice in academic centers, diversity in geography, patient populations, and local telemedicine protocols enhances the generalizability of our findings. However, clinicians from private practice are underrepresented in our sample, so findings may not apply to this practice setting. Patient participants were drawn from a single academic endocrinology division, which includes a diversity of geographic areas. However, findings may not apply to patients who receive endocrinology care for T2D at centers with different telemedicine care protocols.

Conclusions

In conclusion, clinicians and patients perceive the important benefits of telemedicine in increasing access to care, especially for patients who face barriers to in-person care. Given the ongoing shortage of endocrinologists and the prevalence of barriers to in-person endocrinology care, some patients will continue to rely on telemedicine indefinitely in order to access diabetes specialty care for T2D. Thus, it is crucial to use insight from patients and clinicians to inform approaches to improve the quality of care delivered via telemedicine care to reduce existing disparities in diabetes care and outcomes for these populations. Ensuring adequate data sharing through previsit preparation, increased visit frequency based on patient needs, and engaging interdisciplinary teams during and after telemedicine visits can leverage the benefits of virtual care to ensure telemedicine is at least as good as, or even superior to, in-person specialty diabetes care for patients who rely upon it.

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Authors' Contributions

MZ contributed to conceptualization, methodology, writing—original draft, writing—review and editing, funding acquisition, and supervision. MH was involved in methodology, formal analysis, investigation, and writing—review and editing. LA was responsible for formal analysis, investigation, writing—review and editing. AMR contributed to conceptualization, methodology, and writing—review and editing.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Patient codebook.
[PDF File (Adobe PDF File), 28 KB - diabetes_v10i1e60765_app1.pdf]

Multimedia Appendix 2
Provider codebook.
[PDF File (Adobe PDF File), 35 KB - diabetes_v10i1e60765_app2.pdf]

Multimedia Appendix 3
Supplementary File 3: COREQ Checklist.
[PDF File (Adobe PDF File), 89 KB - diabetes_v10i1e60765_app3.pdf]

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Abbreviations

COREQ: Consolidated Criteria for Reporting Qualitative Research
T2D: type 2 diabetes

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Diabetes Medical Group Visits and Type 2 Diabetes Outcomes: Mediation Analysis of Diabetes Distress

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Abstract

Background: Group-based diabetes care, both technology-enabled and in-person, can improve diabetes outcomes in low-income minority women, but the mechanism remains unclear.

Objective: We tested whether diabetes group medical visits (GMVs) reduced hemoglobin A_{1c} (HbA_{1c}) by mitigating diabetes distress (DD), an emotional response affecting nearly half of adults with type 2 diabetes in community settings.

Methods: We conducted a mediation and moderation analysis of data from the Women in Control 2.0 comparative effectiveness study, which showed that both technology-enabled and in-person diabetes GMVs improve HbA_{1c}. We tested whether DD mediated the relationship between diabetes GMV engagement and reductions in HbA_{1c}. We also tested whether this relationship was moderated by depressive symptoms and social support. Participants were 309 low-income and minority women. Diabetes GMV engagement was measured using the Group Climate Questionnaire. The mediator, DD, was measured using the Diabetes Distress Screening Scale. The outcome was the 6-month change in HbA_{1c}. Social support was measured using the Medical Outcomes Study Social Support Survey.

Results: DD mediated the relationship between engagement and 6-month HbA_{1c}. Specifically, group engagement affected HbA_{1c} by reducing distress associated with the regimen of diabetes self-management (P=.04), and possibly the emotional burden of diabetes (P=.09). The relationship between engagement and 6-month HbA_{1c} was moderated by depressive symptoms (P=.02), and possibly social support (P=.08).

Conclusions: Engagement in diabetes GMVs improved HbA_{1c} because it helped reduce diabetes-related distress, especially related to the regimen of diabetes management and possibly related to its emotional burden, and especially for women without depressive symptoms and possibly for women who lacked social support.

Trial Registration: ClinicalTrials.gov NCT02726425; https://clinicaltrials.gov/study/NCT02726425

(JMIR Diabetes 2025;10:e57526) doi:10.2196/57526

KEYWORDS

diabetes; diabetic; diabetes mellitus; DM; type 1 diabetes; type 2 diabetes; diabetes mellitus type 2; diabetes outcomes; diabetes medical group visit; DMGVs; psychosocial functioning; psychosocial; glycemic control; glycemic; shared medical appointments; self-management; mediation analysis; social support; minority women; minority

Introduction

Over 37 million people in the United States live with type 2 diabetes mellitus (T2DM), accounting for 7.8 million hospitalizations and over US $327 billion in health care costs annually, with persistent disparities in diabetes outcomes among low-income and minority adults being attributable to underlying health inequities [1-7]. Unmet social needs, such as housing, job, and food insecurity and structural barriers to health care, among them inadequate access, affordability, and quality make it difficult for underserved communities to access the medical care and support needed to effectively manage diabetes, increasing the burden of living with chronic disease for this segment of the population [8].

The overwhelming stress of diabetes self-management can produce an emotional response characterized as diabetes distress (DD). A distinct psychological consequence of living with T2DM, DD is more common than comorbid depression and

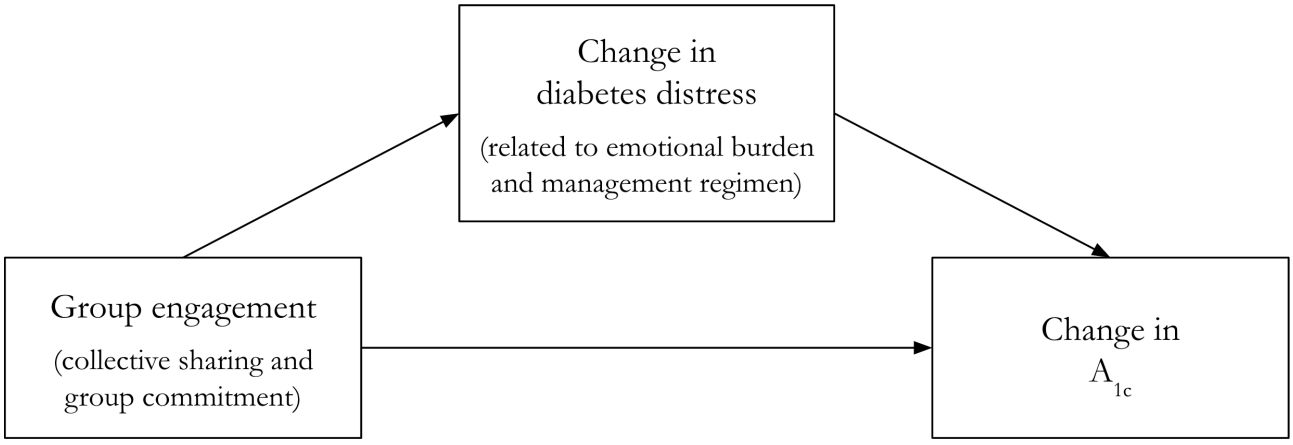
anxiety, with prevalence estimates ranging from 36% to 45% [9-11]. It has been linked to poor glycemic control, self-management, and self-efficacy among adult patients [12-15]. DD is a treatable barrier to effective diabetes self-management that is gaining increasing attention in primary and specialty care. A 2017 position paper from the American Diabetes Association recommended routine screening and integration of psychosocial care, considering emotional status and presence of a social support network, to improve the treatment course of those living with T2DM [9,16].

Identifying scalable approaches that address both the physical and mental health needs of those living with diabetes is a high priority. Emerging research has shown that group-based diabetes care can lead to positive health outcomes. Group-based education is often promoted as an effective approach to managing type 2 diabetes, with the potential to enhance self-management skills and improve health outcomes [17]. An alternative to individual clinical encounters, diabetes group medical visits (GMVs) convene groups of patients to receive peer support, diabetes self-management education, and a clinical consult within the context of a 2-hour shared appointment [18,19]. There is substantial published evidence demonstrating the clinical effectiveness of standard, in-person diabetes GMVs (or shared medical appointments) compared to usual care for adults living with diabetes. Four systematic reviews conclude that diabetes GMVs are clinically supported for improving glycemic control [18-21]. This GMV model of care has been associated with improved self-management mastery, quality of life, and mental health [18,19]. It can also reduce health disparities by fostering more equitable patient-provider relationships, creating relationships of care between patients, and improving health literacy [22]. However, implementing group-based care is not without challenges given heterogeneity of implementation across busy clinical practices, particularly those serving low-income and diverse communities and limited reporting [17,21,23].

Health technologies may bridge gaps in access to effective models of diabetes care, such as diabetes GMVs, but research on the effectiveness and scalability of existing applications is limited. In the Women in Control 2.0 (WIC2) study, our team tested the effectiveness of virtual, technology-enabled diabetes GMVs versus in-person GMVs for low-income, English- and Spanish-speaking minority women with uncontrolled diabetes [24]. Our findings showed that GMVs, whether in-person or technology-enabled, improved not only 6-month hemoglobin A_{1c} (HbA_{1c}), but also 6-month DD. For this reason, we hypothesized that DD may mediate the effect of GMVs on glucose control. We further hypothesized that group-based care reduced DD by cultivating a sense of belonging, an opportunity to feel connected, heard, and understood by other participants with lived experience managing diabetes. The intervention, methods, and main results from the WIC2 study are reported elsewhere [24-26].

To test this conceptual model, we conducted a mediation analysis substudy of clinical trial data from the WIC2 study to determine whether participants' self-reported engagement with other group members affected glucose control by reducing DD or its subcomponents (Figure 1). We also aimed to test whether baseline characteristics moderated the relationship between engagement and HbA_{1c}.

Figure 1. Conceptual model. A_{1c}: hemoglobin A_{1c}.



Methods

Study Design

The WIC2 noninferiority, randomized controlled trial compared over-time changes in HbA_{1c} among 309 women randomly assigned to attend either in-person or technology-enabled GMVs, both led by a prescribing clinician and a trained facilitator for 8 weeks and delivered in English or Spanish, depending on participants' language preferences at baseline. All participants then entered a 16-week maintenance period during which no GMVs took place, but participants were instructed to self-monitor nutrition and physical activity. Of 309 randomized participants, 207 (67%) met per-protocol criteria by attending 6 of 8 sessions. Noninferior improvements were detected in mean HbA_{1c} from baseline to 6 months in both groups: HbA_{1c} declined by −0.7% (SD 1.8%) among participants attending in-person GMV and by −0.5% (SD 1.6%) among participants attending virtual world GMV (P<.001) [23,24].

This WIC2 secondary analysis tested whether the improvements in HbA_{1c} observed in the WIC2 study were associated with group engagement, whether this occurred through lowering DD, and whether that relationship was conditional on the following

moderators measured at baseline: language, health literacy, depressive symptoms, anxiety, patient activation, HbA_{1c}, and social support. These analyses included all participants, irrespective of meeting per-protocol criteria by attending at least 6 sessions.

Mediation

The explanatory variable, group engagement, was measured using the group engagement subscale of the Group Climate Questionnaire (GCQ-S)—a validated survey completed at baseline, 9 weeks, and 6 months assessing group cohesion [27]. Group cohesion has been conceptualized as 2 domains: affective, which is associated with the individual's attraction to the group or its members and ability to collectively share positive, as well as negative, emotional experiences; and behavioral, a domain associated with the individual's sense of commitment to the group [28,29]. The engagement subscale of group cohesion captures both these collective sharing and group commitment domains.

Each question from the GCQ-S was scored from 0 ("not at all") to 6 ("extremely"). A total score was determined by calculating the mean response to questions from the 5 items of the group engagement subscale, shown in Table S1 in Multimedia Appendix 1.

The potential mediators, self-reported DD and its subcomponents, were collected using the Diabetes Distress Screening Scale (DDS-17) at baseline, 9 weeks, and 6 months [10,30]. The subscales for the DDS-17 assess the emotional burden of diabetes, regimen of diabetes management, perceived quality of diabetes care from a physician, and interpersonal support from family and friends. We hypothesized that group engagement influenced HbA_{1c} primarily by reducing distress associated with the emotional burden and regimen of diabetes management, because these were most directly targeted by the peer support and self-management components of the WIC2 curriculum in GMVs. We did not expect that GMVs would directly impact DD related to care from a physician and interpersonal support from family and friends.

Each question on the DDS-17 was scored from 1 ("not a problem") to 6 ("a very serious problem") and is listed in Table S1 in Multimedia Appendix 1. The total DD and subscale scores were calculated by taking the mean of all scale and subscale scores.

Moderation

We also tested whether baseline social support, Spanish as a primary language, health literacy, depressive symptoms, anxiety, patient activation, or HbA_{1c} moderated the relationship between group engagement and the 6-month change in HbA_{1c}.

Because the GMVs were group-based, we expected that they would be particularly helpful for participants who did not already enjoy supportive social networks. To measure social support, we used the Medical Outcomes Study Social Support Survey, a 19-item instrument developed for a 2-year study of patients with chronic conditions. The instrument has 4 subscales capturing emotional or informational, tangible, affectionate, and positive social interaction-related social support [31] (see Table S1 in Multimedia Appendix 1).

We also expected health literacy and patient activation to magnify the effect of group engagement by helping participants take fuller advantage of the WIC2 curriculum. High baseline anxiety or depressive symptoms may dampen the effect of group engagement by compounding the emotional or regimen-related burden of DD. Low baseline HbA_{1c} may produce ceiling effects. Finally, we checked for differences across the culturally equivalent Spanish- and English-language WIC2 curricula.

Statistical Analyses

To identify potential confounders, participants with low group engagement (≤median score) versus high engagement (>median score) were compared on baseline characteristics of the sample with means and SDs or percentages.

To summarize the main outcome variables and potential mediators, we took baseline and 6-month means and SDs as well as mean changes over time with SDs. We performed paired *t* tests on baseline versus 6-month values.

We tested whether the relationship between group engagement and HbA_{1c} was mediated by DD or its subscores in two ways. First, we performed a series of ordinary least squares (OLS) regressions. We regressed the primary outcome (6 mo change in HbA_{1c}) on the explanatory variable (group engagement), the outcome (6 mo change in HbA_{1c}) on the potential mediators (DD and each of its subscales), and the potential mediators (DD and each of its subscales) on the explanatory variable (group engagement). For each, we ran both a bivariate regression and a multivariate regression that included cohort fixed effects and controlled for study arm.

Second, we performed mediation by simulation, using the *mediation* package for R (R Foundation) [32,33]. Using this method, we estimated the average causal mediation effect. As this is a secondary analysis that was not originally powered with causal mediation in mind, we expect this method to underestimate any true mediated effect.

Finally, we used OLS regression to determine whether Spanish as a primary language, health literacy, depressive symptoms, anxiety, patient activation, baseline HbA_{1c}, or social support and its subscores moderated the relationship between group engagement and 6-month change in HbA_{1c}. We regressed the 6-month change in HbA_{1c} on group engagement interacted with each potential moderator. As with mediation by simulation, due to sample size, we expect this to be a conservative estimate of moderated effects.

Ethical Considerations

Informed consent and approval by the Boston University or Boston Medical Center Institutional Review Board (H-34220) are documented in the WIC2 study [24]. All eligible and interested participants were consented and enrolled abiding by the principles of the Belmont Report and the Declaration of Helsinki. The informed consent process included a teach-back approach by which participants' understanding of this study's procedures, risk or benefits, and voluntary nature was confirmed.

Enrolled participants self-reported their answers to research surveys about their health and lived experience with diabetes. All research data were stored in password-protected, HIPAA (Health Insurance Portability and Accountability Act)-compliant systems and linked with a study-generated identifier to protect confidentiality.

Results

Description of the Sample

A full description of the WIC2 study population was previously published [24]. In brief, participants' mean age was 56 (SD 10.4) years and mean HbA_{1c} was 9.93% (SD 1.74%). All participants were female (n=309), 63.1% (195/309) self-identified as Black or African American, while 23.6% (73/309) were Spanish-speaking. A majority of participants (70.9%, 219/309) reported Medicaid, Medicare, or both as their insurance provider. Fifteen percent (47/309) of participants reported an anxiety disorder, and 25.2% (78/309) of participants reported a depressive disorder, including depression, major depression, dysthymia, or minor depression. Mean total DD was 2.27 (maximum score of 6; SD 1.04). See Table 1 for the mean DD subscales. No apparent differences were detected between low-engagement and high-engagement participants on observed characteristics. Remaining characteristics are summarized in Table 1.

Table . Baseline sample characteristics for all participants and participants with above versus below median group engagement.

Characteristics		Total (N=309)	Engage[a] ≤ median (3.8; n=123)	Engage >median (3.8; n=114)
Spanish-speaking, n (%)		73 (24)	30 (24)	29 (25)
Low health literacy, n (%)		87 (28)	36 (29)	33 (29)
Anxiety disorder, n (%)		47 (15)	16 (13)	19 (17)
Depressive disorder[b], n (%)		78 (25)	29 (24)	32 (28)
PAM-13[c], mean (SD)		66.12 (20.56)	66.1 (19.47)	69.31 (19.05)
Social support[d], mean (SD)				
	Overall	3.78 (1.06)	3.68 (1.09)	3.9 (1.02)
	Affectionate	4.05 (1.11)	3.93 (1.16)	4.17 (1.06)
	Emotional or informational	3.82 (1.11)	3.71 (1.16)	3.96 (1.06)
	Positive social interaction	3.80 (1.2)	3.75 (1.2)	3.91 (1.18)
	Tangible	3.51 (1.26)	3.43 (1.23)	3.58 (1.3)
Diabetes distress[e], mean (SD)				
	Total DD[f]	2.27 (1.04)	2.22 (1.08)	2.36 (1.03)
	Regimen DD	2.64 (1.33)	2.56 (1.36)	2.82 (1.34)
	Emotional burden DD	2.69 (1.44)	2.61 (1.47)	2.81 (1.5)
	Physician DD	1.53 (0.99)	1.45 (0.94)	1.56 (1.02)
	Interpersonal DD	1.97 (1.28)	2.05 (1.45)	1.89 (1.12)
HbA_{1c}[g], mean (SD)		9.93 (1.74)	9.74 (1.65)	10.05 (1.86)
Age, mean (SD)		55.62 (10.4)	56.17 (10.1)	53.94 (10.55)
Race, n (%)				
	Black or African American	195 (63)	81 (66)	76 (67)
	White	26 (8)	12 (10)	11 (10)
	Other race	78 (25)	30 (24)	27 (24)
Hispanic, n (%)				
	Yes	105 (35)	41 (33)	40 (35)
	No	195 (65)	82 (66)	74 (65)
Insurance, n (%)				
	Commercial	69 (22)	28 (23)	29 (25)
	Medicare or Medicaid	219 (71)	88 (72)	82 (72)
Education, n (%)				
	High school graduate or less	152 (49)	63 (51)	54 (47)
	Any college, vocational, or trade school	132 (43)	53 (43)	53 (46)
	Any postgraduate	14 (5)	6 (5)	7 (6)
Employment status, n (%)				
	Full-time	75 (24)	28 (23)	35 (31)
	Part-time	44 (14)	19 (15)	16 (14)
	Not employed	156 (50)	68 (55)	51 (45)
Household income, n (%)				
	≤US $29,999	140 (45)	51 (41)	56 (49)

Characteristics		Total (N=309)	Engage[a] ≤ median (3.8; n=123)	Engage >median (3.8; n=114)
	≥US $30,000	59 (19)	25 (20)	23 (21)
	Refused, do not know, or none	101 (33)	47 (38)	35 (31)

[a]Assessed using the engagement subscale of the Group Climate Questionnaire (GCQ-S).

[b]Including depression, major depression, dysthymia, or minor depression.

[c]PAM-13: Patient Activation Measure.

[d]Assessed using the Medical Outcomes Study Social Support Survey.

[e]Assessed using the Diabetes Distress Screening Scale (DDS-17).

[f]DD: diabetes distress.

[g]HbA_{1c}: hemoglobin A_{1c}.

Results of Main Relationships

The outcome, HbA_{1c}, decreased from 9.9% (SD 1.7) at baseline to 9.3% at 6 months (SD 2) on average (P<.001, via paired 2-tailed t test). The potential mediators—total DD score and each DD subscore—also decreased from baseline to 6 months (P<.001 for all DD scores except the physician subscore [P=.095, via paired t test]). The magnitude of this decrease was greatest for the regimen (−0.6, SD 1.2) and emotional burden subscores (−0.6, SD 1.2; Table 2).

Table . Summary of main outcome variables and potential mediators (all participants).

	Baseline, mean (SD)	6 Months, mean (SD)	Change, mean (SD)	P value[a]
Group engagement[b]	N/A[c]	3.6 (1.3)	N/A	N/A
Diabetes distress[d]	2.3 (1)	1.9 (1)	−0.4 (0.9)	<.001
DD[e] regimen	2.6 (1.3)	2.1 (1.2)	−0.6 (1.2)	<.001
DD emotional burden	2.7 (1.4)	2.2 (1.3)	−0.6 (1.2)	<.001
DD physician	1.5 (1)	1.4 (0.9)	−0.1 (1)	.095
DD interpersonal	2 (1.3)	1.7 (1.2)	−0.3 (1.2)	<.001
Hemoglobin A_{1c}	9.9 (1.7)	9.3 (2)	−0.6 (1.7)	<.001

[a]P value from a paired 2-tailed t test.

[b]Assessed using the engagement subscale of the Group Climate Questionnaire (GCQ-S).

[c]N/A: not applicable.

[d]Assessed using the Diabetes Distress Screening Scale (DDS-17).

[e]DD: diabetes distress.

Table 3 summarizes the individual associations between the outcome, mediators, and independent variable, and Figure 2 maps those associations to our conceptual model.

Table . Main relationships between outcome, explanatory variables, and mediators.

	Bivariate[a]		Fixed effects[b]	
	Coefficient (SE)	*P* value	Coefficient (SE)	*P* value
HbA_{1c}[c] on engagement[d]	−0.21 (0.08)	.01[d]	−0.25 (0.08)	.004[d]
Distress (total)[e] on engagement	−0.1 (0.04)	.03[d]	−0.1 (0.05)	.03[d]
Distress (regimen) on engagement	−0.14 (0.06)	.02[d]	−0.16 (0.06)	.01[d]
Distress (emotional burden) on engagement	−0.12 (0.06)	.04[d]	−0.12 (0.06)	.04[d]
Distress (physician) on engagement	−0.1 (0.05)	.04[d]	−0.08 (0.05)	.011[d]
Distress (interpersonal) on engagement	0 (0.06)	.94	0.01 (0.06)	.90
HbA_{1c} on distress (total)	0.24 (0.12)	.048[d]	0.24 (0.12)	.04
HbA_{1c} on distress (regimen)	0.27 (0.09)	.002	0.26 (0.09)	.004
HbA_{1c} on distress (emotional burden)	0.22 (0.09)	.02[d]	0.2 (0.09)	.03[d]
HbA_{1c} on distress (physician)	0 (0.11)	.996	0.04 (0.11)	.74
HbA_{1c} on distress (interpersonal)	−0.02 (0.09)	.84	0 (0.09)	.98

[a]Ordinary least square regression, described in left-hand column.

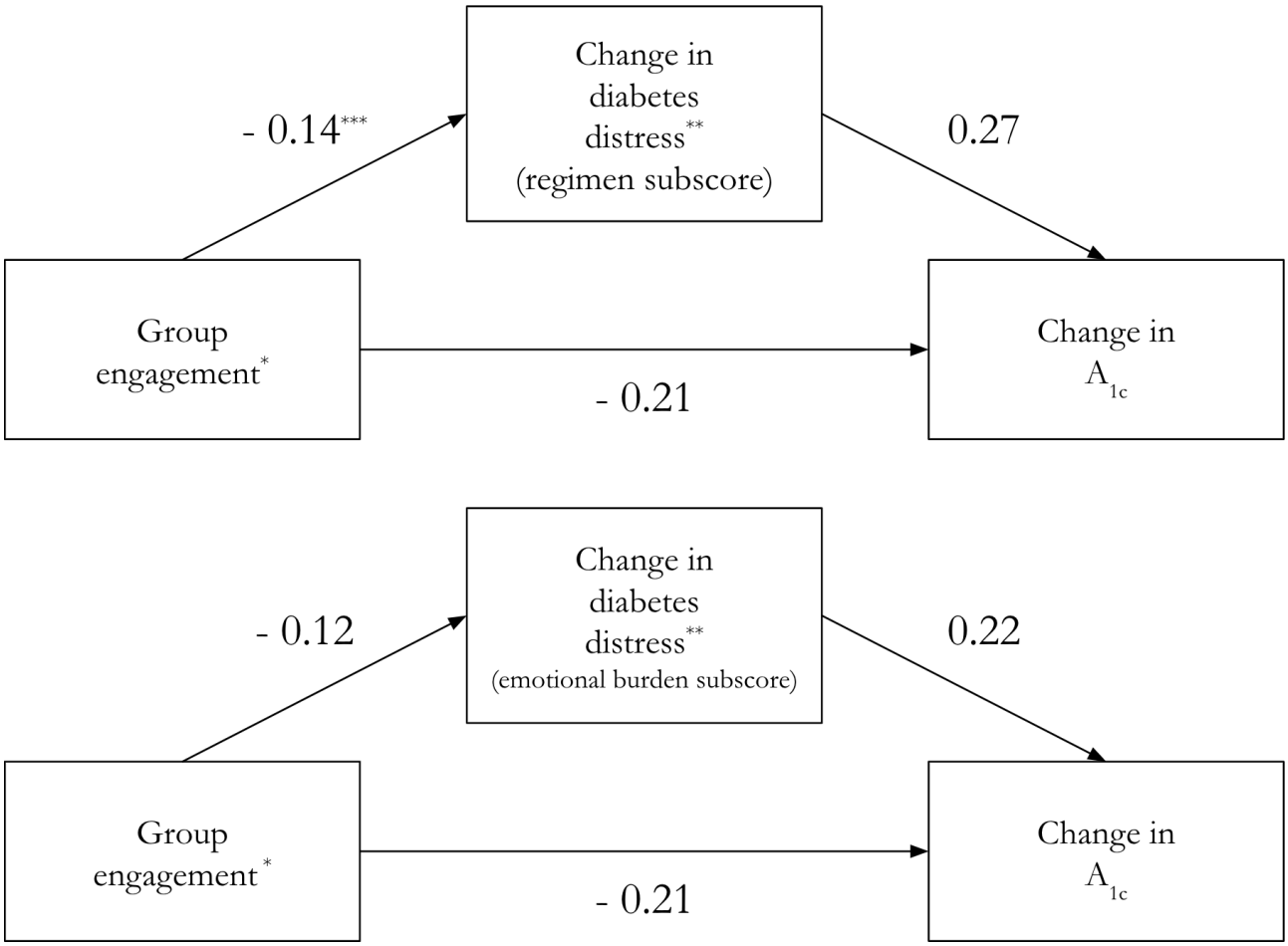
[b]Ordinary least square regression, controlling for study arm and with cohort fixed effects, described in left-hand column.

[c]HbA_{1c}: hemoglobin A_{1c}.

[d]Assessed using the engagement subscale of the Group Climate Questionnaire (GCQ-S).

[e]Assessed using the Diabetes Distress Screening Scale (DDS-17).

Figure 2. Coefficients on mediator relationships of interest from OLS regressions * Assessed using the engagement subscale of the Group Climate Questionnaire (GCQ-S). ** Assessed using regimen and emotional burden subscales of the Diabetes Distress Screening Scale (DDS-17). *** Coefficients and *P* value thresholds derived from Table 3 OLS regressions. DDS-17: Diabetes Distress Screening Scale; GCQ-S: Group Climate Questionnaire; OLS: ordinary least square.



We detected a negative relationship between group engagement score and 6-month change in HbA_{1c}. A one-point increase in group engagement score was associated with, on average, a 0.21 greater decrease in HbA_{1c} from baseline to 6 months. This was true both without (*P*=.01) and with (*P*=.004) cohort fixed effects and controlling for study arm.

In Table 3, we also detected a negative relationship between group engagement and all DD mediators, except for the interpersonal subscore. A one-point increase in group engagement score was associated with, on average, a 0.1 greater decrease in total DD score from baseline to 6 months (*P*=.03), a 0.14 greater decrease in regimen subscore (*P*=.02), a 0.12 greater decrease in emotional burden subscore (*P*=.04), and a 0.1 greater decrease in physician subscore (*P*=.04). The results were similar with and without cohort fixed effects and controlling for study arm.

Finally, we detected a positive relationship between 3 mediators and 6-month change in HbA_{1c}: total DD, and the regimen and emotional burden subscores. A one-point decrease in the regimen subscore was associated with, on average, a 0.27% greater decrease in HbA_{1c} from baseline to 6 months, again both without (*P*=.002) and with (*P*=.004) cohort fixed effects and controlling for study arm. A one-point decrease in the emotional burden subscore was associated with, on average, a 0.22% greater decrease in the change in HbA_{1c} from baseline to 6 months, both without (*P*= .02) and with (*P*=.03) cohort fixed effects and controlling for study arm.

Results of Mediator Analysis

Table 4 lists the total effect of engagement on the 6-month change in HbA_{1c}, the average causal mediation effect (the proportion of the total effect that runs through the mediator), and the average direct effect (the remaining proportion of the total effect that does not run through the mediator), calculated by simulation, for each of five possible mediators: DD and each of its 4 subscores.

Table . Mediator analysis[a].

Mediator	Total effect	*P* value	ADE[b]	*P* value	ACME[c]	*P* value
Diabetes distress (total)[d]	−0.2	.02[a]	−0.18	.026[a]	−0.02	.20
Distress (regimen)	−0.2	.02[a]	−0.16	.048[a]	−0.04	.04[a]
Distress (emotional burden)	−0.2	.02[a]	−0.18	.042[a]	−0.02	.09
Distress (physician)	−0.2	.01[a]	−0.2	.014[a]	0	.798
Distress (interpersonal)	−0.2	.02[a]	−0.2	.02[a]	0	.92

[a]Mediation by simulation performed using *mediate* package in R.

[b]ADE: average direct effect.

[c]ACME: average causally mediated effect.

[d]Assessed using the Diabetes Distress Screening Scale (DDS-17).

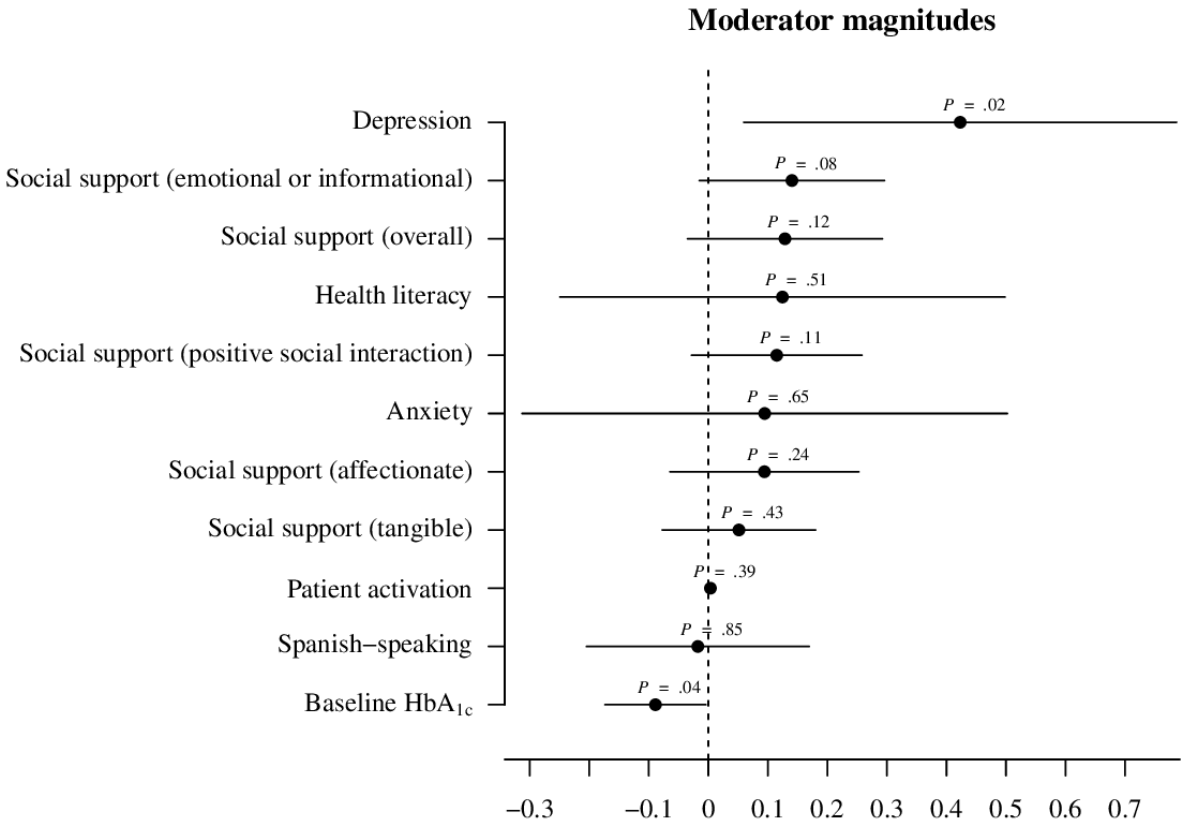
An average causally mediated effect of group engagement on 6-month change in HbA_{1c} was detected that runs through the regimen (*P*=.04) of DD. An average causally mediated effect of group engagement on 6-month change in HbA_{1c} may also run through the emotional burden of DD (*P*=.094).

There was no evidence that total DD mediated the relationship between group engagement and 6-month change in HbA_{1c} (*P*=.20). There was also no evidence that the physician (*P*=.798) or interpersonal (*P*=.92) DD subscores mediated this relationship.

Results of Moderator Analyses

Figure 3 plots coefficients with 95% CIs from the interaction terms of each OLS model regressing 6-month change in HbA_{1c} on engagement interacted with the potential moderators. Baseline depressive symptoms, emotional or informationally based social support, and baseline HbA_{1c} were found to moderate the relationship between group engagement and 6-month change in HbA_{1c}. Participants that did not report depression, major depression, dysthymia, or minor depressive symptoms at baseline saw their HbA_{1c} decline by an additional 0.42% for each one-point increase in group engagement score (*P*=.02). For each lower point of self-reported emotional or informationally based social support, participants saw their HbA_{1c} decline by an additional 0.14% for each one-point increase in group engagement score (*P*=.08), though a larger sample size is needed to confirm this result. For each additional percentage point of baseline HbA_{1c}, participants saw their 6-month HbA_{1c} decline by an additional 0.09% with each one-point increase in group engagement score (*P*=.04).

Figure 3. Moderator effects are plotted as coefficients on OLS model interaction terms with 95% CIs. *P* values are for each OLS model interaction term. Social support and subscores were assessed using the Medical Outcomes Study Social Support Survey. Health literacy was assessed with the yes or no question "Do you usually ask someone to help you read materials you receive from the hospital?" Patient activation was assessed using PAM-13. Depression includes depression, major depression, dysthymia, or minor depression. OLS: ordinary least square; PAM-13: Patient Activation Measure.



Discussion

Summary of Findings

While GMVs are associated with improved glucose control, the underlying mechanism of how group-based care is linked to improved outcomes has been unclear. This analysis of mediators provides evidence that engaging in GMVs (either in-person or technology-enabled) works to lower HbA_{1c}, in part, by reducing the components of DD associated with the management regimen of diabetes, and possibly also the emotional burden of diabetes management.

Specifically, we found that while the regimen and possibly the emotional burden components of DD mediated the effect of GMVs, the physician or interpersonal (with family or friends) components of DD did not. The mediated effect for total DD, measured as a summary score from the DDS-17, was not significant (*P*=.20), and was likely diluted by the components of total DD making up the physician and interpersonal subscores.

These findings are consistent with our hypothesis that GMVs target a participant's ability to self-manage diabetes and, possibly, cultivate a sense of belonging and shared understanding by relating to others within the group. In particular, GMVs may improve regimen-related DD by alleviating the stigma of failing in self-management behaviors, fostering peer-supported adherence to treatment, and improving health literacy. GMVs likely target emotional burden-related DD by building psychological safety, providing social acceptance, and mitigating feelings of powerlessness. This is also consistent with findings from the DDS-17 developers that the regimen and emotional burden distress subscales contribute most significantly to the total DD [34].

These findings also suggest that GMVs may be less relevant for how participants relate to their broader social networks outside the group, such as friends, family, and physicians. Support from peers specifically within the GMVs may be key to the relationship between GMV engagement, improved DD, and improved glycemic control, as previous studies have also found that peer-to-peer social, emotional and informational support, both with and without technology supplement, can improve glycemic control and reduce DD among minority groups [35-38].

Our moderation analysis showed that engagement in group visits was most strongly associated with decline in HbA_{1c} for participants with higher baseline HbA_{1c}, without depressive symptoms at baseline, and, possibly, who reported little emotional or informationally based social support.

Participants that reported low emotional and informational social support may have especially benefited from GMVs that offered an empathetic social setting that they may have otherwise

lacked, though a larger sample size is required to confirm this result.

In contrast, participants with comorbid depressive symptoms may have struggled with practicing the self-management behaviors prescribed in the GMVs. Existing research has also found that depressive symptoms can inhibit self-management mastery and undermine treatment focused on diabetes empowerment [39,40]. Individuals who feel they have little control over their T2DM and are unable to reach treatment goals report less motivation to manage their condition [41]. In light of studies showing that DD, but not depressive symptoms by themselves, have a concurrent and longitudinal association with HbA_{1c} levels, these findings suggest that comorbid depressive symptoms may negatively influence HbA_{1c} primarily by rendering diabetes self-management education and support less effective [12].

Limitations

First, these analyses tested mediators of group engagement, rather than a direct measure of the intervention. Testing for a mediator of the study arm was not possible because these data were generated by a noninferiority trial that, by design, randomized participants to 2 interventions that both improved HbA_{1c}. As technology-enabled GMVs were noninferior to their in-person counterparts, the study arm by itself does not generate meaningful variation on the explanatory variable. Furthermore, testing for an effect of intervention adherence sacrifices sample size, as few participants had substantially low attendance. Engagement offered the variation on the explanatory variable while still representing a meaningful measure of participation in GMVs. In the absence of validated standalone measures of engagement for group interventions, we used the engagement subcomponent of the GCQ-S. Nevertheless, we did replicate our mediation analysis using the study arm, and these results are summarized in Table S2 in Multimedia Appendix 1.

Second, this was a secondary analysis of data from the existing, published WIC2 study, which was not originally powered to detect mediation or moderation. This biases us toward type II error (false negatives), or against detecting a mediated or moderated effect even where one may exist. In practice, our sample size can support the simple OLS regressions we use in our first mediation analysis (Table 3 and Figure 2), but may be too small for more complex analysis such as mediation by simulation (Table 4) and interaction effects (Figure 3). For this reason, in addition to reporting findings where $P<.05$, we also report findings for P values lower than 0.1 and interpret them as suggestive of relationships that we might detect given a larger sample. In particular, our analyses may underestimate the role of the emotional burden of DD as a mediator; while our mediation analysis using regression did detect a mediation effect for the emotional burden of DD in models both with and without controls and cohort fixed effects, our mediation analysis using simulation can only suggest this at $P=.09$.

Third, while this study detected an average causally mediated effect of regimen-related and emotional burden-related DD, it also estimated an average direct effect that runs through other mediators. Specifically, regimen-related and emotional burden-related DD were found to mediate 30% of the total effect of engagement on HbA_{1c}, leaving 70% of the effect, which runs through other mediators, to be explained in further research.

Finally, because group engagement was not randomly assigned, though no observed confounding was detected, this study cannot rule out unobserved confounding on the relationship between engagement and DD or on the relationship between DD and HbA_{1c}.

Conclusions

Our findings showed that engagement in group-based diabetes care improved HbA_{1c} by way of reducing diabetes-related distress, especially the components related to the regimen and possibly the emotional burden of living with T2DM. Strategies that encourage collective sharing and group commitment should be actively integrated in GMVs to positively influence diabetes outcomes such as DD and glucose control. Additionally, it is important to identify patients with comorbid depressive symptoms and, possibly, those lacking social support separate from the GMVs, as our findings confirmed previous research suggesting that untreated depressive symptoms may interfere with the positive effects of medical group-based care [39,40]. Future research should explore how care models can be more effective in specifically treating patients with depressive symptoms and other comorbid conditions.

Acknowledgments

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Conflicts of Interest

SM holds equity in See Yourself Health LLC, a digital health service provider.

Multimedia Appendix 1
Group cohesion, diabetes distress, and social support instruments; relationships with this study's treatment; full group cohesion measure; and moderator predicted values.
[DOCX File, 163 KB - diabetes_v10i1e57526_app1.docx]

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Abbreviations

DD: diabetes distress
DDS-17: Diabetes Distress Screening Scale
GCQ-S: Group Climate Questionnaire
GMV: group medical visit
HbA_{1c}: hemoglobin A_{1c}
HIPAA: Health Insurance Portability and Accountability Act
OLS: ordinary least square
T2DM: type 2 diabetes mellitus
WIC2: Women in Control 2.0

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Applications of AI in Predicting Drug Responses for Type 2 Diabetes

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Abstract

Type 2 diabetes mellitus has seen a continuous rise in prevalence in recent years, and a similar trend has been observed in the increased availability of glucose-lowering drugs. There is a need to understand the variation in treatment response to these drugs to be able to predict people who will respond well or poorly to a drug. Electronic health records, clinical trials, and observational studies provide a huge amount of data to explore predictors of drug response. The use of artificial intelligence (AI), which includes machine learning and deep learning techniques, has the capacity to improve the prediction of treatment response in patients. AI can assist in the analysis of vast datasets to identify patterns and may provide valuable information on selecting an effective drug. Predicting an individual's response to a drug can aid in treatment selection, optimizing therapy, exploring new therapeutic options, and personalized medicine. This viewpoint highlights the growing evidence supporting the potential of AI-based methods to predict drug response with accuracy. Furthermore, the methods highlight a trend toward using ensemble methods as preferred models in drug response prediction studies.

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KEYWORDS

type 2 diabetes; artificial intelligence; machine learning; drug response; treatment response prediction; ML; AI; deep learning

Introduction

Type 2 diabetes mellitus stands as one of the most common metabolic disorders, comprising 90% - 95% of all cases of diabetes and affecting millions of people worldwide. The condition arises from 2 main factors: malfunctions in insulin secretion by pancreatic β-cells and the resistance of insulin-sensitive tissues to insulin [1]. The aim of treatment for type 2 diabetes is to maintain good blood sugar (glucose) levels, which can reduce the risk of development of complications related to diabetes, such as retinopathy, nephropathy, neuropathy, and cardiovascular diseases. Initial therapies include lifestyle changes and certain medications such as metformin and sulfonylureas. The specific drug or combination of drugs used is based on individual needs and medical history. Treatment with certain drugs may be unsuccessful depending on the physiological and pathological characteristics of individuals.

There is considerable heterogeneity among people with type 2 diabetes and their response to different drugs. The use of ineffective drugs results in the deterioration of a patient's condition and raises health care expenses. Thus, there is a need to develop reliable drug response prediction methods to help identify the efficacy of potential treatments for an individual. The heterogeneity of disease and treatment response emphasizes the need for advanced analytical methods, such as artificial intelligence (AI), to understand complex patterns within data, identify patient subgroups with distinct characteristics and ultimately pave the way for personalized and precision medicine.

The main objective of this viewpoint is to review the literature exploring the use of AI-based techniques for predicting drug response in type 2 diabetes, as well as drawing upon other disease areas such as rheumatoid arthritis, multiple sclerosis, and cardiovascular diseases. For type 2 diabetes, AI methods can help gain insights into the determinants or predictors of drug response (age, sex, type of drug, dosage, duration, medical history, ethnicity, socioeconomics, blood biochemistry, and genetics) and identify characteristics that are responsible for poor drug response. The goal is to provide an extensive overview of the key findings, methodologies, algorithms, outcomes, and limitations identified in the reviewed studies. Through a critical evaluation, this review aims to assess the strengths and weaknesses of certain AI-based algorithms in predicting treatment response and to identify potential areas of future research.

Understanding the Role of AI

AI in Drug Response Prediction

AI presents a compelling solution for drug response prediction due to several key factors. Traditional approaches to determining drug response often rely on limited datasets and simpler regression models, which may overlook the complex interplay of factors influencing treatment outcomes. Furthermore, these methods focus on a narrow set of variables, potentially missing crucial insights into individual patient characteristics and treatment responses. However, with the advancement of AI, particularly machine learning (ML) algorithms, there is an opportunity to leverage vast amounts of data, including electronic health records (EHRs), genomics data and real-world patient data [2]. AI enables a more comprehensive analysis, by considering multiple variables and confounders simultaneously [3]. By examining data holistically and identifying intricate patterns across diverse sources of information, AI has the potential to increase our understanding of drug response mechanisms.

Leveraging a Diverse Data Source

There are a lot of data types available when considering drug response. AI can potentially use all of these to enable drug response prediction. The data that can be used by AI systems for observational studies includes laboratory findings, EHRs, claims and bills, genome sequencing data, clinical data, disease registries, patient-reported outcomes, data from wearable devices and sensors, pharmacogenomics data, demography data, hematology, etc [4,5]. Additionally, EHR data can itself provide detailed information about a patient's medical history, diagnoses, treatments, drug prescription records, dosage, clinical outcomes, etc. Furthermore, genetic data of patients, such as their genomic profiles can be helpful to understand individualized treatment responses. Pharmacogenomics studies can examine genetic variations and their influence on drug responses.

AI Techniques and Their Applications

AI is a broad field comprising a wide range of technologies and techniques for building systems that can independently perform tasks associated with human intelligence. The applications of AI in health care have been used in patient data management, predictive medicine, clinical decision-making, diagnostics, and personalized medicine [6,7]. AI includes a range of methods, among which ML and deep learning (DL) stand out as 2 prominent subsets [8]. ML is involved in building systems that are capable of learning from data, identifying patterns, and making decisions. On the other hand, DL, is a special form of ML inspired by the structure and function of the brain, especially neural networks. These models learn from data autonomously and are adaptable to various features.

The most prominent methods for prediction modelling are ensemble-based methods, such as random forest (RF) and gradient boosting machines [9-11]. These methods combine the predictions of multiple models to produce a stronger overall prediction. They can reduce overfitting and increase robustness by using the diversity of the constituent models. This is achieved by training multiple base learners on different subsets of the data or with different algorithms and then combining their predictions [12].

Explainable Artificial Intelligence

It is important to understand how AI functions to ensure trust and transparency. This is where explainable artificial intelligence (XAI) methods come into play [13-15]. In their review, Loh et al [13] discuss XAI and its practical applications. XAI methods have undergone significant advancements to enhance our trust in a model's predictions by providing insights into the reasoning behind them. Further, XAI proves to be a valuable tool alongside traditional statistical approaches when analyzing the connections between variables and outcomes. Some of the most popular XAI methods include local interpretable model-agnostic explanations, gradient-weighted class activation mapping, and Shapley additive explanations [16,17]. These methods are combined with ML models to make predictions. They showcase the importance of features independently of the model's structure, and the direction of influence from predictive variables.

Advanced Modeling Techniques

Methods exploring interactions among input variables should also be considered in predictive modelling. These techniques capture complex relationships and nonlinear effects between predictors, improving model performance. Several methods can identify potential interactions, such as introducing polynomial features, adding interaction terms by multiplying variables, using tree-based algorithms, performing feature engineering, implementing neural networks to automatically learn complex interactions, and using domain knowledge. By accounting for these interactions, predictive models can become more accurate and informative, enabling better decision-making and personalized treatment strategies.

Ensuring Transparency and Reproducibility

In drug response studies, mainly those leveraging AI techniques, adherence to transparent and standardized reporting guidelines is important. The Transparent Reporting of a Multivariable Prediction Model for Individual Prognosis or Diagnosis guidelines [18] ensures the robustness and reliability of predictive models. These guidelines provide a structured framework for model development, validation, and performance evaluation, thus enhancing transparency and reproducibility. Moreover, adherence to TRIPOD(Transparent Reporting of a Multivariable Prediction Model for Individual Prognosis or Diagnosis) guidelines enhances the clinical relevance of predictive models by promoting clarity and consistency in reporting key elements such as patient's characteristics, predictor variables, outcome measures, and model performance metrics.

Model Selection and Performance Evaluation

Selecting the best AI model is a critical task. The ideal model is expected to be accurate and suitable for a specific task. Opting for a model with higher performance ensures reliable outcomes, improved predictions, and informed decision-making. Thus, performance comparison of different models is necessary to find the model with the highest accuracy and efficiency. The process involves evaluating the model's performance against each other using a set of metrices and techniques. Performance

comparison can be done through various approaches, such as root-mean-square-error, accuracy, sensitivity, specificity, precision, area under the curve (AUC), mean absolute relative difference, receiver operating characteristic curve, mean squared error, etc [9,19]. These metrices offer insights into various aspects of model performance. In terms of AUC in drug response prediction, a higher AUC indicates better discriminative ability of the model, with values closer to 1 indicating stronger predictive performance. However, the interpretation of AUC should also consider factors such as the balance between specificity and sensitivity, as well as the clinical significance of false positives and false negatives [20].

Additionally, techniques such as cross-validation can be used to obtain robust performance comparison by assessing the model's generalization capabilities. This involves splitting the data into multiple folds and training or testing the models on subsets of data to perform a more comprehensive evaluation. It helps to reduce the chances of overfitting or underfitting by providing a more realistic estimate of the performance of any model. Methods for addressing generalizability in predictive modelling also include techniques such as bootstrapping and external validation. These methods ensure that the model's performance is not overly influenced by the specific characteristics of the training dataset and can be applied to new populations.

Modeling Drug Response Using AI

To better understand the key aspects of drug response prediction methods using AI-based models, we examined the existing literature on the recent ML and DL-based models in specific disease domains. A comprehensive search was conducted in July 2023, across multiple academic databases, including PubMed, Scopus, and bioRxiv, using keywords related to drug treatment response, ML, and specific disease areas. The search strategy included keywords grouped into 2 sets: "AI-based keywords" and "drug response-based keywords." These keywords were selected based on a combination of domain knowledge, a review of existing literature, and consultation with subject matter experts. These 2 sets were combined using the Boolean operator "AND" to narrow down the search and identify relevant studies.

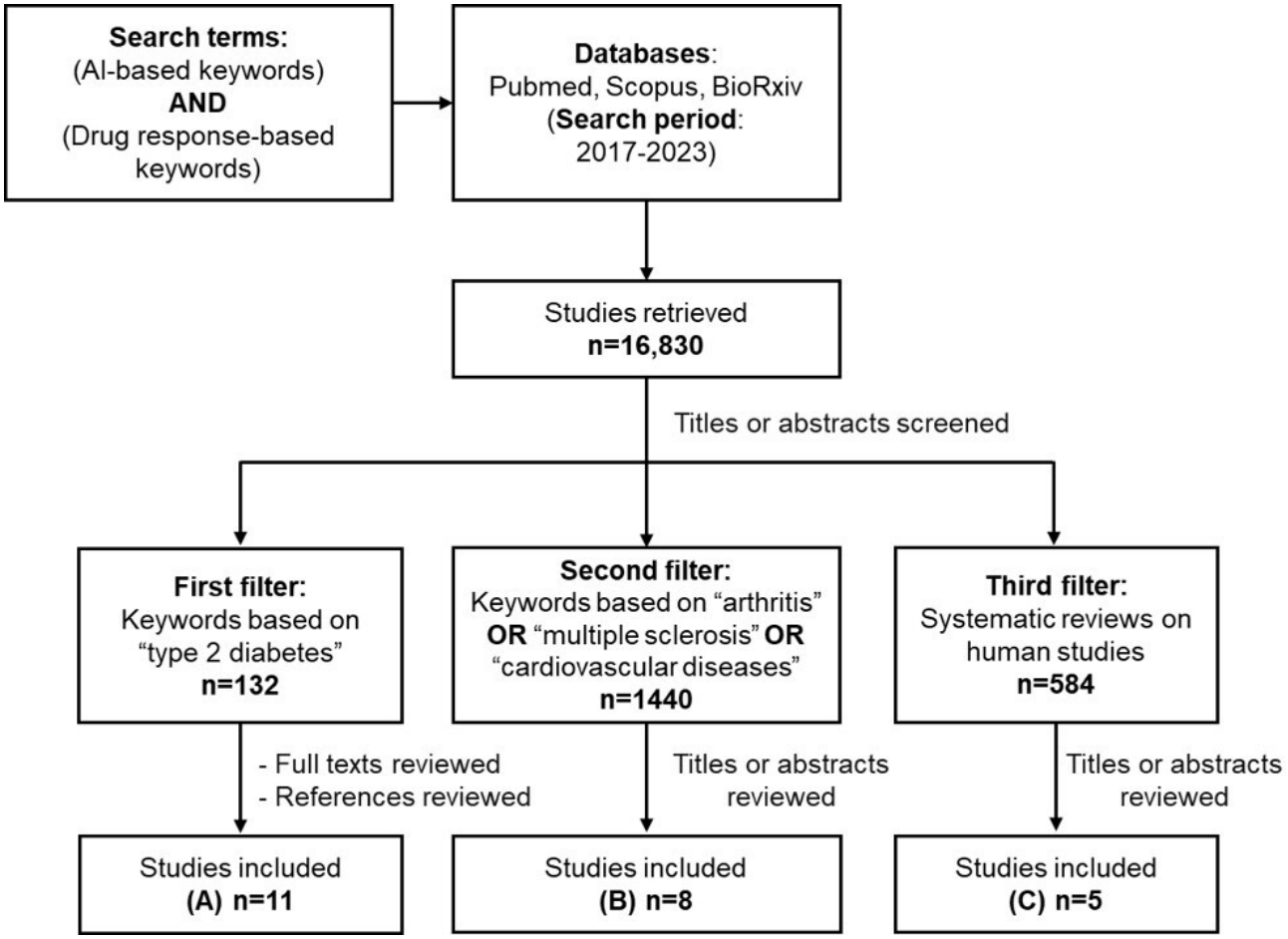
Keywords for AI were combined using the Boolean operator "OR" to capture a wide range of AI-related concepts: ("machine learning" OR "artificial intelligence" OR "deep learning" OR "prediction model" OR "statistical model" OR "neural network" OR "data science" OR "computational intelligence" OR "graph data" OR "machine intelligence" OR "convolutional network" OR "random forest" OR "reinforcement learning").

Keywords for drug response were similarly combined using the Boolean operators "OR" to encompass various related terms: ("treatment response" OR "drug response" OR "response prediction" OR "treatment prediction" OR "treatment outcome" OR "drug response prediction" OR "clinical outcome" OR "therapeutic outcome").

The studies were first filtered for "type 2 diabetes" and then for other disease areas such as arthritis, multiple sclerosis, and cardiovascular diseases (Figure 1A-C). These additional conditions were chosen because they are widely studied in relation to drug response and represent areas where AI methods have shown emerging applications. Additionally, we filtered for systematic reviews published on human studies to identify already published papers, as they provide a comprehensive summary of existing evidence.

The references of the retrieved studies were also reviewed to locate additional relevant papers. For this review, studies published between 2017 and 2023 were considered. We focused on papers that applied ML and DL algorithms specifically predicting treatment responses in clinical trials or observational studies.

Figure 1. A flowchart representing this study's selection process. (A) references [21-31], (B) references [32-39], and (C) references [5-8,13].



AI and Drug Response in Type 2 Diabetes

While much literature has been published on AI methods, their applications in life sciences are still comparatively limited. The field that has been most explored is oncology, where drug response prediction models are built using pharmacogenomic databases and cancer cell lines due to the impracticality and cost of clinical trials studies across diverse cancers [4,40,41]. Cardiometabolic diseases are a young upcoming field in the application of AI methodologies, likely due to limitations in data availability. The 11 studies identified in type 2 diabetes from the years 2017 to 2023 highlight the promise of data-driven insights in this field.

Most studies focus on predicting treatment responses to combinations of drugs, which aligns more closely with real-world scenarios where patients often receive multiple medications to treat the medical conditions. These studies use various criteria to make binary classification models. Some aim to predict whether a patient achieves a target HbA_{1c} (glycated hemoglobin) goal, while others focus on predicting if the patient experiences a reduction in HbA_{1c} by a certain number of units. Performance is evaluated using metrics such as AUC or accuracy, depending on the context. Additionally, we compare the quantity and nature of data used, as well as AI methods and outcomes.

In the field of drug response studies, traditional linear and logistic regression models have been staples for quite some time. For instance, Pantalone et al [21] developed a logistic regression model on 6973 patients to predict responders—patients who achieve an HbA_{1c} goal of less than 8% when treated with a combination of multiple antidiabetic drugs (Table 1). Their binary classification model achieved an AUC of 0.648. In a separate observational study, Wang et al [22] used a logistic regression model alongside multiple ML models on 2787 patients' data to predict patients who achieve an HbA_{1c} goal of less than 7% when treated with insulin. While the logistic regression model yielded an accuracy of 0.55, the RF reached an accuracy of 0.75, and both the back propagation artificial neural network and the support vector machine achieved an accuracy of 0.73. Notably, the support vector machine, RF, and back propagation artificial neural network models outperformed the logistic regression model in the accuracy metric. Both studies relied on traditional logistic regression models, which, as indicated by the results, demonstrated lower performance compared to ML methods [21,22]. These traditional models assume linear relationships between variables, which may not be well-suited for real-world data. As a result, they fail to capture the necessary associations for making accurate predictions.

Table . Studies incorporating AI[a] to predict treatment response in type 2 diabetes using clinical trials or observational data.

Reference	Study objective	Data type and number of patients (n)	Drug treatment (single or in combination)	AI methods	Prediction outcome	Performance
Tao et al [27]	Machine learning models to predict fasting blood glucose and HbA_{1c}[b] after 3 months of treatment	Retrospective study n=2169	Metformin, sulfonylurea, thiazolidinediones, GLP-1[c], DPP-4[d], SGLT2[e], acarbose, meglitinide, insulin	Logistic regression, SGD[f], decision tree, Gaussian NB[g], QDA[h], Bernoulli NB, LDA[i], Multinomial NB, RF[j], Extra Tree, passive aggressive, AdaBoost, begging, GBM[k], XGBoost, ensemble learning	Reach HbA_{1c} target below 7%	• AUC[l] (ensemble)>0.9
Berchialla et al [24]	Machine learning models to predict treatment outcome	Clinical trials n=385	Metformin, sulfonylurea, DPP-4 inhibitors	Ensemble algorithm (super learner: GBM, GLM[m], RF, MARS[n], SVM[o], CART[p], BART)[q]	Reduction in HbA_{1c} of at least 0.5%	• AUC: 0.92
Sun et al [28]	Effective treatment recommendations using reinforcement learning	Observational study n=189,520	Metformin, sulfonylurea, thiazolidinediones, DPP-4, GLP-1, SGLT2, acarbose (AGI[r]), basal insulin, premixed insulin	Multivariate logistic regression, reinforcement learning	Odds of achieving target HbA_{1c}<7% among concordant compared to nonconcordant group	• Odds ratio: 1.73 (95% CI 1.69 to 1.76)
Pantalone et al [21]	Prediction model on probability of HbA_{1c} goal attainment	Retrospective cohort study n=6973	Metformin, sulfonylurea, thiazolidinediones, DPP-4, GLP-1, SGLT2, AGI, insulin	Logistic regression	Reach HbA_{1c} target below 8%	• AUC: 0.648 (95% CI 0.633 to 0.663)
Wang et al [22]	Machine learning models for predicting HbA_{1c} among patients treated with insulin	Observational study n=2787	Insulin	Logistic Regression, RF, SVM, BP-ANN[s]	Reach HbA_{1c} target below 7%	• AUC (LR[t]): 0.74 • AUC (RF): 0.75 • AUC (SVM): 0.72 • AUC (BP-ANN): 0.72
Dennis [29]	Using individualized prediction models to optimize selection of treatment	Observational study n=8798	Metformin, sulfonylurea, thiazolidinediones, DPP-4, GLP-1, SGLT2	Individualized prediction models	3-year change from baseline in HbA_{1c}	• Reduction in HbA_{1c} (mmol/mol): • Concordant: −16.9 (95% CI −18.2 to −15.6)
Lopez et al [25]	Predicting the response to short-term intensive insulin therapy	Clinical trial n=24	Insulin	RF	Percentage change in ISSI-2[u]	• AUC: 0.951
Ngufor et al [30]	Mixed effect machine learning for predicting longitudinal change in HbA_{1c}	Observational study n=27,005	Metformin, sulfonylurea, thiazolidinediones, insulin, Meglitinide, AGI, GLP-1, DPP-4, amylinomimetics	Mixed effect Machine learning, RF, GBM, GLMs	Reach HbA_{1c} target below 7%	• AUC: 0.7 - 0.8

Reference	Study objective	Data type and number of patients (n)	Drug treatment (single or in combination)	AI methods	Prediction outcome	Performance
Del Parigi et al [23]	Machine learning to identify predictors of drug response	Phase III clinical trial data n=1363	SGLT2, DPP-4	RF, classification trees	Reach HbA_{1c} target below 7%	• Prediction accuracy: 0.77 - 0.82
Nagaraj et al [31]	Machine learning models to predict short and long-term HbA_{1c} response	Observational study n=1188	Insulin	Generalized linear regression, SVM, RF	Reduction in HbA_{1c}≥5 mmol/mol or reach target HbA_{1c} below ≤53 mmol/mol	• AUC (short term): 0.80 (95% CI 0.78 to 0.83) • AUC (long term): 0.81 (95% CI 0.79 to 0.84)
Murphree et al [26]	Machine learning models to predict response after 1 year of metformin therapy	Health records n=12,147	Metformin	Stacked classifiers (ensemble): LR, RF, NN[v], k-NN[w], stochastic gradient boosting, SVM, CART, averaged neural network, FDA[x], GBM, PLS[y], SLDA[z]	Reach HbA_{1c} target below 7%	• AUC: 0.58 - 0.75

[a]AI: artificial intelligence.
[b]HbA_{1c}: glycated hemoglobin.
[c]GLP-1: glucagon-like peptide 1.
[d]DPP-4: dipeptidyl peptidase 4.
[e]SGLT2: sodium-glucose cotransporter 2.
[f]SGD: stochastic gradient descent.
[g]NB: Naïve Bayes.
[h]QDA: quadratic discriminant analysis.
[i]LDA: linear discriminant analysis.
[j]RF: random forest.
[k]GBM: gradient boosted machine.
[l]AUC: area under the curve.
[m]GLM: generalized linear model.
[n]MARS: multivariate adaptive regression spline.
[o]SVM: support vector machine.
[p]CART: classification and regression tree.
[q]BART: Bayesian additive regression tree.
[r]AGI: alpha-glucosidase inhibitor.
[s]BP-ANN: back propagation artificial neural network.
[t]LR: linear regression.
[u]ISSI-2: insulin secretion-sensitivity index-2.
[v]NN: neural network.
[w]k-NN: k-nearest neighbor.
[x]FDA: flexible discriminant analysis.
[y]PLS: partial least square.
[z]SLDA: sparse linear discriminant analysis.

Some of these studies use clinical trial data, which is more organized, and cleaner compared to observational data for building ML models. Del Parigi et al [23] used a clinical trial data of 1363 patients and applied 2 ML algorithms, namely RF and classification trees, to find predictors of glycemic control in patients treated with a combination of sodium-glucose cotransporter 2 and dipeptidyl peptidase 4 inhibitors, both as dual-therapy and mono-therapy. The prediction accuracy of their models ranged from 0.77 to 0.82, with fasting plasma glucose and HbA_{1c} emerging as the most influential predictors of achieving glycemic control.

Berchialla et al [24] used a clinical trial data of 385 patients and used a weighted combination of 7 algorithms (Table 1) using an ensemble approach known as the super learner to predict responders, specifically patients who achieve a reduction in HbA_{1c} of at least 0.5% when treated with conventional drugs and dipeptidyl peptidase 4 inhibitors. Their ensemble model yielded an AUC of 0.92. In a different study, Lopez et al [25] used clinical trial data from 24 patients to develop an RF model for predicting the response to short-term intensive insulin therapy. Their binary classification model yielded an accuracy of 0.91 and an AUC of 0.951. These 2 analyses yield very high AUC values, which raise some concerns. Their sample sizes are very small, presenting a high risk of overfitting. Models trained on such limited data may not generalize well to broader populations. Additionally, with a small sample size, there is a higher risk of selection bias, where the characteristics of the patients could be very similar and may not represent larger populations. This can skew the results and lead to an overestimation of model performance.

We found that most studies that used ML approaches used ensemble-based methods to build predictive models [22-27,30]. Ensemble-based techniques, such as gradient boosting machines, RFs, and stacking, have become popular due to their high performance and capability to work with complex datasets. For instance, Murphree et al [26] established an ensemble-based ML model using 20 base models (Table 1) to predict glycemic response after 1 year of metformin therapy. Their models achieved AUC values ranging from 0.58 to 0.75 with baseline HbA_{1c}, metformin dosage, and diabetic complications being the strongest predictors. In a different study, Tao et al [27], also developed ensemble-based ML models to predict patients who achieve an HbA_{1c} goal of less than 7% after 3 months of treatment with multiple antidiabetic drugs. They compared the performance of 16 different ML models (Table 1), where AUC values of the top 5 models were all greater than 0.9. Overall, these ensemble-based methods have the capability to combine multiple weak learners and generate a more accurate and robust final model, that can reduce bias and overfitting, resulting in better predictions [42,43]. Additionally, these methods have become more accessible with the development of user-friendly libraries and packages, which helps researchers use them effectively.

All these ML models identified the significant features associated with drug response. The most crucial indicators of drug response included the patient's baseline HbA_{1c}, fasting blood glucose, BMI, medication compliance, dietary habits, age, race, family history, diabetes duration, blood pressure, and dosage and usage of specific antidiabetic drugs [21-31]. These variables are derived from a combination of clinical trials and health records.

These studies provide a basis for understanding observational data, clinical data, interpreting drug responses, using statistical and ML algorithms, and suggesting tools and packages for data analysis. In most of the studies, a general trend of using ensemble-based models is observed, but it is essential to consider other DL-based modelling techniques for more complex datasets or when dealing with nonlinear relationships between variables. These advanced AI methods can offer the potential to find predictive factors that can help identify patients who can benefit most from a given treatment.

AI and Drug Response in Other Disease Areas

Exploring disease areas other than diabetes that have used ML models for predicting drug responses can offer a broader perspective and valuable insights. By studying how AI models are applied in other disease contexts, we can adapt and refine these methods for type 2 diabetes. Further, learning additional techniques for data processing, feature engineering, and cross-validation can enhance the reliability of AI-driven drug response models. We identified numerous examples in the literature of the application of ML and DL methodologies in various disease domains [5,32-39], including rheumatoid arthritis, multiple sclerosis, cardiovascular disorders, and neurological conditions (Table 2).

Table . Studies incorporating AI[a] to predict treatment response using clinical trials or observational data in nondiabetes conditions.

Reference	Study objective	Disease state	Data type and number of patients (N)	AI methods	Performance
Zhao et al [36]	Machine learning and statistical analysis to predict drug treatment outcome	Pediatric epilepsy	Retrospective study n=103	Multilayer perceptron, logistic regression, Naïve Bayes, SVM[b], RF[c], decision tree	• AUC:[d] 0.812
Duong et al [37]	Using machine learning to find clinical predictors of drug response	Rheumatoid arthritis	Clinical trial data n=775	LASSO[e] regression, RF	• AUC (LASSO): 0.74 - 0.84 • AUC (RF): 0.62 - 0.73
Myasoedova et al [38]	Using machine learning for individualized prediction of drug response	Rheumatoid arthritis	Observational study n=643	RF	• AUC: 0.84
Falet et al [35]	Using deep learning to estimate individual treatment effect on disability progression	Multiple sclerosis	Clinical trial data n=3830	Multilayer perceptron	• HR:[f] 0.743
Koo et al [32]	To develop machine learning models for predicting remission in patients treated with biologics.	Rheumatoid arthritis	Observational study n=1204	LASSO and ridge regression, SVM, RF, XGBoost, SHAP[g]	• Accuracy: 52.8% - 72.9% • AUC: 0.511 - 0.694
Liang et al [39]	Machine learning to predict response after cardiac resynchronization therapy	Cardiovascular disease	Retrospective study n=752	LR[h], SVM, RF, LASSO, ridge, NN[i], EN[j], k-NN[k], XGBoost	• AUC>0.77
Norgeot et al [34]	Using longitudinal deep learning model to predict controlled or uncontrolled state with clinical disease activity index	Rheumatoid arthritis	Electronic health records n=820	Longitudinal deep learning	• AUC (UH[l] cohort): 0.86 - 0.96 • AUC (SNH[m] cohort: 0.65 - 0.83)
Guan et al [33]	Using AI to predict the responses to TNF[n] inhibitors in patients using clinical and genetic markers	Rheumatoid arthritis	Observational study n=2572	Gaussian process regression model	• AUC: 0.66 • Correlation coefficient: 0.405

[a]AI: artificial intelligence.
[b]SVM: support vector machine.
[c]RF: random forest.
[d]AUC: area under the curve.
[e]LASSO: least absolute shrinkage and selection operator.
[f]HR: hazard ratio.
[g]SHAP: Shapley additive explanation.
[h]LR: linear regression.
[i]NN: neural network.
[j]EN: elastic net.
[k]k-NN: k-nearest neighbor.
[l]UH: university hospital.
[m]SNH: safety-net hospital.
[n]TNF: tumor necrosis factor.

In the case of rheumatoid arthritis, Koo et al [32] developed multiple ML models (Table 2) for prediction of remission in patients who are treated with biologic disease-modifying antirheumatic drugs. They used Shapley additive explanation values for explaining the predictions and ranking of important features. The AUC for these models ranged from 0.511 to 0.694. Guan et al [33] developed a Gaussian process regression model for the prediction of responses in terms of changes in Disease

Activity Score-28 to tumor necrosis factor inhibitors. They used clinical and genetics data, and their model yielded an AUC of 0.66. In another study, Norgeot et al [34] developed a longitudinal DL model with clinical disease activity index to predict controlled (low activity or remission) or uncontrolled state (moderate or high activity). The AUC ranged from 0.86 to 0.96 in 1 cohort and from 0.65 to 0.83 in another cohort.

For predicting treatment response to anti-CD20 monoclonal antibodies in multiple sclerosis, Falet et al [35] used a DL-based method called multilayer perceptron (MLP). Their model yielded hazard ratio of 0.743. Similarly, Zhao et al [36] used multiple ML models (Table 2) and MLP in case of pediatric epilepsy to predict the drug treatment outcomes of antiseizure medications. Their top performing MLP model achieved an AUC of 0.812. The MLP is based on a neural network architecture with the ability to approximate any mathematical function, handle nonlinear relationships and work with diverse datasets. MLPs can compute outputs based on input data through a process called feed propagation. MLPs use an optimization algorithm called backpropagation to adjust the weights and minimize the prediction error. The flexibility of MLPs contribute to their role in various classification and regression tasks [44,45].

Challenges and Limitations

Data Quality and Accessibility

Using AI for predicting treatment response from observational studies comes with several challenges and limitations that must be carefully considered. First, obtaining high-quality and diverse patient data, including longitudinal and genetic data, can be challenging. Obtaining individual-level patient data linked to health outcomes can be restricted in several geographic regions, and not adequately linked. Real-world data often presents a high burden of curation and contains gaps, such as mixed-up units or incorrect health care recordings which diminish the data quality. Moreover, there are very few data sources that offer harmonized data across different medical systems, further complicating analysis, and interpretation.

Data Biases and Missingness

Limited or biased data may prevent the AI model's ability to make precise predictions across various patient populations. Biases in the data could arise from various sources, such as demographic biases (eg, underrepresentation of certain age groups or ethnicities), clinical biases (eg, overrepresentation of patients with certain medical conditions or treatments), or geographic biases (eg, data collected predominantly from specific regions or health care settings). Furthermore, data limitations could arise from insufficient sample sizes, imbalanced class distributions, missing or incomplete data points, etc. These limitations can impact a model's ability to perform better.

It is also possible that some of the important predictive factors are not measured and therefore not included in most of the analyses. For instance, when predicting disease progression or treatment response, factors such as patient's socioeconomic status, medication history, adherence to treatment regimens, genetic variations, or lifestyle behaviors (eg, diet or exercise) could be critical for accurate predictions. However, if these factors are not routinely collected or integrated into the analysis, the model's predictive performance may be compromised.

Data Security and Privacy

It is important to address concerns related to data security and privacy when handling patient data. Health care organizations must safeguard sensitive patient information from unauthorized access or misuse to ensure patient confidentiality. Additionally, there are ethical considerations in AI pertaining to how AI systems are developed, deployed, and used in health care. AI models should not discriminate against certain demographic groups or perpetuate existing biases in health care delivery.

Model Interpretability, Validation, and Clinical Integration

Furthermore, ensuring the interpretability and explainability of AI models is crucial, as clinicians and researchers require insight into the factors influencing predictions for improved understanding and translation, to see increased adoption. Thorough validation and testing of the model's performance on an independent patient set is essential to ensure the clinical utility. Moreover, the integration of AI models into existing clinical workflows requires clinical collaborations. Addressing these challenges requires a collective action from stakeholders across the health care ecosystem, including researchers, policy makers, health care providers, and technology developers. By acknowledging and overcoming these challenges, AI can be a valuable tool in predicting treatment responses.

Conclusion

This viewpoint highlights the potential of AI in predicting treatment response in people with type 2 diabetes as well as other diseases. From this literature survey, we discovered that methods such as Gaussian process regression and DL techniques such as the MLP that have been used successfully in other disease areas have not been extensively investigated for predicting drug responses in type 2 diabetes. Yet, they show significant potential for developing prediction models due to several factors. Gaussian process regression offers the advantage of providing probabilistic predictions, which can capture uncertainty in the data. On the other hand, DL techniques such as the MLP has capabilities to learn complex patterns and representations from large-scale datasets, which is useful in capturing heterogeneous drug response.

After reviewing the literature, it becomes evident that integrating diverse data sources, using feature selection algorithms, implementing effective model optimization strategies, and validation through external validation have collectively resulted in the development of robust predictive models. Moving forward, it is essential to continue exploring the innovative approaches to overcome limitations, such as the interpretability, the curse of dimensionality [46], and low-quality data.

Our viewpoint sheds light on the limitations of traditional statistical models in handling high-dimensional data effectively. To overcome these constraints, advanced ML methods should be considered, such as ensemble methods and DL, which

demonstrate high performance in handling complex datasets. However, while these models excel in predictive accuracy, their opaque nature presents challenges in understanding the contributions of individual features to predictions. This underscores the importance of exploring methods to enhance the transparency and interpretability of models by including XAI techniques.

In summary, the literature reviewed demonstrates the successful use of AI methods for predicting drug responses in type 2 diabetes, while also identifying key clinical predictors of drug response. These models lay the foundation for the development of treatment recommendation systems, offering the potential for enhanced diabetes management, and ultimately leading to improved patient care.

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Authors' Contributions

EP contributed to conceptualization and supervision. SG collected the existing studies and wrote the original draft. SG, EP, RK, and RG contributed to the reviewing and editing.

Conflicts of Interest

None declared.

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Abbreviations

AI: artificial intelligence
AUC: area under the curve
DL: deep learning
EHR: electronic health record
HbA_{1c}: glycated hemoglobin
ML: machine learning
MLP: multilayer perceptron
RF: random forest
XAI: explainable artificial intelligence

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Digital Decision Support for Perioperative Care of Patients With Type 2 Diabetes: A Call to Action

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Abstract

Type 2 diabetes mellitus affects over 500 million people globally, with 10% - 20% requiring surgery. Patients with diabetes are at increased risk for perioperative complications, including prolonged hospital stays and higher mortality, primarily due to perioperative hyperglycemia. Managing blood glucose during the perioperative period is challenging, and conventional monitoring is often inadequate to detect rapid fluctuations. Clinical decision support systems (CDSS) are emerging tools to improve perioperative diabetes management by providing real-time glucose data and medication recommendations. This viewpoint examines the role of CDSS in perioperative diabetes care, highlighting their benefits and limitations. CDSS can help manage blood glucose more effectively, preventing both hyperglycemia and hypoglycemia. However, technical and integration challenges, along with clinician acceptance, remain significant barriers.

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KEYWORDS

perioperative diabetes; artificial intelligence; clinical decision support systems

Impact of Type 2 Diabetes Mellitus in the Perioperative Period

Type 2 diabetes mellitus affects over 500 million individuals globally with 10% - 20% of these patients requiring surgery during hospitalization [1,2]. Throughout the whole perioperative period, patients with diabetes need more stringent blood glucose management, thorough complication evaluation, and multidisciplinary collaboration to mitigate mortality risk and enhance recovery, because diabetes is associated with an increased frequency of surgical interventions and prolonged hospital stays, with perioperative death rates 50% greater than those in the population without diabetes [3]. The contributing factors for these negative outcomes are multiple, but the main reason is perioperative hyperglycemia [4]. It can result in severe metabolic and organ dysfunction, exacerbate organ damage, trigger various disorders, increase infection risk, and even lead to postoperative death [5]. Although optimal glycemic control significantly improves postoperative outcomes in patients with diabetes, particularly in mitigating the risk of infection [6], there have long been obstacles regarding achieving the ideal method for managing blood glucose levels.

Limitations of Current Perioperative Blood Glucose Management

Currently, perioperative blood glucose management is primarily categorized into three phases: preoperative assessment, intraoperative care and monitoring, and postoperative medication and diet [7]. Regular blood glucose monitoring during surgery is essential for effective perioperative control, often necessitating checks every 2 hours [8]. Nonetheless, stress responses, medication interventions, and several other circumstances can cause significant short-term elevations and rapid fluctuations in blood glucose levels [9]. Conventional measurement intervals are inadequate for detecting fast fluctuations in blood glucose

levels and the cumulative impact of risk variables, thereby overlooking critical intervention chances. The American Diabetes Association's Standard states that perioperative patients require more frequent blood glucose monitoring, particularly when insulin therapy is administered [10]. A 2-hour measurement interval may be insufficient for real-time control; thus, more frequent or continuous monitoring during surgery is recommended. In addition, blood glucose variability exposes patients to dual risks of hyperglycemia and hypoglycemia. Throughout this period, the Centre for Perioperative Care recommendations advise maintaining blood glucose levels between 6 and 12 mmol/L [1], contingent upon the administration of insulin and glucose, while either stringent or lenient blood glucose management may easily disrupt this "equilibrium." Consequently, tools are required for real-time glucose data monitoring and individualized medication distribution [11].

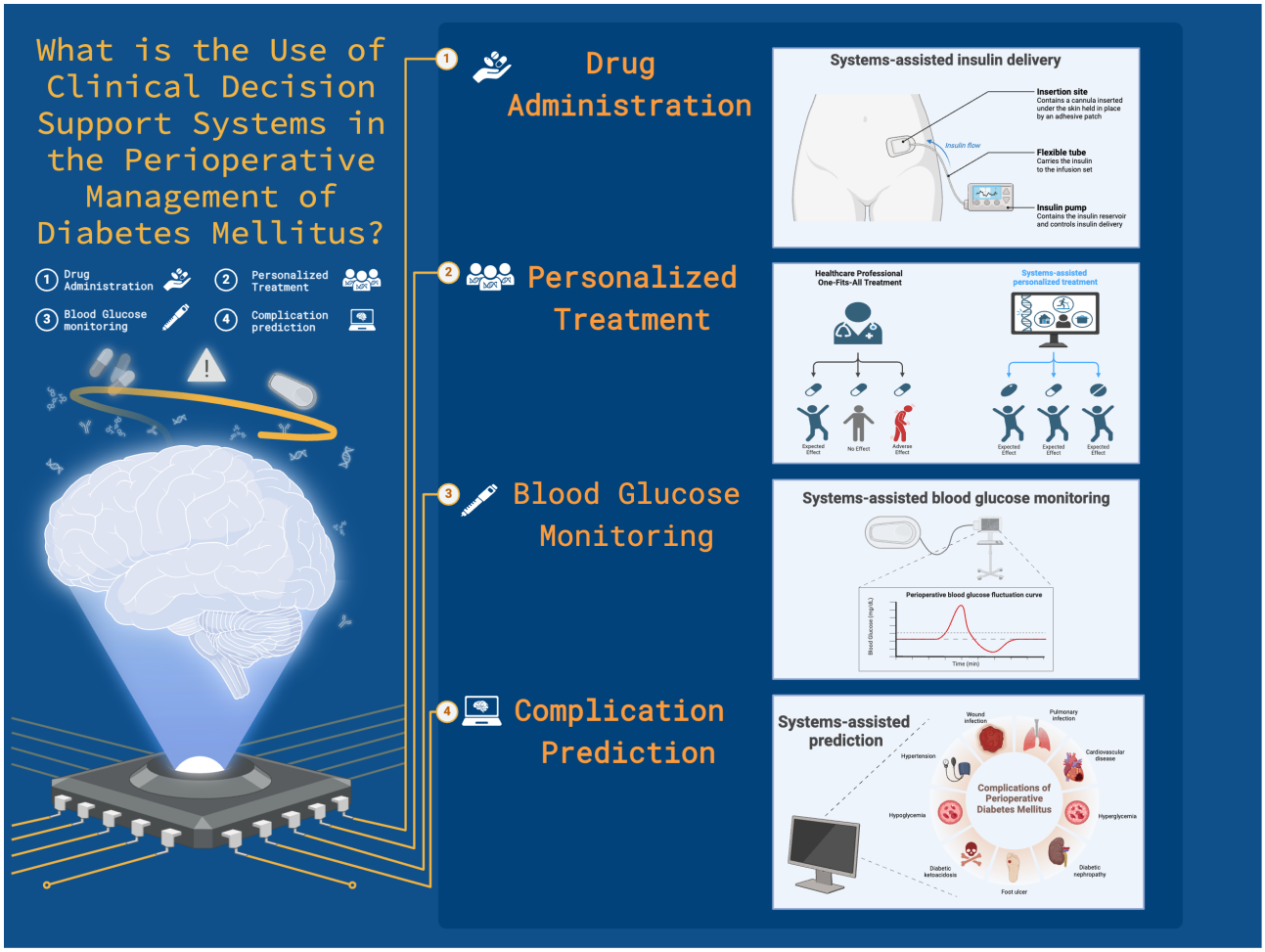
Potential of Clinical Decision Support Systems in Perioperative Blood Glucose Management

Clinical Decision Support Systems

Clinical decision support systems (CDSS) have gained significant traction due to the widespread adoption of electronic medical records and electronic health records in the past decades. These computerized systems may provide clinicians with a wide range of support, from basic pop-up warnings for medication errors to sophisticated tools that offer evidence-based recommendations for certain clinical situations (Figure 1) [12-14]. During the perioperative period, surgeons and anesthesiologists must consider multifaceted care, including blood glucose management, which requires experience and integrity in practice. The complexity of these tasks can be challenging for junior physicians and may create a gap between real-world clinical effectiveness and the efficacy observed in clinical trials. However, the advent of CDSS has introduced novel technical advancements to conventional perioperative management techniques.

A systematic review by Cai and colleagues summarizes trials and observational studies about the effectiveness of the CDSS in real-world settings [15]. As the American Association of Clinical Endocrinology stated in their 2023 Type 2 Diabetes Management Algorithm [16], personalized care is emphasized through evidence-based tools such as continuous glucose monitoring and automated insulin dosing systems. These technologies facilitated the ongoing surveillance of glucose levels and the secure delivery of insulin during surgical procedures. Furthermore, they have the potential to mitigate the likelihood of perioperative complications by assuring adherence to optimal glucose management guidelines [17]. Considering the aforementioned qualities, in contrast to conventional perioperative blood glucose control techniques, CDSS can address the challenge of detecting fast changes inherent in typical 2-hour monitoring intervals and provide real-time data to seize the critical intervention opportunities. Simultaneously, CDSS may precisely modify insulin dose according to real-time blood glucose data and specific patient situations, mitigating the twin hazards of hyperglycemia and hypoglycemia, thereby facilitating more effective and safer blood glucose regulation.

Figure 1. Application of clinical decision support systems in the perioperative care and management of diabetes mellitus.



Personalized Drug Delivery

Glucommander (Glytec) has set an example as an electronic glycemic management system since 1984 using a computer-based algorithm to guide the administration of intravenous insulin [18]. Glucommander (Glytec) formulates insulin dosage recommendations by analyzing patient-specific blood glucose patterns after health care professionals choose either a personalized dosage or a weight-based multiplier as the first dosing approach for the first 24 hours [19]. Until now, after undergoing integration and evaluation at multiple medical centers, Glucommander (Glytec) has demonstrated its effectiveness in enhancing outcomes for surgical patients with both type 1 and type 2 diabetes. Specifically, it has reduced the occurrence of hyperglycemia and hypoglycemia, treated diabetes ketoacidosis, and increased adherence to the guidelines for achieving individualized treatment [20-22].

Intraoperative Blood Glucose Level Monitoring

Similarly, there are CDSS that continuously monitor changes in perioperative blood glucose levels by providing in-room pop-up prompts. In a systematic review [15], one of the included studies [23] designed and evaluated a new CDSS using Epic's best practice advisory (BPA) framework. This tool is designed to remind anesthesia providers to measure blood glucose levels at specified intervals for patients at risk of abnormal perioperative blood glucose levels. The research results found that the implementation of the BPA CDSS significantly improved intraoperative blood glucose monitoring and management in the postanesthesia care unit (PACU). The PACU hyperglycemia rate decreased from no CDSS to the BPA CDSS (10.4% to 7.2%, *P*=.031).

Dispersion and Untimely Integration of Data Affects the Functionality of CDSS

Barriers Hindering the Effectiveness of CDSS

Notably, several barriers currently hinder the effectiveness of CDSS, highlighting the call for action. For patients with type 2 diabetes during the perioperative period, multimodal data are necessary for the development and maintenance of an effective CDSS, such as blood glucose monitoring data, drug information, surgical types, comorbidity, and more. However, such data are often scattered across various systems and require manual input. The integration of a substantial volume of data from many systems and the necessity for real-time updates in CDSS impose significant requirements on technical and system compatibility attributes. Moreover, blood glucose levels change continuously throughout the whole perioperative period caused by surgery, stress, or fasting. Without timely integration, decisions may be delayed or based on outdated information, thereby adversely impacting patient outcomes. Insufficient integration between electronic health records and CDSS might compromise the real-time prediction and accuracy of critical data [24].

Alarm Fatigue and Clinician Skepticism

CDSS-based decisions combine data, algorithms, clinicians' expertise, and clinical judgment. An estimated 95% of CDSS alerts were declined by clinicians [25]. The sheer volume of redundant messages exacerbates the burden in the practice. Some clinicians may develop "alarm fatigue" and become desensitized to all warnings, including those that are clinically valuable. Nonetheless, placing excessive reliance on CDSS recommendations is not always appropriate. Despite the exceptional accuracy of the generated data, CDSS are fundamentally an opaque system with an internal operational mechanism that is hard to interpret [26]. If professionals simply press the button of CDSS without comprehending the underlying principles, such decisions will be very dangerous. Assuming that patients with diabetes mellitus experience hypoglycemia and hyperglycemia crises, professionals should not only be proficient in how to obtain emergency care advice through CDSS, but also implement appropriate care measures based on their own experience and understanding of patient data. Therefore, what stands out the most is striking a balance between CDSS and clinicians, or in other words, algorithms and clinical experience of diabetes management.

Balancing Cost-Effectiveness

The development and maintenance of CDSS require acknowledging the need for robust data sources, advanced informatics systems, technical support, and personnel training. Building CDSS from the ground up to meet criteria can incur substantial costs, ranging from hundreds of thousands to millions of dollars. Custom-developed systems also require ongoing maintenance and upgrades. Maintenance expense usually varies from 10% to 20% of the original development expenditure. The annual cost of maintaining CDSS for diabetes management is approximately US $9500 for one small-sized institute, US $20,600 for medium-sized, and US $76,000 for large-sized ones [27]. For medical institutions with limited resources, managers need to weigh whether the potential improvements in patient outcomes or compliance with perioperative medical personnel guidelines are worth the high cost [28]. After rigorous evaluation, the effectiveness of some CDSS has been found to be disappointing. Jeffery and colleagues [29] systematically reviewed 15 randomized trials that assessed the effectiveness of CDSS in diabetes mellitus management compared with a non-CDSS control group (usual care, seminars, educational material, and glucose monitoring systems), but found no significant outcome that CDSS could reduce hospitalizations and improve quality of life. Meanwhile, the study found that in the third month, the pooled estimate of the change in glycated hemoglobin (HbA_{1c}) was 5 mmol/mol (95% CI –9 to 1; ie, –0.5%, 95% CI –1.0 to 0.1), but it is only a clinically significant threshold and this result is not significant. Blindly using CDSS may result in getting half the results with double the effort.

Future Direction

The number of CDSS specifically designed for diabetes management remains limited. The majority of CDSS development is directed towards traditional perioperative patients, emphasizing factors such as surgical type, patient age, and vital signs; however, limited attention is given to comorbidities, such as diabetes, in patients undergoing surgery. A prospective study in 29 countries across Europe identified diabetes mellitus as the fourth most common long-term condition (15.4%). Meanwhile, diabetes mellitus also accounts for a large share of patients with multimorbidity, with 19.4% of patients having two long-term health conditions and 43.8% having more than three long-term health conditions [30]. The coexistence of multiple diseases substantially elevates the mortality rate of patients undergoing surgery, sometimes doubling it. Poorly controlled chronic diseases, such as those with high American Society of Anesthesiologists scores, and compromised functional status (eg, frailty) further heighten these risks. If the database used for developing CDSS does not cover specific patients (such as those with complex comorbidities), this deficiency may lead to the system ignoring the risk factors of specific patients and providing treatment recommendations with biased risks.

The disparity in diabetes care throughout the world is becoming worse. The treatment rate of diabetes has remained low and relatively unchanged for many low-income and middle-income nations during the last several decades. More than 90% of people with diabetes in some nations did not get treatment between 1990 and 2022 [31]. Limited by the ratio of doctors-to-patients and infrastructure, diabetes may impose a heavier burden on these low-resource clinical environments, which may require the introduction of CDSS. However, its effectiveness in the low-resource environment remains to be explored [32]. In the presently advanced CDSS applications, the initial datasets used for development mostly originate from populations in developed countries, and their efficacy is often poor when applied to other locations or populations. A skin cancer diagnostic algorithm developed using data from White patients may have reduced efficacy for those with darker skin tones [33]. Prior to implementing these systems, it is essential to analyze data bias to avert unjust decision-making and mitigate health disparities among ethnic minorities or resource-limited regions. Furthermore, the deployment of CDSS necessitates the integration of information systems and financial investment, taking into account the restricted accessibility and technical capacities in resource-constrained regions. This has prompted demands for international collaboration, including the implementation of remote medical platforms or the direct supply of digital medical assistance [34].

In light of the issues faced by present CDSS implementations, the following recommendations are anticipated to be implemented (Table 1). Initially, at the source, deep learning techniques may be used to extract unstructured data from multimodal text and combine it into a unified system for analysis after standardization [35]. This metric enhances both the frequency of CDSS use and its real-time performance [36]. A potential innovation is the digital twin, a mathematical model of a system created from all accessible data. This technique may generate a virtual personal twin of a perioperative patient, capture the patient's perioperative trajectory without affecting their physiological condition, and be used for complication prevention and rehabilitation treatment [37]. Secondly, given that clinical physicians' adoption of CDSS and alarm fatigue may arise from their skepticism towards the system and their

proficiency in computer abilities, it is essential to investigate their requirements and formulate targeted training programs during the design phase of CDSS [36]. The alarm system may be enhanced by applying human factors engineering principles, hence minimizing false alarms and overlooked alerts [38]. Lastly, a systematic, step-by-step strategy is essential. It is advisable to do feasibility studies and pilot studies prior to real-world implementation, not only to identify software and hardware difficulties during the deployment phase but also to assess the long-term cost-effectiveness across various health care settings [39].

Table . Functions of clinical decision support systems (CDSS), limitations, and evidence-based solutions.

Functions of CDSS	Limitation of CDSS	Solutions to break limitations	Explanation of solutions
Personalized Drug Delivery Based on real-time blood glucose data and the patient's specific condition to calculate and recommend the appropriate insulin dosage.	**Data Integration Defects** The data required for CDSS are usually scattered across various systems and require manual input, which affect the real-time performance of analysis.	Integrate the required data for analysis into the same system adopting new technologies.	Deep learning techniques can extract and analyze relevant unstructured information from clinical records, including single concept extraction, temporal event extraction, relation extraction, and abbreviation expansion [35].
Blood Glucose Monitoring Real-time monitor changes in perioperative blood glucose levels by providing in-room pop-up prompts.	**Alarm Fatigue** Too many unnecessary alerts or suggestions lead to providers losing trust or being insensitive to CDSS.	Applying human factors engineering principles to design the alarm systems.	A system designed based on human factors principles may alleviate alarm fatigue, with specific strategies including reducing errors related to availability, delivering clinical data nearer to the decision point, and presenting alert text in a tabular style [38].
Blood Glucose Management Adherence to clinical guidelines to perform clinical procedures.	**Clinician Skepticism** Clinicians have a resistant or opposing attitude towards the opinions or suggestions given by CDSS.	Consider the needs of clinicians and develop specific training plans.	Clinicians should be involved in the design and development of CDSS in the early stages, and receive hands-on training and education before implementation. Clinicians' negative attitudes and resistance towards CDSS can be alleviated during this process [36].
Complication Prediction Utilizing patient perioperative information to predict the incidence of adverse events (such as hyperglycemia, hypoglycemia, etc)	**Cost Challenges** The development and maintenance of CDSS may consume capital or human resources and cannot guarantee long-term cost-effectiveness.	Do feasibility studies and pilot studies prior to real-world implementation. Long term follow-up to collect cost-effectiveness data.	Feasibility studies and pilot studies can help determine whether CDSS can transfer its good performance from the development phase to real-world settings, ensuring its correct and safe use in health care practice [39]. In addition to collecting cost data, long-term indicators such as patient prognosis or quality-adjusted life years should also be collected to determine whether the implementation of CDSS is a good return on investment for both hospitals and patients [28].

Conclusion

In summary, CDSS are revolutionizing the paradigm of perioperative diabetes mellitus care and management in the real world, shifting from conventional strategies to data-driven real-time monitoring and individualized treatment. Given the high volume of surgeries for patients with diabetes and the elevated incidence of postoperative complications, these systems are promising in many ways: integrating patients' blood glucose monitoring data and providing real-time blood glucose fluctuation warnings, offering personalized medication recommendations to prevent drug interactions or improper dosage adjustments, and assisting health care providers in predicting the surgical risk based on the patient's historical data (HbA_{1c}, preoperative blood glucose control, complications, and other factors). However, several barriers currently hinder the effectiveness of CDSS, though the original intention of these intelligent health intervention measures is to address the existing difficulties in the management and care of perioperative patients with diabetes mellitus. Thus, future research on CDSS must prioritize model optimization, particularly enhancing performance for patients with intricate comorbidities, especially diabetes, and develop techniques to bolster physicians' confidence and acceptance. Several randomized controlled trials and cost-benefit analyses with extended follow-up durations across various countries to validate the system's efficacy, universality, and practicality, and a pilot study are recommended before implementation. This will ultimately ensure that the

system can cover high-risk factors and provide evidence-based treatment recommendations, reducing the worldwide diabetes care disparity and advancing health equality.

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Authors' Contributions

JC wrote the first draft of this manuscript. All authors (JC, PL, WL, XH, SL, and TZ) developed the viewpoint design, carefully reviewed the manuscript, and edited the whole manuscript.

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Conflicts of Interest

The Co-Editor in Chief of *JMIR Diabetes*, SL, is a co-author on this paper.

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Abbreviations

BPA: best practice advisory
CDSS: clinical decision support systems
HbA_{1c}: glycated hemoglobin
PACU: postanesthesia care unit

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Viewpoint

Enhancing Health Equity and Patient Engagement in Diabetes Care: Technology-Aided Continuous Glucose Monitoring Pilot Implementation Project

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Abstract

Federally Qualified Health Centers (FQHCs) provide service to medically underserved areas and communities, providing care to over 32 million patients annually. The burden of diabetes is increasing, but often, the vulnerable communities served by FQHCs lag in the management of the disease due to limited resources and related social determinants of health. With the increasing adoption of technologies in health care delivery, digital tools for continuous glucose monitoring (CGM) are being used to improve disease management and increase patient engagement. In this viewpoint, we share insights on the implementation of a CGM program at an FQHC, the Community-University Health Care Center (CUHCC) in Minneapolis, Minnesota. Our intent is to improve diabetes management through better monitoring of glucose and to ensure that the CGM program enables our organization's overarching digital strategy. Given the resource limitations of our population, we provided Libre Pro devices to uninsured patients through grants to improve health care equity. We used an interdisciplinary approach involving pharmacists, nurses, and clinicians and used hemoglobin A1c (HbA1c) levels as a measure of diabetes management. We assessed the CGM program and noted key aspects to guide future implementation and scalability. We recruited 148 participants with a mean age of 54 years; 39.8% (59/148) self-identified their race as non-White, 9.5% (14/148) self-identified their ethnicity as Hispanic or Latino, and one-third (53/148, 35.8%) were uninsured. Participants had diverse language preferences, with Spanish (54/148, 36.5%), English (52/148, 35.1%), Somali (21/148, 14.2%), and other languages (21/148, 14.2%). Their clinical characteristics included an average BMI of 29.91 kg/m2 and a mean baseline HbA1c level of 9.73%. Results indicate that the CGM program reduced HbA1c levels significantly from baseline to first follow-up (P<.001) and second follow-up (P<.001), but no significant difference between the first and second follow-up (P=.94). We share key lessons learned on cultural and language barriers, the digital divide, technical issues, and interoperability needs. These key lessons are generalizable for improving implementation at FQHCs and refining digital strategies for future scalability.

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KEYWORDS

consumer health informatics; patient engagement; diabetes mellitus; DM; glucose monitoring; continuous glucose monitoring; CGM; health equity; health information technology; patient centered care; diabetes; pharmacists; clinicians; nurses; device; patient monitoring; technology-aided; health informatics

Introduction

Growing Burden of Diabetes

Diabetes mellitus is a chronic metabolic, autoimmune, and genetic disease involving elevated levels of blood glucose [1,2]. It poses a significant public health challenge globally as the estimated prevalence of diabetes among people aged 20-70 years was 10.5% in 2021, or approximately 536 million people. It is expected to rise to 12.2% (783.2 million people) by 2045. The burden of diabetes is rising among vulnerable populations too, because they frequently face obstacles to effective diabetes management [3,4]. According to the Health Center Program Uniform Data System by Health Resource and Service Administration (HRSA), the percentage of patients with diabetes has been increasing in the last 5 years [5].

Digital Technology for Diabetes Management, Patient Engagement, and Health Equity

Current health care processes are increasingly utilizing digital technology to provide innovative solutions for patient care and management [6]. One example is remote patient monitoring (RPM) technologies, such as continuous glucose monitoring (CGM) devices, which are becoming an important tool used in diabetes management [7-9]. The CGM devices provide continuous monitoring of blood glucose levels, thereby offering an all-encompassing picture of glucose fluctuations throughout the day and night [8,10]. In contrast to conventional glucose monitoring methods, which require intermittent finger stick tests, CGM devices use sensors positioned under the skin to measure sugar levels continuously [11-13]. This real-time data help patients and clinicians to make decisions about identifying appropriate drugs for intervention and adjusting drug therapy. The patient can also make changes in lifestyle or dietary choices based on monitoring information. These interventions by clinician and patient can lead to better diabetes management [14-16].

Evidence suggests that an underserved population could benefit from digital technologies like CGM. However, many obstacles still exist in providing service to these communities [17,18]. From the health care provider's perspective, these challenges include a lack of infrastructure, insufficient staffing, lack of electronic data exchange, and limited patient engagement capacity [19,20]. From a patient's perspective, inadequate broadband access, language barriers, and lack of digital literacy are some important barriers to accessing digital health [20-22]. The limited literature on RPM and telehealth outcomes among racial minority populations and vulnerable groups indicates that health care disparities still exist and stresses the need for targeted efforts to overcome these barriers [8,23].

Prior Research

Evidence has emerged that shows that the use of RPM in health care settings helps reduce hemoglobin A_{1c} (HbA_{1c}) levels in patients with type 2 diabetes [24-26]. In addition, research also suggests that CGM devices show higher acceptance by patients, help in lowering HbA_{1c} levels, and reduce incidences of hypoglycemic events [27]. A pilot study provided evidence for the feasibility of using CGM devices such as Libre Pro in medically vulnerable and underserved populations at a Federally Qualified Health Center (FQHC). It also showed that this digital technology can be used in resource-constraint organizations like primary care health centers [28]. However, the prescription of CGM devices is low in Black and Hispanic populations in comparison to their White counterparts. At the same time, the rate of diabetes is higher in the Black and Hispanic populations [29-31].

Population Served and Services at the Community-University Health Care Center

Our health care clinic, the Community-University Health Care Center (CUHCC) was founded in 1966 by 2 University of Minnesota pediatricians and is the first and longest-running Community Health Center in Minnesota [32]. It is an FQHC providing comprehensive primary care services to the medically underserved area/population and is funded by the HRSA [33,34]. The CUHCC, being an FQHC, provides services to everyone regardless of their ability to pay and offers sliding scale fees. This makes sure that care is available to all patients regardless of their insurance status, which plays a role in reducing health care inequities [34,35]. The CUHCC provides medical, dental, mental health, and social services to about 10,000 patients a year across 49,000 visits annually. It operates with approximately 170 full-time equivalent (FTE) staff members, have an operating budget of US $26 million, and supports over 170 learners annually [36]. The CUHCC serves a diverse and underserved population, with 91% of patients having a known income level at or below 200% of the federal poverty guidelines in 2021. Of the patient population, 29% identify as Hispanic and 37% as BIPOC (Black, Indigenous, and People of Color). In 2022, close to half (48%) of the CUHCC's patients preferred a language other than English for their care. A majority of CUHCC patients are covered by Medicaid/Children's Health Insurance Program (57%) or uninsured (25%), reinforcing its role as a critical health care safety net for vulnerable populations. The burden of diabetes in our population is higher than the national statistics, per HRSA data [5,37].

Project Objective

Recognizing these gaps, we implemented a CGM program at our site, the CUHCC. Our objective is to share insights on the implementation and outcome of the CGM program for diabetes management among the CUHCC's patient population and to enumerate lessons learned for an overarching digital strategy for our organization.

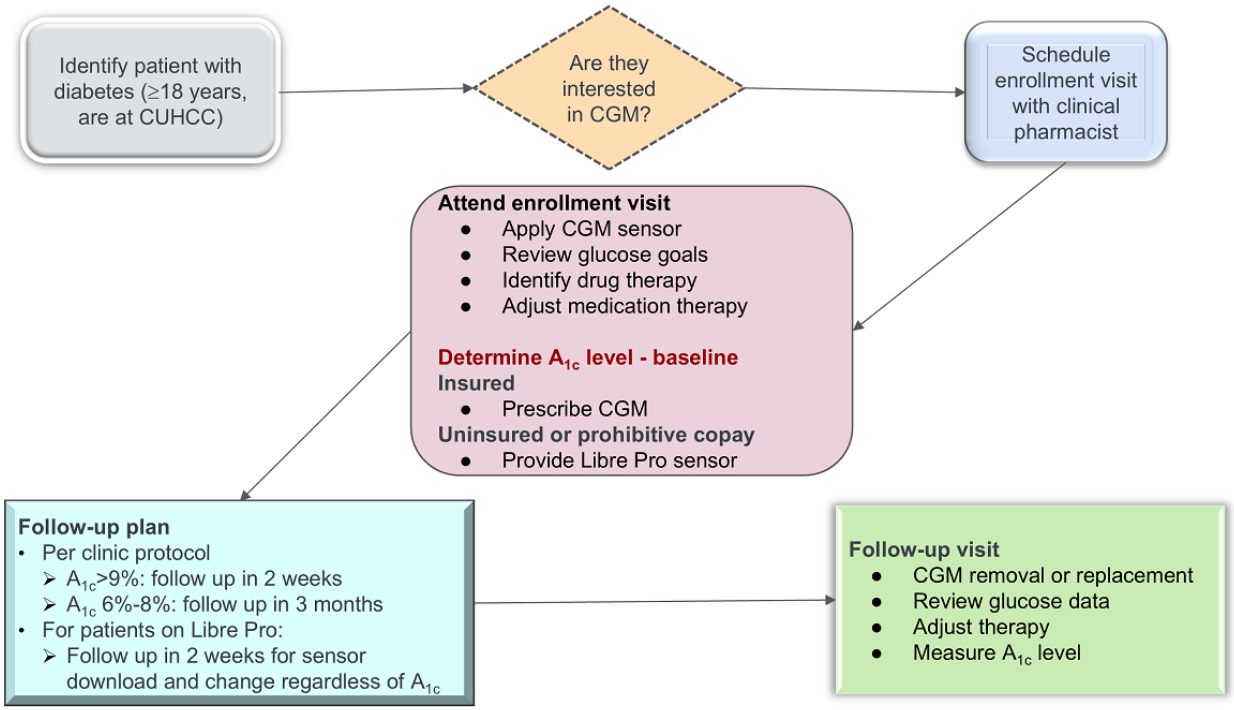
Methods

Study Eligibility Criteria and Approach

Patients were eligible for the CGM program if they had established care at the CUHCC, were aged 18 years or older, and had been diagnosed with diabetes. Clinicians and nurse practitioners introduced the option of CGM to eligible patients during routine visits. Patients who agreed to participate in the program were scheduled for enrollment visits with clinical pharmacists.

Our pilot implementation study of CGM was led by a pharmacist team, which consisted of 1.2 FTE clinical pharmacists and 2 FTE pharmacy residents. This interdisciplinary approach with recruitments by clinicians and nurses and follow-up by pharmacy team was chosen based on the evidence that collaborative health care teams are effective in integrating digital health in primary care settings [38,39]. The detailed schema of our approach is depicted in Figure 1.

Figure 1. Process for CGM implementation. CGM: continuous glucose monitoring; CUHCC: Community-University Health Care Center.



CGM Program Protocol and Analysis

The CGM program followed a structured protocol (refer to Figure 1). During enrollment and subsequent visits, pharmacists were responsible for the application and removal of CGM sensors. They also provided patient education and instructions on how to use CGM devices. There was no real-time monitoring of CGM data given the technological barriers, but in follow-up visits, pharmacists downloaded and reviewed the glucose data and adjusted patients' medications. Follow-up visits were scheduled according to the patient's HbA_{1c} levels. For patients with HbA_{1c} levels greater than 9%, follow-up visits were recommended every 2 weeks. In contrast, patients with HbA_{1c} levels between 6% and 8% (relatively stable glucose control) were scheduled for follow-up every 3 months. For patients receiving Libre Pro sensors from the clinic, follow-up is required every 2 weeks for sensor download and replacement. The program ensured CGM device accessibility to all eligible patients. For insured patients, a CGM device was prescribed and dispensed through their pharmacy. The CUHCC used Libre Pro CGM sensors donated by the funder to patients who were uninsured or those with unaffordable copays. We defined the outcome measure of interest as the change in levels of HbA_{1c} over time. Baseline HbA_{1c} level is defined as the result closest in time prior to CGM enrollment. Follow-up HbA_{1c} level is defined as the first and second results (about 3 months after the baseline HbA_{1c} level and 6 months after the baseline HbA_{1c} level, respectively) after CGM enrollment.

To assess the effectiveness of the CGM program, a repeated measure ANOVA with Greenhouse-Geisser correction and post hoc pairwise comparisons with Bonferroni correction was performed. These tests are used to determine if there is a statistically significant difference in mean HbA_{1c} level between 3 points: baseline, first follow-up, and second follow-up.

Lessons Learned

We enumerated the key takeaways from this project with a team-based approach involving key stakeholders in the program including the lead pharmacist and the data analyst. The chief executive officer and the chief innovation & strategy officer, both of whom are advocates for digital technology to address health equity, were an integral part of this collaborative effort.

Ethical Considerations

This study was a quality improvement project at the CUHCC and did not require institutional review board determination.

Participation was voluntary, and patients verbally consented to participate in the CGM program. Program details were shared with participants including data protection, sharing of data from devices, use of individual data for diabetes management, and deidentified data for secondary purposes. One patient opted out of data sharing and their data were removed from this program evaluation. There was no monetary compensation for participation in this project. Patients who were not able to afford the CGM sensor were provided with Libre Pro CGM sensors, which were donated to the CUHCC by Abbott.

Results

Demographics and Clinical Characteristics

There were 149 patients who were enrolled in the CGM program at the CUHCC from January 20, 2022, to September 27, 2023. One patient opted out of sharing their medical records and was excluded from the analysis. As shown in Table 1, the patient cohort had a mean age of 54 years, ranging from 19 to 86 years, and consisted of 54.7% (n=81) female participants. The cohort was racially diverse, with one-third (50/148, 33.8%) being Black and African American, 4.1% (6/148) being American Indian or Alaska Native, and 2% (3/148) being Asian. There were 18 (12.2%) patients whose race was unknown, and the rest identified as White (71/148, 48%). In terms of ethnicity, 9.5% (n=14) of the patients identified as Hispanic or Latinx, and ethnicity was not documented for 29.7% (n=44) of patients. Table 1 also shows that the group had a diversity of language preferences, with one-third speaking Spanish (54/148, 36.5%), followed by English (52/148, 35.1%), Somali (21/148, 14.2%), and other languages (21/148, 14.2%). In terms of insurance, approximately one-third (53/148, 35.8%) were uninsured, and the rest (95/148, 64.2%) were insured. The average BMI of the participants was 29.91 (SD 7.66) kg/m^2, with a range from 18.27 to 56.64 kg/m^2. The baseline HbA_{1c} levels average 9.73% (SD 2.24), with a range from 5% to 14%. Of the 148 patients in the sample, 65 (43.9%) received Libre Pro CGM sensors, which were provided by the CUHCC.

Table 1. Sociodemographic and clinical characteristics of participants (n=148).

Variable	Values, n (%)
Age group (years)	
18-40	22 (14.9)
41-63	91 (61.5)
64-86	35 (23.6)
Sex	
Female	81 (54.7)
Male	67 (45.3)
Race	
White	71 (48.0)
Black or African American	50 (33.8)
American Indian or Alaska Native	6 (4.1)
Asian	3 (2.0)
Unknown	18 (12.2)
Ethnicity	
Hispanic or Latino	14 (9.5)
Non-Hispanic or Latino	90 (60.8)
Unknown	44 (29.7)
Preferred language	
Spanish	54 (36.5)
English	52 (35.1)
Somali	21 (14.2)
Other[a]	21 (14.2)
Insurance status	
Insured	95 (64.2)
Uninsured	53 (35.8)

[a]Other languages were Central Khmer, Hmong, Korean, Oromo, sign language, and Vietnamese.

HbA_{1c} Level Outcome

A repeated-measure ANOVA with Greenhouse-Geisser correction was used, as the same metric (HbA_{1c}) was measured in participants over time, which enabled the ability to attribute differences related to treatments. This test showed that the difference between the mean HbA_{1c} levels among the 3 points (baseline, first follow-up, and second follow-up) was statistically significant ($F_{1.153,113.38}$=38.29; P<.001). As presented in Table 2, post hoc pairwise comparisons with Bonferroni correction indicated a statistically significant reduction in HbA_{1c} levels from baseline to the first follow-up (P<.001) and from baseline to second follow-up (P<.001), but no significant difference between the first and second follow-up (P=.94).

Table 2. Comparison of follow-up hemoglobin A_{1c} (HbA_{1c}) measurements.

Time period	HbA_{1c} measurements			
	Mean difference in HbA_{1c} level (%)	SE	95% CI	*P* value
Baseline to first follow-up	–1.66	0.22	2.20 to –1.13	<.001
Baseline to second follow-up	–1.68	0.26	–2.32 to –1.03	<.001
Between first and second follow-up	–0.01	0.156	–0.39 to 0.37	.94

Lessons Learned

During the implementation of the CGM program, several key lessons were learned that had implications for the future scalability and sustainability of the program, along with laying the groundwork for an overarching digital strategy for the organization (presented in Table 3).

Table 3. Lessons learned from technology-aided patient engagement.

Topic	Lessons learned	Program implications
Patient perspectives		
Cultural and language barriers	Diverse patient population requires tailored communication strategies	Enhance staff training in cultural competence and develop multilingual resources
Patient education	Importance of comprehensive education on CGM[a] benefits and use	Develop comprehensive patient education materials in multiple languages and provide ongoing support
Financial barriers	Half of patients (44%) required financial assistance for CGM devices, and this needs to be addressed to promote health equity	Secure funding or subsidies to ensure equitable access
Follow-up adherence	Effective follow-up based on HbA_{1c}[b] levels requires active communication	Implement robust patient follow-up systems and reminders
Social drivers of health	Numerous socioeconomic and contextual factors influence health	Develop RPM[c] in context of SDoH[d] for sustainability
Organizational perspectives		
Health equity	Technology offers various tools to improve access but needs to focus on digital equity	Ensure that technology implementations have health equity at the forefront
Digital divide	Some subsets of the population do not have access to technology or the ability to use it	Need for digital navigators for assistance
Interdisciplinary collaboration	Pharmacist-led approach proved valuable for diabetes management	Foster interdisciplinary teamwork in program design and implementation
Patient motivation	Maintaining patient motivation over time was challenging	Use motivational strategies and digital tools to keep patients engaged
Staff time and effort to set up programs	Recognizing that technology implementations do require time and effort to set up	Gain efficiencies quickly to demonstrate ROI[e] for these programs
Technical perspectives		
Technical barriers	Some patients had difficulties using digital health tools	Provide more extensive technology training support
Need for interoperability	Data need to flow seamlessly across devices and settings	Address data entry burden for staff by device data integration
Workflow integration	Integration of CGM data requires adjusting clinic workflows and appointment structures	Design workflows that include specific times for CGM review during patient visits
Utility of PROM[f] data	CGM data need to be integrated into clinical decision-making	Explore solutions and national standards to integrate CGM data in EHRs[g], along with visuals/trends for providers
Digital strategy	CGM/RPM enables technology-aided patient engagement	Include these tools as part of an overall digital strategy for the organization

[a]CGM: continuous glucose monitoring.

[b]HbA_{1c}: hemoglobin A_{1c}.

[c]RPM: remote patient monitoring.

[d]SDoH: social drivers of health.

[e]ROI: return on investment.

[f]PROM: patient-reported outcome measure.

[g]EHR: electronic health record.

Discussion

Findings and Implications

Our pilot project was able to successfully recruit 148 participants for the CGM program, along with an enumeration of lessons learned. The reduction of HbA_{1c} levels from baseline to follow-up periods demonstrates the potential and possibility of CGM devices in glycemic control. This suggests that CGM is an effective tool for the management of diabetes, even in resource-constrained environments serving diverse patient populations. Along with statistical significance, these results are clinically significant as achieving this reduction in HbA_{1c} level has the immense benefits of reducing complications from diabetes. Our program evaluation also identified several lessons that include education, financial barriers, follow-up adherence, cultural and language barriers, and context around social drivers of health from a patient's perspective. In terms of organization,

the insights for future implementation are health equity, digital divide, staff time and efforts, and patient motivation.

From the technical side, the barriers include the need for interoperability, workflow integration, and the utility of patient-reported outcome measure data. The result of the CGM program at an FQHC builds on recent literature on RPM and CGM in diabetes. For example, a Digital Health Pilot program for diabetes was implemented at a rural FQHC, which led to improvement in HbA_{1c} levels in the participants [31]. Another pilot study demonstrates a reduction of HbA_{1c} levels and a decrease in hypoglycemic episodes after the implementation of CGM program at an FQHC [33]. These findings have implications for future scalability, sustainability of CGM programs, overall RPM programs, and overarching digital strategy for an organization.

Strengths and Limitations

An important strength of our pilot project is its focus on a diverse and medically underserved population. This is valuable because there is a scarcity of research focused on these communities. The use of an interdisciplinary approach led by pharmacists, clinicians, nurse practitioners, and nutritionists/dieticians is consistent with the growing evidence of the impact of using collaborative models for disease management. Additionally, our program used broad eligibility criteria, ensuring inclusivity and making certain that patients who meet basic requirements get access to the program.

There are several limitations that need to be addressed. First, the program was implemented at a single site and with a limited number of participants. This may limit the generalizability of the findings to other settings, such as rural FQHCs or other private clinics. Second, this pilot project did not include control groups, which may limit our ability to attribute the changes in HbA_{1c} levels solely to CGM intervention.

Future Directions

This CGM pilot implementation resulted in an improvement in HbA_{1c} levels in patients with diabetes at an urban FQHC serving a diverse, medically underserved patient population. Our program has expanded to include nurses to make it scalable. Given these positive findings, we are exploring options for the continuation of this program, including ongoing collaboration with Abbott for the CGM sensors and pursuing additional sources for support. Additionally, we are planning a qualitative study with interviews to elicit further details about what worked and what is needed to sustain and scale this program. We advocate for additional studies to be conducted in other FQHCs to determine if this can be replicated and if there are site-specific factors that influence implementation and outcomes. Future research needs to evaluate patient and clinician satisfaction with CGM and other related RPM tools.

Conclusions

Our pilot experience at the CUHCC indicates that the implementation of digital technologies like the CGM program is feasible and effective in the management of diabetes in a diverse and medically underserved population. The future success of our CGM program will depend on addressing the lessons learned and developing an overarching digital strategy for our organization to promote health equity.

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Data Availability

The datasets generated and analyzed for this study are not publicly available as the data used are protected with individual identifiers and collected as part of the care delivery process.

Authors' Contributions

The conceptualization of this pilot project was done by the site leadership (RD and EWM). The project was implemented by KNT and her team, and data extraction and analysis were completed by AT. MT and SR supported the drafting of the manuscript and its revisions. All authors read and approved the final version.

Conflicts of Interest

None declared.

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Abbreviations

BIPOC: Black, Indigenous, and People of Color
CGM: continuous glucose monitoring
CUHCC: Community-University Health Care Center
FQHC: Federally Qualified Health Center
FTE: full-time equivalent
HbA1c: hemoglobin A1c
HRSA: Health Resource and Service Administration
RPM: remote patient monitoring

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Early Detection of Elevated Ketone Bodies in Type 1 Diabetes Using Insulin and Glucose Dynamics Across Age Groups: Model Development Study

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Abstract

Background: Diabetic ketoacidosis represents a significant and potentially life-threatening complication of diabetes, predominantly observed in individuals with type 1 diabetes (T1D). Studies have documented suboptimal adherence to diabetes management among children and adolescents, as evidenced by deficient ketone monitoring practices.

Objective: The aim of the study was to explore the potential for prediction of elevated ketone bodies from continuous glucose monitoring (CGM) and insulin data in pediatric and adult patients with T1D using a closed-loop system.

Methods: Participants used the Dexcom G6 CGM system and the iLet Bionic Pancreas system for insulin administration for up to 13 weeks. We used supervised binary classification machine learning, incorporating feature engineering to identify elevated ketone bodies (>0.6 mmol/L). Features were derived from CGM, insulin delivery data, and self-monitoring of blood glucose to develop an extreme gradient boosting-based prediction model. A total of 259 participants aged 6-79 years with over 49,000 days of full-time monitoring were included in the study.

Results: Among the participants, 1768 ketone samples were eligible for modeling, including 383 event samples with elevated ketone bodies (≥0.6 mmol/L). Insulin, self-monitoring of blood glucose, and current glucose measurements provided discriminative information on elevated ketone bodies (receiver operating characteristic area under the curve [ROC-AUC] 0.64 - 0.69). The CGM-derived features exhibited stronger discrimination (ROC-AUC 0.75 - 0.76). Integration of all feature types resulted in an ROC-AUC estimate of 0.82 (SD 0.01) and a precision recall-AUC of 0.53 (SD 0.03).

Conclusions: CGM and insulin data present a valuable avenue for early prediction of patients at risk of elevated ketone bodies. Furthermore, our findings indicate the potential application of such predictive models in both pediatric and adult populations with T1D.

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KEYWORDS

type 1 diabetes; machine learning; diabetic ketoacidosis; ketone level; diabetic complication; prediction model

Introduction

Diabetic ketoacidosis (DKA) represents a significant and potentially life-threatening complication of diabetes, predominantly observed in individuals with type 1 diabetes (T1D), although occurrences in those with type 2 diabetes are not uncommon [1,2]. DKA arises from an inadequate supply of insulin, leading to dysregulation of blood glucose levels. Consequently, the body resorts to metabolizing fat for energy, resulting in the accumulation of ketone bodies in the bloodstream alongside elevated blood sugar levels. This metabolic disturbance manifests in symptoms such as nausea, vomiting, abdominal pain, confusion, excessive thirst, and frequent urination [1]. If left untreated, DKA can progress to coma and, in severe cases to mortality, necessitating immediate medical intervention comprising insulin administration and fluid replacement to restore normal blood glucose and ketone levels [3] .

Children and adolescents are particularly susceptible to DKA due to their ongoing growth and development, which introduce complexities in diabetes management [4]. Factors such as missed insulin doses, illness, or infection can rapidly precipitate DKA in this demographic.

Studies have documented suboptimal adherence to diabetes management among children and adolescents, as evidenced by deficient ketone monitoring practices [5-7] . For instance, a recent study involving 2995 participants revealed that a significant proportion lacked ketone testing supplies at home, with a considerable proportion reporting infrequent ketone checks, particularly in instances of elevated glucose levels [7].

Closed-loop systems offer a promising approach to addressing the challenges of diabetes management in both pediatric and adult populations [8,9]. Leveraging CGM technology provides real-time feedback on blood glucose levels, facilitating automated adjustments to insulin delivery via an insulin pump. By delivering precise insulin doses tailored to individual glucose fluctuations, closed-loop systems can reduce the risks of both hypoglycemia and hyperglycemia, thereby diminishing the likelihood of DKA development. However, this technology does not eliminate the risk of DKA [10-12].

A recent study by Cichosz and Bender [13] demonstrated the potential of CGM data in predicting elevated ketone levels among adults with T1D. However, such investigations remain scarce in pediatric populations and have not incorporated insulin data. Consequently, this study aims to explore the predictive potential of CGM and insulin data for elevated ketone bodies in pediatric and adult patients with T1D using a closed-loop system.

Methods

Data Sources

To ascertain whether patterns derived from CGM and insulin usage could serve as predictive indicators for elevated ketone bodies—a potential risk factor for DKA in individuals with diabetes—data sourced from the intervention arm of The Insulin-Only Bionic Pancreas Pivotal Trial (NCT04200313) [14] were analyzed. This trial constituted a multicenter randomized controlled study comparing an at-home closed-loop system with the prevailing standard of care.

The participant cohort encompassed individuals diagnosed with T1D aged 6 to 79 years. Participants used the Dexcom G6 CGM system in conjunction with the iLet Bionic Pancreas system for insulin administration for up to 13 weeks. Additionally, participants were equipped with a blood ketone meter and test strips and were provided instructions to measure ketone levels if glucose readings surpassed 300 mg/dL. The intervention group comprised 219 patients with T1D, exhibiting a mean glycated hemoglobin of 7.9 (SD 1.2%); 63 mmol/mol with a mean age of 28 (SD 19) years, and a female representation of 49% (n=107) within the cohort.

For this analysis, inclusion criteria required the presence of ketone measurements along with corresponding CGM and insulin data within a 12-hour timeframe preceding the ketone measurements. CGM data periods had to demonstrate a wear time of ≥50% to be considered for inclusion. Given the sampling rate of the CGM system of 12 readings per hour, inclusion mandated a minimum of 72 glucose samples within the 12-hour observation window.

This study adheres to the recommended guidelines delineated in the “Transparent Reporting of a Multivariable Prediction Model for Individual Prognosis or Diagnosis” (TRIPOD).

Model Target

In this study, we used a supervised binary classification machine learning methodology to discern elevated ketone bodies. It is well established that ketone levels below 0.6 mmol/L fall within the reference range, whereas levels at or above 0.6 mmol/L pose a significantly augmented risk of DKA [15]. Therefore, we defined the binary classification task as the identification of elevated ketone bodies (≥0.6 mmol/L) versus nonelevated ketone bodies (<0.6 mmol/L) during episodes of elevated glucose readings.

Feature Engineering

Feature engineering is a process within machine learning wherein new features are generated from raw data through a series of transformations, aggregations, or extractions of information from existing variables. The primary objective is to enhance the performance of machine learning algorithms by constructing new features that more accurately capture the underlying relationships in the data, thereby augmenting prediction accuracy and model effectiveness [16]. To identify the most relevant predictors of elevated ketone levels in patients with diabetes, we explored a broad range of potential features over the preceding 12-hour period. This included absolute values, summations, and dynamic patterns to capture temporal variations. Given the limited literature on the most effective individual features or their optimal combinations for detecting ketone elevation, our approach aimed to systematically identify the best subset of predictors.

A total of 26 features were extracted from CGM, insulin data, and glucose meter readings within a 6- and 12-hour window preceding the ketone samples, as depicted in Figure 1. Table 1 enumerates the features extracted from each data source. These features encompassed mathematical transformations of the signals to characterize their dynamics, range of variation, cumulative effects, distribution, and extreme values. The methodology adopted was data-driven and exploratory, devoid of prior assumptions regarding which features of the signal that would yield optimal discriminative information when combined. The dynamics of glucose levels are intricately shaped by diurnal patterns, influenced by factors such as dietary intake, basal and bolus insulin administration, endocrine activity, and behavioral habits including physical exertion and sleep.

Figure 1. Overview of the data pipeline for predicting ketone levels using machine learning. Data from multiple sources, including the iLet closed-loop system, continuous glucose monitor (CGM), glucometer, and ketone meter, are collected and processed. A window of CGM, insulin, and self-monitored blood glucose (SMBG) data is extracted for feature engineering. Various feature subsets, such as the hour of day, SMBG, insulin, and CGM trends over different timeframes, are used as input to train a model. Stratified cross-validation ensures balanced class distribution, and model performance is evaluated using receiver operating characteristic (ROC) and precision-recall (PR) curves.

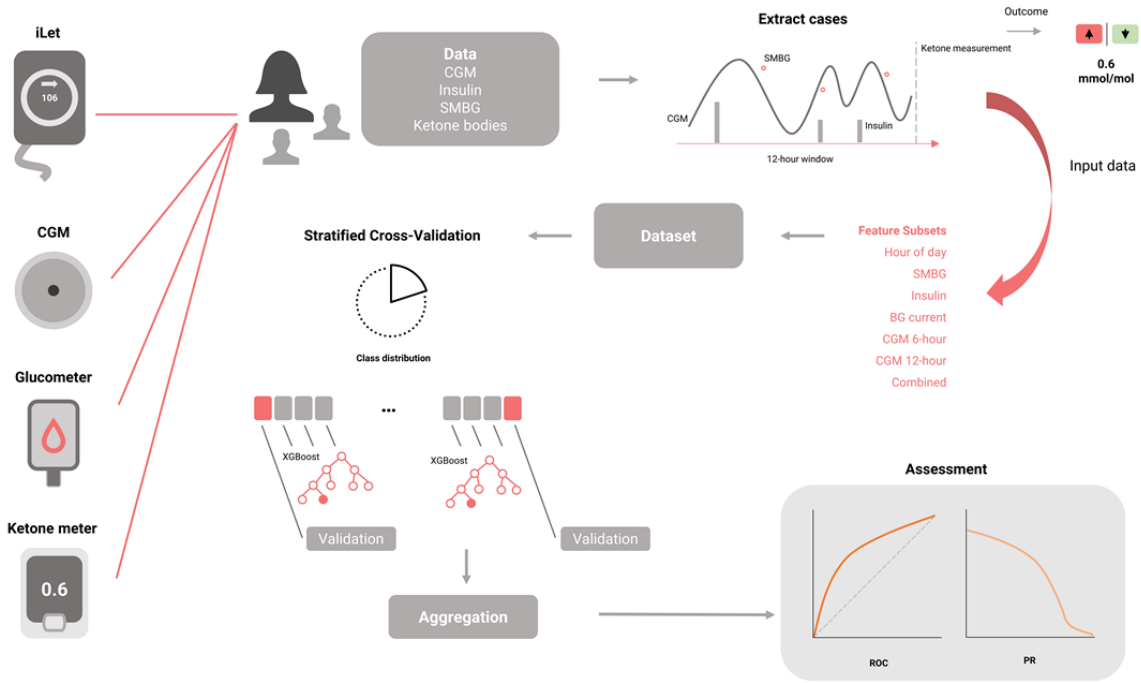


Table . Extracted features for CGM[a], insulin, and BGM[b] data. Features marked with "√" indicate inclusion for the respective data type and time division.

Feature	CGM (6h)	CGM (12h)	Insulin basal (6 - 12h)[c]	Insulin bolus (6 - 12h)[c]	Insulin meal (6 - 12h)[c]	BGM (12h)
Latest	√	√				
Maximum	√	√				√
Minimum	√	√				√
Sum			√	√	√	
Mean	√	√				
Standard deviation	√	√				
Time spent when blood glucose levels >300 mg/dL	√	√				
Decreases ratio	√	√				
Mean decrease	√	√				
Hour of the day	√					

[a]CGM: continuous glucose monitoring.

[b]BGM: blood glucose monitoring.

[c] Insulin features are extracted from both a 0 - 6 hour and a 6 - 12 hour window.

While many features entailed straightforward mathematical derivatives such as summations, standard deviations, and the proportion of time spent above 300 mg/dL blood glucose levels, we additionally incorporated a metric assessing the rate of glucose decline relative to preceding measurements to capture finer-scale dynamics within the glucose signal. The formulation for this calculation is delineated below:

$$cgm=[x1,x2,x3...xn]$$

$$Decreasesn=\sum i=1n-1\{1ifi+1-xi<00otherwise$$

$$Decreaseratio=decreasesn/cgm/$$

Model Development

For model development, we used a supervised binary classification approach using an extreme gradient boosting

(XGBoost) classifier to predict elevated levels of ketone bodies. XGBoost is a renowned machine learning algorithm known for its ability to handle intricate datasets by amalgamating weak prediction models (decision trees) into a robust ensemble [17]. It excels in capturing nonlinear relationships, managing missing or imbalanced data, and mitigating overfitting, thereby typically yielding high predictive performance. This efficacy has been demonstrated in clinical prediction models across a spectrum of medical domains [18-21].

The model was trained using features from each data type individually and in combination, aiming to ascertain their predictive capacity for the target variable. We used 5-fold stratified cross-validation to ensure an unbiased estimation of the model's performance and hyperparameter estimation, with stratification ensuring uniform proportions of events across folds [22]. The following parameters were optimized using a grid search strategy: learning rate (0.01, 0.1, 0.3), number of estimators (50, 100, 150), max depth (2, 4, 8), minimum child weight (1, 3, 5), subsample (0.6, 0.8, 1.0), and γ (0, 1, 5).

All analyses were conducted using MATLAB (version R2021b; MathWorks) and Python (version 3; Python Software Foundation), leveraging the Scikit-learn package (version 0.23.2) for machine learning utilities, the SHapley Additive exPlanations (SHAP) package (version 0.43.0) for interpretability assessment, and the XGBoost package (version 1.7.5) for implementing the classifier.

Model Assessment and Interpretability

The discriminative performance of the model was assessed using the computation of the area under the receiver operating characteristic curve (ROC-AUC) and the area under the precision-recall curve (PR-AUC) [23]. The uncertainty of estimates was calculated as the SD across folds. To enhance model interpretability, SHAP average values across folds were leveraged for explanatory purposes. These values offer insights into the contribution of individual features towards model predictions, thereby enhancing the interpretability and transparency of the modeling process [24]. .

Sensitivity Analysis

In a sensitivity analysis, we restricted the subgroup to patients aged <18 years. The objective of this analysis was to assess the model's performance in pediatric and adolescent patients, as these groups have a higher risk of developing DKA [25]. The objective was to test whether any substantial difference was observed in ROC-AUC performance in patients under 18 years.

Ethical Considerations

This study is a reanalysis of existing and anonymized data from the Insulin Only Bionic Pancreas Pivotal Trial [14]. According to Danish law (Komitéloven, kap. 4, § 14, stk. 3) on the ethical review of health science research projects and health data science research projects, this study did not require approval from an institutional or licensing committee.

The original Insulin Only Bionic Pancreas Pivotal Trial protocol and informed consent forms were approved by institutional review boards. Written informed consent was obtained from each participant prior to enrollment. An independent data and safety monitoring board provided trial oversight reviewing unmasked safety data during the conduct of the study.

We confirm that all methods were carried out in accordance with relevant guidelines and regulations. The data was accessed and analyzed in an anonymized form.

Results

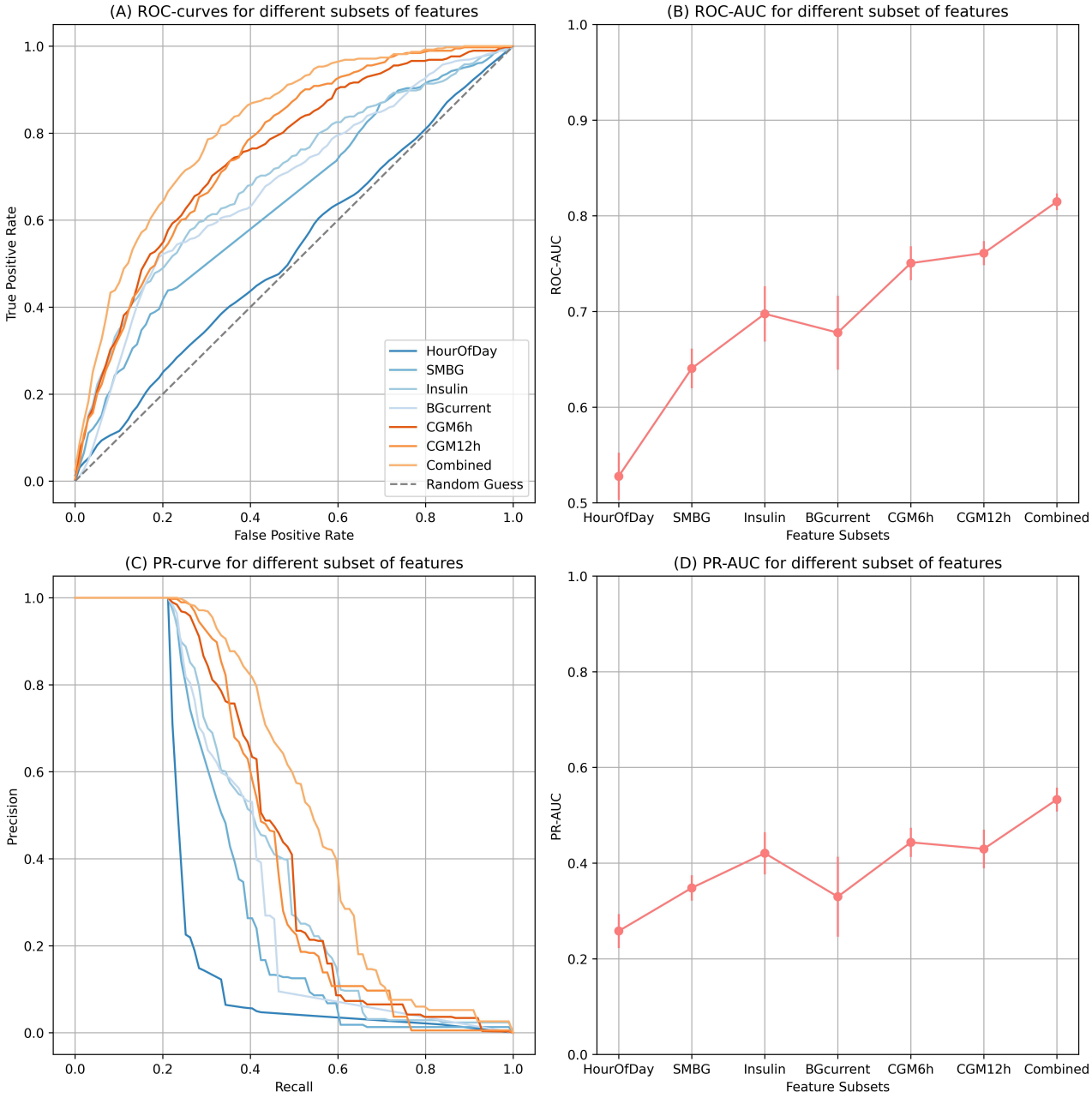
Participant Characteristics

In total, 259 patients (n=93 for patients aged <18 years) were included in the analysis. Another 181 patients did not have qualified ketone measurements with a CGM window (n=71) or were part of the control group, which did not use a connected insulin pump (n=110). Among the included patients, 1768 ketone samples were eligible for modeling, including 383 event samples with ketone levels ≥0.6 mmol/L. Overall, the patients had over 14,300,000 CGM measurements, corresponding to over 49,000 days of full-time monitoring.

Model Performance

The ROC-AUC, PR-AUC, and individual curves are presented in Figure 2. The plots illustrate the performance of adding individual datatypes and a combined estimate. Insulin, self-monitoring of blood glucose (SMBG), and current glucose measurements, all provided discriminative information on elevated ketone bodies (ROC-AUC 0.64 - 0.69). The features derived from the CGM window demonstrated greater discrimination (ROC-AUC 0.75 - 0.76). Notably, extending the CGM window from6 hours to 12 hours only added minimal discriminative power, as measured by ROC-AUC. Combining all feature types yielded an ROC-AUC estimate of 0.82 (SD 0.01) and a PR-AUC of 0.53 (SD 0.03). In the sensitivity analysis including only pediatric patients (age <18 years), the ROC-AUC estimate was 0.80 (SD 0.01). The final selected hyperparameters were a learning rate of 0.2, 100 estimators, a maximum depth of 8, a minimum child weight of 1, a subsample ratio of 1.0, and a γ value of 1.

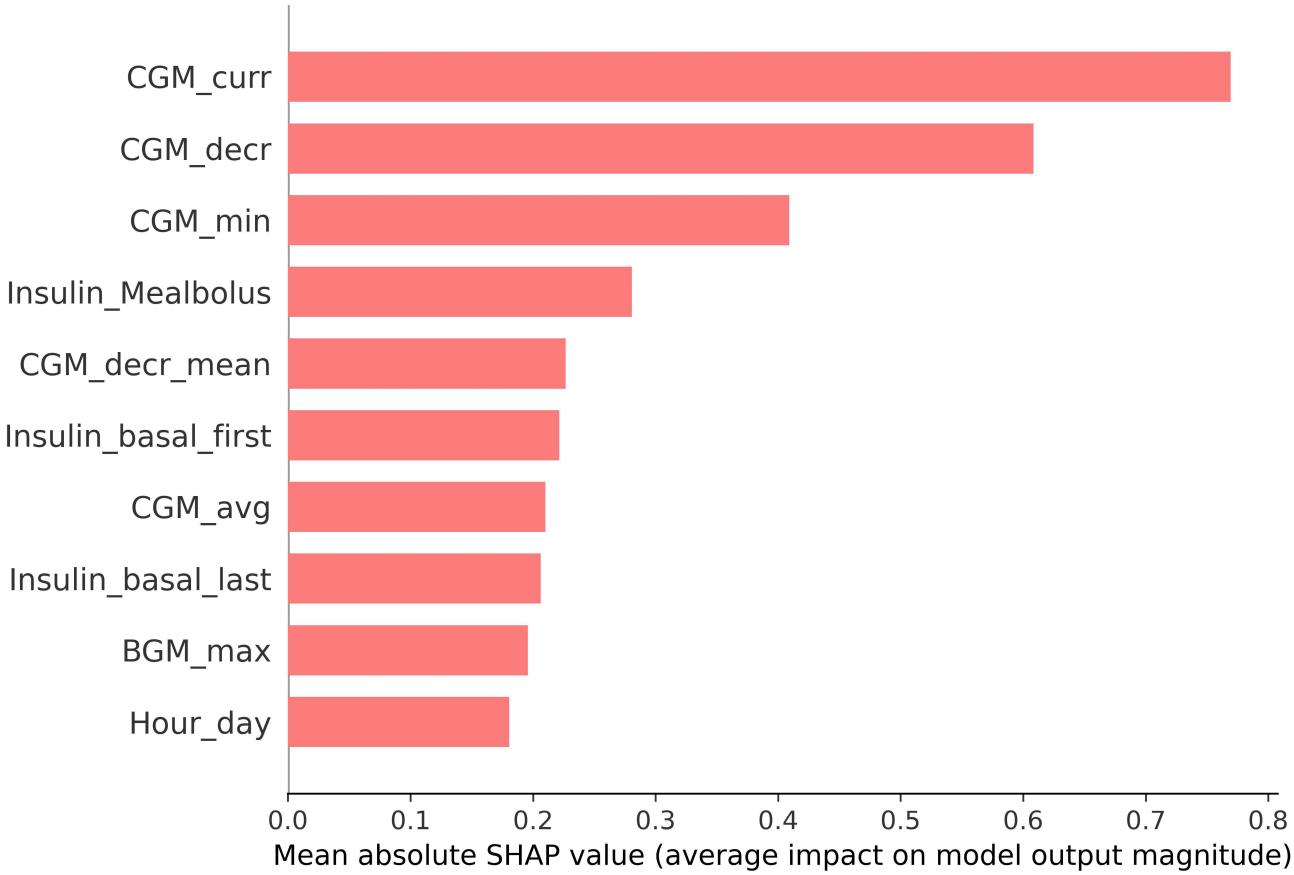
Figure 2. For endpoint 1, (A) ROC-curves for different subsets of features, (B) ROC-AUC for different subset of features , (C) PR-curve for different subset of features, (D) PR-AUC for different subset of features. AUC: area under the curve; BG: blood glucose; CGM: continuous glucose monitoring; PR: precision recall; ROC: receiver operating characteristics; SMBG: self-monitoring of blood glucose.



Interpretability

Feature importance analysis including the combined features showed that data from both CGM and insulin deliveries adds significant information to the models' predictive capabilities. The mean SHAP values for the 10 highest-ranking features are presented in Figure 3. Furthermore, a SHAP Beeswarm plot is provided in Multimedia Appendix 1. As expected, the current CGM value had the highest contribution, followed by the ratio of decrease in the CGM window. Further, insulin-related features such as meal bolus and basal insulin deliveries had significant impacts.

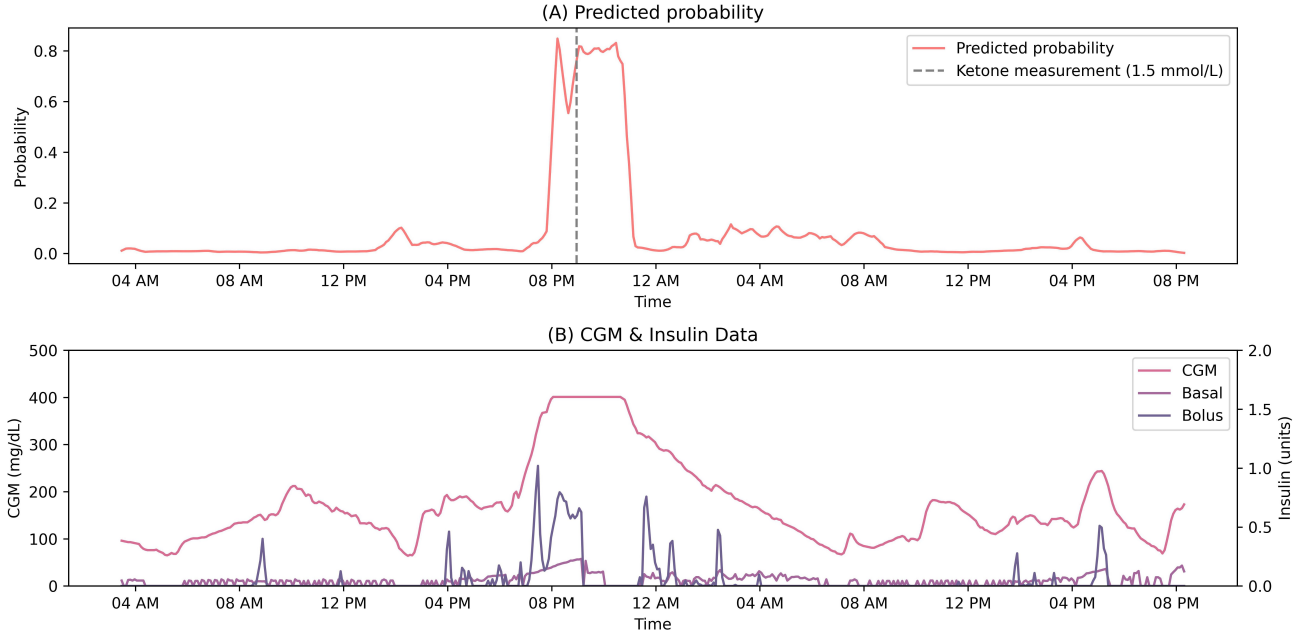
Figure 3. SHAP bar plot illustrating the 10 features with most important features in the model's prediction. BGM: blood glucose measurement; CGM: continuous glucose monitoring; Avg: average; Min: minimum; Decr: decrease; Max: maximum.



Patient Example

An illustrative depiction of the predicted probability, representing the model output for elevated ketone bodies, is presented alongside CGM data and insulin delivery records for a specific patient in Figure 4. Notably, the probability of a heightened risk of elevated ketone bodies increases around 8 PM, coinciding with a ketone meter measurement confirming elevated ketones at 9 PM. This example underscores the potential utility of a predictive model, such as the one proposed in our study, for identifying impending instances of elevated ketone levels based on continuous monitoring of patients' data. Such a model holds promise for alerting patients to take timely action, thereby mitigating the progression of adverse developments associated with diabetic ketoacidosis.

Figure 4. Patient example: (A) Predicted probability for elevated ketone bodies over two days of monitoring; (B) The corresponding CGM and insulin inputs to the model. CGM: continuous glucose monitoring.



Discussion

Principal Findings

The objective of this investigation was to formulate and assess various data sources, including CGM, insulin, and SMBG, as potential inputs for a prediction model designed to provide timely alerts regarding the risk of developing DKA through elevated ketone body levels. The findings underscore the potential utility of patterns derived from CGM data obtained from individuals with T1D in identifying and signaling patients at risk of elevated ketone levels. It is imperative to note that elevated ketone levels serve as a precursor to DKA, a critical and potentially life-threatening complication of diabetes.

We previously showed that CGM data could be used for prediction of elevated ketone bodies in an adult population with T1D [13]. The present findings validate this observation and expand on the initial findings by examining the added predictive value of insulin and SMBG data. Furthermore, this study strongly indicates that this approach is applicable to both pediatric and adult individuals. To our knowledge, this study, along with our previously published study, is the first to explore the potential of predicting elevated ketone bodies using a combination of CGM and insulin data. However, numerous studies have reported the usage of CGM for prediction of other complications related to diabetes and diabetes treatment, such as hypoglycemia, gastroparesis, and future glucose levels [26-31].

The clinical implications of implementing a system based on the proposed model in our study are vividly illustrated through the patient's continuous data depicted in Figure 4. The predicted risk or probability of elevated ketone bodies offers patients a more nuanced and informative warning compared to solely relying on glucose levels. This enhanced information could prompt early intervention to prevent further progression to DKA. Potential actions triggered by these alerts may include promptly checking ketone bodies using a ketone meter, verifying the functionality of the infusion set to ensure proper insulin delivery, and corroborating CGM measurements with SMBG readings. By facilitating proactive measures, such a system has the potential to significantly mitigate the risk of adverse outcomes associated with DKA.

Limitations

Despite the robust design of our study, which encompassed a substantial dataset and measures to estimate generalizability, several limitations warrant acknowledgment. First, while our analysis involved a sample size of 259 individuals with numerous measurements of ketone bodies (n=1768), the number of outcome events (elevated ketone levels ≥0.6 mmol/L) remained relatively small (n=383). This limited number of outcome events is reflected in the SD of the estimate observed in the ROC-AUC. Consequently, the reliability of our model's performance on new data remains uncertain, despite indicative evidence of valuable information within the dataset. These findings need to be validated in independent datasets. An avenue for potential improvement lies in the exploration of larger datasets to enhance predictive performance and further validate these findings. While our study encompassed a diverse population spanning children, adolescents, and adults, the analysis did not delve into subgroup-specific performance. Consequently, the efficacy of our predictive model across distinct subgroups remains unexplored, potentially subject to interindividual variability. Future investigations could address this limitation by conducting subgroup analyses to elucidate performance variations across demographic or clinical strata. Our findings from patients using closed-loop insulin delivery technology cannot be extrapolated to other treatment regimens without further investigation. A key limitation is that participants only measured ketones during prolonged hyperglycemia, which, coupled with generally low adherence and possible medication influences (eg, sodium-glucose cotransporter-2 inhibitors), may introduce selection bias. Importantly, ketone levels serve as

surrogate outcomes and do not necessarily predict ketoacidosis events.

Conclusion

The innovative methodology used in this study for detecting elevated ketone levels among individuals with t1D underscores the potential of integrating CGM and insulin data as a valuable resource for early prediction of patients at risk. Moreover, our findings suggest that such a predictive model holds promise for application in both pediatric and adult populations with T1D, particularly within closed-loop systems.

Future studies are imperative to validate the robustness and reliability of these findings. Furthermore, there is a need for comprehensive investigations to assess the real-world impact of implementing a system based on the proposed prediction model. Such investigations will be instrumental in elucidating the efficacy and practical implications of leveraging predictive modeling in clinical practice for proactive management of diabetes-related complications, including DKA.

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Disclaimer

The source of the data is the Insulin Only Bionic Pancreas Pivotal Trial (NCT04200313), but the analyses, content and conclusions presented herein are solely the responsibility of the authors and have not been reviewed or approved by the Bionic Pancreas Research Group or Beta Bionics.

Authors' Contributions

Conceptualization: CB, SC
Data curation: SC
Formal analysis: CB, SC
Methodology: CB, SC
Writing – original draft: SC
Writing – review & editing: CB

Conflicts of Interest

The research was funded by i-SENS, Inc (Seoul, South Korea) and SC’s involvement with the company did not influence the design, implementation, or interpretation of the study. SC have received research funding from i-SENS, Inc (Seoul, South Korea), which manufactures some of the product types discussed in this paper. However, the study was conducted independently, and the authors declare that their involvement with i-SENS, Inc (Seoul, South Korea) did not influence the findings or conclusions of the study.

Multimedia Appendix 1
SHAP Beeswarm plot
[DOCX File, 184 KB - diabetes_v10i1e67867_app1.docx]

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Abbreviations

AUC: area under the curve
CGM: continuous glucose monitoring
DKA: diabetic ketoacidosis
PR: precision recall
ROC: receiver operating characteristic
SHAP: SHapley additive exPlanations
T1D: type 1 diabetes
TRIPOD: Transparent Reporting of a Multivariable Prediction Model for Individual Prognosis or Diagnosis
XGBoost: extreme gradient boosting

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Original Paper

“Now I can see it works!” Perspectives on Using a Nutrition-Focused Approach When Initiating Continuous Glucose Monitoring in People with Type 2 Diabetes: Qualitative Interview Study

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Abstract

Background: Food choices play a significant role in achieving glycemic goals and optimizing overall health for people with type 2 diabetes (T2D). Continuous glucose monitoring (CGM) can provide a comprehensive look at the impact of foods and other behaviors on glucose in real time and over the course of time. The impact of using a nutrition-focused approach (NFA) when initiating CGM in people with T2D is unknown.

Objective: This study aims to understand the perspectives and behaviors of people with T2D who participated in an NFA during CGM initiation.

Methods: Semistructured qualitative interviews were conducted with UNITE (Using Nutrition to Improve Time in Range) study participants. UNITE was a 2-session intervention designed to introduce and initiate CGM using an NFA in people with T2D who do not use insulin. The intervention included CGM initiation materials that emphasized the continuous glucose monitor as a tool to guide evidence-based food choices. The materials were designed to support conversation between the CGM user and diabetes care provider conducting the sessions. A rapid matrix analysis approach was designed to answer two main questions: (1) How do people who participate in an NFA during CGM initiation describe this experience? and (2) How do people who participate in an NFA during CGM initiation use CGM data to make food-related decisions, and what food-related changes do they make?

Results: Overall, 15 people completed interviews after completion of the UNITE study intervention: 87% (n=13) identified as White, 60% (n=9) identified as male, mean age of 64 (SD 7.4) years, mean T2D duration of 7.5 (SD 3.8) years, and mean hemoglobin A_{1c} level of 7.5% (SD 0.4%). Participants fluently discussed glycemic metrics such as time in range (percent time with glucose 70-180 mg/dL) and reported regularly using real-time and retrospective CGM data. Participants liked the simplicity of the intervention materials (eg, images and messaging), which demonstrated how to use CGM data to learn the glycemic impact of food choices and suggested how to adjust food choices for improved glycemia. Participants reported that CGM data impacted how they thought about food, and most participants made changes because of seeing these data. Many of the reported changes aligned with evidence-based guidance for a healthy lifestyle, including prioritizing nonstarchy vegetables, reducing foods with added sugar, or walking more; however, some people reported behavior changes, such as skipping or delaying meals to stay in the target glucose range. A few participants reported that the CGM amplified negative feelings about food or eating.

Conclusions: Participants agreed that pairing nutrition information with CGM initiation instructions was helpful for their diabetes care. In general, the NFA during CGM initiation was well received and led to positive changes in food choices and behaviors during a 2-month intervention.

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KEYWORDS

diabetic; diabetes mellitus; DM; type 2 diabetes; T2D; endocrinology; nutrition; diet; continuous glucose monitoring; glucose monitor; glucose; glycemic control; time in range; self-care; education; mHealth

Introduction

Background

First-line therapy for the management of type 2 diabetes (T2D) is lifestyle modification, which includes following evidence-based nutrition and physical activity guidelines [1]. Food choices can play a significant role in achieving glycemic goals and optimizing overall health for people with T2D [2]. Moreover, continuous glucose monitoring (CGM) has also been shown to improve glycemic outcomes for people with T2D [3]. CGM can provide a comprehensive assessment of the impact of foods and other behaviors on glucose in real time and over the course of time. People with T2D may benefit from using CGM data to guide food choices that help achieve their desired glycemic goals, including time in range (TIR; percent time with glucose levels between 70-180 mg/dL).

However, people with T2D may encounter challenges with knowing how to use CGM data to make food choices, especially making food choices that can maximize TIR and that are good for overall health. In other words, it may not be clear which food choices keep glucose in the desired target range and align with current evidence-based nutrition guidance for people with diabetes [4].

Optimal CGM use requires education, training, and support [5]. Various tools [6], methods [7], and programs [8] have been created to educate CGM users on the effective use of CGM technology and its associated data. However, specific emphasis on evidence-based nutrition guidance has not been embedded into these trainings, and this could have consequences. For example, without nutrition guidance, a continuous glucose monitor could lead its user to regularly choose *less healthy* foods if those foods keep glucose in the target range of 70 to 180 mg/dL (eg, choosing high-fat red meats or highly processed low-carbohydrate snack foods); however, these *less healthy* foods may be detrimental to other aspects of health and lead to unintended consequences.

Research suggests that people who are empowered and skilled to self-manage their diabetes have improved health outcomes [9,10]. Discovery learning is one self-care opportunity, which has been described by Polonsky et al [11] as a time when an individual with diabetes is supported to make use of new information (such as one's own glucose values) to gain insights through personal experience and reflection. Having CGM data available before and after meals can provide a profound opportunity for the user to make connections between a given glucose value and food choices, portions, or circumstances, which, in turn, could promote data-driven behavior changes. Thus, this suggests that evidence-based nutrition recommendations at the time of CGM introduction and initiation could be beneficial.

This Study

The purpose of this research was to understand the perspectives and behaviors of people who participated in a nutrition-focused approach (NFA) when starting CGM. More specifically, this research in non–insulin-using people with T2D describes the following: (1) How do people who participate in an NFA during CGM initiation describe this experience (ie, intervention receipt)? and (2) How do people who participate in an NFA during CGM initiation use CGM data to make food-related decisions, and what food-related changes do they make (ie, intervention enactment)?

The outcomes of this research can help identify gaps in knowledge regarding how new CGM users understand and use their CGM data to make food-related decisions. This research can also provide the diabetes care community with considerations for how to present or position nutrition messages when initiating CGM in people with T2D.

Methods

Study Design

This qualitative study is part of the larger UNITE (Using Nutrition to Improve Time in Range) study (NCT05928572). UNITE is a randomized clinical trial designed to understand if there are differences in glycemia and dietary intake when people with T2D are introduced to CGM using 2 different methods. The 2 CGM initiation methods were an NFA and a self-directed approach (SDA). Participants were randomly assigned to participate in either the NFA or SDA when initiating a Dexcom G7 (Dexcom, Inc) CGM sensor paired with a smartphone app. All UNITE study participants used the G7 sensor and smartphone app continuously for approximately 2 months.

The focus of the NFA was to help CGM users use their CGM data to identify which food choices align with evidence-based nutrition recommendations and help achieve glycemic goals. Development of the NFA has been previously described by Willis et al [12]. In brief, the NFA included the following three components: (1) a 60-minute, in-person CGM initiation session; (2) a 30-minute, remote CGM data review session occurring approximately 14 days after CGM initiation; and (3) nutrition-focused CGM initiation materials designed to support both the CGM user and the diabetes care provider conducting the sessions. The materials included a brief interactive slide presentation containing graphic images and a 1-page CGM nutrition guide. The materials encouraged the CGM user *to know* their glucose goals (including a target glucose range of 70-180 mg/dL and TIR of >70%); *to learn* how their body responds to foods and activity using a *1, 2, 3* approach (a method for following glucose before and after meals and activity to learn the body's response); and to consider how *to adjust* food choices using a *yes/less* framework (a highly simplified version of evidence-based nutrition recommendations). Excerpts of the

materials and how they were used are published elsewhere [12]. A registered dietitian nutritionist served as the diabetes care provider for both sessions; however, the sessions were not intended to replace medical nutrition therapy (eg, the NFA did not include a full nutrition assessment or diagnosis). While a registered dietitian nutritionist would be an excellent candidate to deliver the NFA, the nutrition-specific content was developed to be general enough that other care providers could be trained to deliver the intervention. An intervention manual was used to keep the content and sessions consistent among all participants in the UNITE study.

A rapid matrix analysis approach with semistructured qualitative interviews [13,14] was designed to describe intervention receipt (this included information about the quality and quantity of information delivered and about the intervention materials, including the interactive slides and the CGM nutrition guide) and intervention enactment (this included thoughts and behaviors related to CGM use and food choices).

A deductive approach (ie, one that uses an existing framework to guide the qualitative coding process) [15] was selected because the National Institutes of Health fidelity framework [16] provided an appropriate a priori coding tree that could be applied to the NFA intervention. Constructs included a description of the participants' diabetes history; intervention receipt, including interventionist and intervention materials; and intervention enactment, including CGM only (no food) and food with or without CGM. The qualitative study was designed and reported following the COREQ (Consolidated Criteria for Reporting Qualitative Research) guidelines [17].

Ethical Considerations

All protocols and procedures for this qualitative study were reviewed and approved by the HealthPartners Institutional Review Board (study A22-279) in July 2023; this was approved before contacting participants. Verbal informed consent, as approved by the institutional review board, was obtained from each participant at the time of the interview. Participant confidentiality and privacy were maintained using the following methods: (1) study staff were trained in human subjects research protections and Health Insurance Portability and Accountability Act compliance, (2) any study-related data were collected and stored on password-protected servers behind a firewall to which only study staff had access, and (3) participant information was deidentified, to the extent possible, using numerical IDs. Participants who completed the interview received a US $25 Target gift card.

Recruitment and Participants

Participants were eligible for the qualitative study if they met inclusion criteria for the larger UNITE study, were randomly assigned to the NFA arm, completed all components of the 2-month intervention, had adequate CGM data at the final postintervention assessment, and were willing to participate in a recorded interview. In brief, eligibility criteria for the UNITE study included being aged ≥18 years; a T2D diagnosis; having a hemoglobin A_{1c} (HbA_{1c}) of 7% to 10% at the time of screening; having a stable diabetes medication regimen for at least 30 days excluding any form of insulin, sulfonylureas, meglitinides, or other medications with known hypoglycemia risk; and having no personal CGM use within 90 days before the start of the study.

Individuals who met screening criteria were asked by UNITE study staff via phone if they were interested in participating in a qualitative interview. If so, they were scheduled for a single 30-minute phone call that took place at the clinic after their final UNITE study visit. Only the participant and the interviewer were present during the interview. Participants were informed that they were speaking with a trained health care interviewer and that the purpose of the interview was to learn about their experience in the study to improve CGM initiation options in the future. To increase the likelihood of saturation in qualitative analysis [18], up to 15 interviews were planned, and an effort was made to balance the invitation of participants by gender identity.

Data Collection

Phone interviews were conducted using an interview guide aligned with the a priori coding tree described earlier, starting with intervention receipt followed by enactment. The guide was developed by the research team (HJW, MMJ, MSGH, and LJZ; all identified as female) following the best practices for semistructured interviewing [19]. Interviews included a series of open-ended root questions with follow-up probes to elicit richer data from participants. The interview started with an easy-to-answer rapport-building question to set the tone and then funneled from broad to more specific questions, ending with a final cool-down question. During the intervention receipt portion of the interview, participants were asked to recall the intervention materials unprompted and were asked to look at copies of the materials to encourage more detailed recall. In the intervention enactment portion, participants were asked to describe how they used CGM data and how the data affected their thoughts about food, food choices, and eating behaviors. Interviewers were encouraged to probe for specific examples. The interview was designed to be completed within 30 minutes. Textbox 1 summarizes the interview questions. The full interview guide can be found in the Multimedia Appendix 1.

Interviews were conducted by trained qualitative interviewers (MSGH and LJZ) with master's degrees in health-related fields and experience conducting interviews with participants in health care–related research studies. The interviewers were involved in previous qualitative research on CGM use by people with diabetes and diabetes care providers. Interviewers also received study-specific interview training from a diabetes researcher (HJW) and conducted practice interviews with diabetes care and education specialists. Ongoing supervision by a qualitative researcher (MMJ) was provided to prevent drift in facilitation over time.

Textbox 1. Interview guide summary, including question purpose, summarized interview questions, and probes.

Rapport building

- What do you remember about when you were first diagnosed with diabetes?
  - How did you take care of your diabetes at that time?
  - Did you think about nutrition or food choices at that time?
  - Did you ever talk with a diabetes educator or dietitian? Tell me about that experience.

Intervention receipt (how do people with type 2 diabetes who participate in a nutrition-focused approach during continuous glucose monitoring [CGM] initiation describe their experience?)

- What do you remember talking about with your diabetes care provider when you first started using your CGM?
  - What did you think about the nutrition-focused information you received and how it was presented?
  - What did you like (or what could be improved) about the materials that were used to help you learn to use your CGM? (this question was asked unprompted and prompted)
  - Do you think focusing on nutrition (food choices) is a good way to help someone get started using their CGM? Why or why not?

Intervention enactment (how do people who participate in a nutrition-focused approach during CGM initiation use CGM data to make food-related decisions and what food-related changes do they make?)

- How did you use your continuous glucose monitor and its data?
  - What information on the app did you use most often?
- How, if at all, did your CGM data affect how you thought about food and the food choices you made?
  - Did seeing your glucose information cause you to change the amount, type, timing, or something else about the foods you ate? What changes did you make? What did you eat more of or less of?
  - Did you try any yes/less choices (Nutrition Guidance) to help reach your glucose targets? Why or why not?
  - What made it hard to use your CGM numbers to make decisions about your food? What would have made it easier to use your CGM to guide your food choices?

Cooldown

- What else do you want to share about your experience learning how to use information from your CGM, or about how you now think about food choices with diabetes?

Qualitative Data Analysis

Interviews were audio-recorded and transcribed using automated transcription software (Microsoft Teams). Interviewers took detailed field notes during the interview and memos [20] after the interview in a field note and memo guide in REDCap (Research Electronic Data Capture; Vanderbilt University) [21], which corresponded with the a priori coding tree. As interviews were completed, a lead qualitative analyst (MMJ) imported recordings, transcripts, field notes, and memos into qualitative analysis software (NVivo version 12; Lumivero). The lead analyst followed a sort-and-sift matrix analysis approach [22] to identify emergent themes within each research question and summarized key findings across interviews, identifying representative quotes. The analysis team (MMJ, HJW, MSGH, and LJZ) met for iterative reviews and to refine key findings. Although the concept of saturation does not directly translate to the rapid sort-and-sift matrix approach used in our study [23], analysts did consider the concept broadly and made note of when no new major themes emerged related to the a priori framework. This was done with issues of reflexivity in mind and to increase the correctness of findings [24]. Finally, a codebook and audit trail were maintained by the analysis team (MMJ, HW, MSGH, and LJZ) to ensure rigor and increase reproducibility.

Qualitative themes within each research question are presented along with representative quotes, which are embedded into the text to aid in the communication and richness of the findings described within each a priori construct in the coding tree [25]. Descriptive statistics, including means, SDs, frequencies, and percentages, are presented where appropriate. Participants did not review transcripts, codebooks, or other findings during or after analysis.

Results

Participant and Interview Characteristics

A total of 15 (88%) of the 17 eligible UNITE study participants agreed to participate in the qualitative interviews; 2 (12%) declined due to time constraints. Saturation was believed to be reached, as no new major themes emerged with iterative ongoing analysis. Most (13/15, 87%) interview participants identified as White and male (9/15, 60%). At the start of the UNITE study

intervention, participants had a mean age of 64 (SD 7.4) years, had T2D for 7.5 (SD 3.8) years, had an HbA_{1c} of 7.5% (SD 0.4%), and had a TIR of 51% (SD 25%; Table 1). Interviews lasted an average of 31 (SD 5) minutes and were conducted between September 2023 and March 2024.

Table 1. Descriptive participant data (N=15).

Characteristics	Values
Self-identified as male, n (%)	9 (60)
Age (y), mean (SD)	64.2 (7.4)
Racial or ethnic group, n (%)[a]	
African Native; American Indian or Alaskan Native; Asian (including Hmong, Chinese, Asian Indian, Vietnamese, etc); Black or African American; Hispanic or Latino, Latina, or Latinx; Middle Eastern or North African; or Native Hawaiian or Other Pacific Islander	1 (7)
White	13 (87)
Chose not to answer	1 (7)
Duration since T2D[b] diagnosis (y), mean (SD)	7.5 (3.8)
Usual finger stick frequency at baseline, n (%)	
Never or less than once per month	3 (20)
1-3 times per month	3 (20)
1-6 times per week	4 (27)
Once per day	4 (27)
2-4 times per day	1 (7)
Food secure, n (%)[c]	14 (93)
Baseline HbA_{1c}[d] (%), mean (SD)	7.5 (0.4)
Baseline time in range (%; time with glucose 70-180 mg/dL), mean (SD)	51 (25)

[a]Racial and ethnic groups were merged for data presentation to protect participant confidentiality.

[b]T2D: type 2 diabetes.

[c]Food security was confirmed if there was a positive answer to either of the following two questions: (1) "Within the past 12 months, I worried whether my food would run out before I had money to buy more." (2) "Within the past 12 months, the food I bought just didn't last, and I didn't have money to get more."

[d]HbA_{1c}: hemoglobin A_{1c}.

Results of Research Question 1: How Do People Who Participate in an NFA During CGM Initiation Describe This Experience (ie, Intervention Receipt)?

During the first CGM initiation session, the CGM sensor and its data were explained to participants as tools to help guide their food choices. Participants were oriented to the CGM data displayed on the G7 smartphone app and encouraged to know (and remember) their glucose targets.

Approximately 2 months after the original CGM initiation session, the qualitative interviews were conducted, and it was clear that participants understood their CGM data. Participants were able to fluently and easily discuss real-time glucose values and metrics such as TIR and average glucose with their interviewers. While there were nuanced differences in the reported use of the data across participants (described in subsequent sections), these new CGM users seemed to have no difficulty understanding the CGM data, glucose targets, or how to use them.

Most of the participants remembered the nutrition-focused CGM initiation materials, and they generally liked the content and format. They could describe the core concepts presented in the materials (eg, the *1, 2, 3* approach and *yes/less* framework) in simple terms, even if not using the specific terminology. Some participants were able to discuss the materials unprompted, while others needed a brief review of the materials:

> *[After a brief review of the materials] That 1, 2, 3 approach—about checking my glucose before I eat, note what I ate, then note what happened after I ate—that became the real solid basis of my first two or three weeks with the monitor. It really helped me change my diet and I saw some pretty immediate benefits.* [Participant #3]

The nutrition information presented within the materials was recognized by participants as consistent with prior nutrition-related education. This repetition was not seen as negative, and some viewed it as a strength. Several participants commented that the plated food images and the message of "half the plate as vegetables" along with the CGM data were helpful for guiding adjustments to their food intake:

> *In fact, I was even thinking a little bit about it this morning, the pictures of the plate, the plate method did stick with me. That helped...The actual pictures of plates and having non-starchy vegetables as half and then a quarter protein, that was useful.* [Participant #1]

Many participants specifically noted liking the simplicity of the messages around using CGM data to understand the impact of food choices on their glucose numbers and the utility of having flexible glucose targets (eg, glucose 70-180 mg/dL and >70% TIR). No substantial suggestions to improve the content or format of the nutrition intervention materials were provided. One participant described the materials as "highly polished," and many described the pictures and images as supporting their understanding of what to do with CGM data and food choices:

> *I've made a few PowerPoint presentations in my time, and I'd say these are very good, very, very good...the most educational part of the slide set was about the quantity and choices for what foods to eat; the fact that they talked about it at all, because I don't pay attention to that. I have the foods that I like, and I think I know enough about them to know whether I'm having a good food or not...So, I would say being more aware of high-sugar foods and trying to minimize them [was a helpful message in the slides].* [Participant #6]

Participants described the 2 sessions with their diabetes care provider (the in-person initiation and remote check-in) as positive and useful and described the care providers as pleasant, kind, respectful, clear, knowledgeable, and thorough. One participant described the time with the care provider as feeling "more like a conversation about my health" than being "talked at," and another participant described their care provider as especially helpful in dealing with feelings of guilt and blame related to food and diabetes.

One participant described the content of the discussions with the care provider as consistent with prior experiences but the tone as being distinctly more respectful, positive, and motivating. Another felt part of their success in using the CGM device to guide food choices was due to the consistent messaging from the diabetes care provider throughout the intervention period. However, others suggested that additional planned follow-up sessions with the diabetes care providers would have added benefits (ie, more appointments for CGM data review and discussion):

> *Checking in and reinforcing or affirming more [would have been useful during the program]. Maybe nudging and encouraging more health choices, because there's a lot of emotional and cultural baggage that people have with foods you know, and it's not an easy thing to change.* [Participant #5]

Overall, participants agreed that focusing on nutrition and food choices was a good way to help someone with T2D initiate CGM use and that this approach was beneficial for their diabetes care. Several participants specifically shared their appreciation for both the nutrition-focused intervention materials and the time with the diabetes care provider:

> *[In the past] I saw a nutritionist and it didn't help me—and, I was given a glucose meter and it didn't help me...But, the combination of that real-time glucose and then getting the tips [from the care provider] on what to try...it's like, yes, what they're telling me, now I can see it works!* [Participant #14]

Many described starting to use a CGM and considering their food and nutrition choices as essential. For participants who felt they were knowledgeable about nutrition before the intervention, they presumed they would have naturally thought about food choices when initiating CGM; however, this is challenging to ascertain, especially as it relates to consideration for food choices that align with evidence-based guidelines:

> *Well, nutrition, exercise, and medication is what I would consider to be the triangle. You have to [have these] to be successful...[Use of the CGM without the nutrition guidance] would not have been as good, not as effective...the effectiveness of the control of the blood sugar would have been less.* [Participant #6]

Results of Research Question 2: How Do People Who Participate in an NFA During CGM Initiation Use CGM Data to Make Food-Related Decisions, and What Food-Related Changes Do They Make (ie, Intervention Enactment)?

All participants described regularly (eg, multiple times per day) using the G7 app to follow their glucose after the initial CGM initiation session. Difficulty using or interpreting CGM data was rarely described. Participants explained using CGM data both retrospectively (ie, the 3 or 14-day TIR) and in real time (ie, the glucose bubble, arrow, and 3-, 6-, 12-, or 24-hour glucose trend lines). Several participants expressed specific appreciation for the new diabetes management concepts, such as CGM-derived average glucose and TIR, and they described using these as guides for their diabetes care:

> *I thought that it was interesting where the time in range was. It helped me understand what you're specifically looking at...I paid attention to it all the time.*" [Participant #4]

Many talked about following glucose levels before and after meals and activity, as recommended by the intervention's *1, 2, 3* approach. However, some described "checking it all the time" or looking at the app "obsessively." Participants described using the CGM data to make decisions in real time, and some described relying on the trend arrows as a way to make decisions about what to eat in the moment:

> *If I'm about to have dinner and [my numbers were near the top of the range] I would make different decisions about either what to eat or how much to eat...I might have a little less, or something that was lower carb, or definitely start with vegetables first. –* [Participant #1]

Many participants described using the recommended techniques (eg, the *1, 2, 3* approach) to learn how various foods and meals affected their glucose. Participants described experimenting to see the impact of *yes* foods (eg, nonstarchy vegetables), and 1 participant described trying various food substitutions to come

up with a meal plan that worked well for their glucose management:

> *While it's very helpful to see the numbers on your CGM, knowing more about how food impacts those numbers is so helpful...[I can see] if I fill up on vegetables my numbers will stay more consistent and/or lower...and, I swear that I enjoy my salads a lot more now...I found more satisfaction with my vegetables.* [Participant #9]

Many also described experimenting with *less* foods (eg, starchy snacks or sweetened foods) to learn how those foods affected their glucose levels. Some described the results of this type of experimentation as "surprising," specifically noting they learned how long their glucose stayed elevated after eating foods they considered small "cheats" or "slipups." Others also described using experimentation with *less* foods as an "excuse" to eat these foods "guilt free:"

> *I just ate things like a peanut butter and jelly sandwich or chocolate milk and, wow, for me drinking milk really makes the blood sugar go up. That was a sad thing to learn because I love drinking milk.* [Participant #13]

Others described experimenting with the timing and portion sizes of meals, including smaller meals throughout the day, delaying or skipping meals, trying to eat more protein before bed, or adding in physical activity throughout the day, especially right after meals. For most, experimentation with foods led to new perspectives and knowledge about the impact of foods and activity on glucose.

One participant described learning from her CGM data that allowing some feelings of hunger was "safe" for her diabetes management; in other words, she learned that hunger did not mean she needed to eat to prevent low glucose. For some, the increased knowledge and immediate feedback from experimentation led to changes in their perceptions of food, with a few describing a better appreciation for the value of foods. One participant described "losing the craving" for *less* foods because they were not "worth it"; for this participant, they described attaching more value to *yes* foods because they saw the beneficial impact on glucose:

> *[The CGM] helped me appreciate the value of foods. I love carbohydrates and could eat bread and pastry all day long and it will have a bad impact on my blood sugar—an enormously bad impact. And I like sweets. If I indulge in a sweet, it was a real reminder that I may be loving this sensation in my mouth and whatever is going on in my brain chemistry, but I'm not doing my overall health any good...Then, similarly for vegetables, I'm not a real fan of vegetables. But, watching a really high fiber, high vegetable meal have a low impact on my blood sugar, I had a very tangible reminder that these things are actually good for me.* [Participant #3]

Most participants described making at least some dietary changes to positively impact their glucose, and they actively extended experimentation into efforts to maintain improved glycemia or TIR. There were some clear, broad-level changes to food choices or behaviors that emerged as common among participants (eg, eating more nonstarchy vegetables, reducing overall carbohydrates or sugars, and choosing smaller portions); however, these interviews also highlighted that changes to specific foods and other behaviors were nuanced and unique to the individual. Table 2 provides an individual-level summary of some of the main food-related changes and behavior strategies the participants reported using to improve their glucose.

For example, individual participants reported details, such as switching from oatmeal and bananas for breakfast to cottage cheese and strawberries, choosing roasted peanuts in the shell for a snack to slow eating, or relying on cauliflower crust for pizzas. One participant reported making substantial changes to the amount of food consumed, stating that since seeing the CGM data, "I eat about half as much food now." Another reported using their CGM to "guide every decision about food" when first starting with the device and then coming up with a meal plan and using the CGM data to determine when or if more changes were needed.

Not all participants made substantial changes to their food choices or behaviors. Some described a gap between increased knowledge and their perceived or realized ability to make changes. One participant specifically mentioned foods related to holidays, traditions, and culture as being hard to change even when seeing the CGM data. This seemed to pair with a few participants self-describing themselves as "poor eaters" or having negative opinions about their own eating patterns. While infrequent, it is also important to note that some people described CGM as amplifying feelings of needing to "try harder" and noted that CGM added stress because it was hard to avoid seeing the impacts of certain foods when the device "was always measuring me." One person reported not liking the amount of mental energy they spent thinking about glucose and food; therefore, they ended up returning to old food habits:

> *It was always in my head that my blood sugar was always high even when it was at its lowest; it was still too high. So when I ate it would just be way too high...it kinda made me afraid to eat.* [Participant #2]

Table 2. Examples of the individual-level food and behavior changes participants described implementing after seeing their continuous glucose monitoring (CGM) data.

ID	Food changes	Behavior changes
1	• More: nonstarchy vegetables, other vegetables, and melon • Less: rice	Chose overall lower carbohydrates, ate vegetables before eating other foods, chose smaller portions, chose smaller meals spaced more evenly throughout the day, stopped eating before feeling full, skipped meals, and walked frequently (sometimes as much as every hour)
2	• More: roasted peanuts in a shell • Less: rice (smaller portions), mini-candy bars, and candy	Chose smaller portions and added activity after meals
3	• More: cottage cheese and strawberries, large salads, leafy greens, fish, nuts, vegetables, and protein foods • Less: oatmeal and grapes	Chose smaller portions, delayed evening meals, ate very low carbohydrate dinners, and walked in the afternoon
4	• More: vegetables and homemade nonprocessed foods • Less: fast food; sweets; and chocolate kisses	None noted
5	• More: salads, peanut butter, sweet potato, and cauliflower crust for pizza • Less: rice, crackers, chips, bread, Italian pasta, and alcohol	Measured portions, chose smaller portions overall (eg, half as much food), chose smaller portions of carbohydrates (eg, 1 piece of bread instead of 2), skipped meals, and walked more (even if only 10 min)
6	• More: whole-wheat bread, whole-wheat pasta, and white meat • Less: Soda, fruit juices, candy, and chocolate bars	None noted
7	• More: none noted • Less: cereal and bread	Chose smaller portions and walked more
8	• More: Green leafy vegetables, other vegetables, fresh fruit, fresh whole foods, and low-sugar yogurt • Less: candy, pure sugar foods, and chips	Chose smaller portions and chose lower carbohydrate options
9	• More: water, black coffee, vegetables, salads, cucumbers, celery, eggs, popcorn, and protein foods • Less: cereals	Chose smaller portions, reduced carbohydrate-heavy meals, delayed mealtimes, and walked after meals when glucose was high
10	• More: vegetables and fruit • Less: certain carbohydrates and certain types and amounts of cereals	Measured out servings, chose smaller portions (eg, half bagel instead of whole), and chose overall lower carbohydrate
11	• More: no specific changes were noted; however, the participant reported confidence in using the CGM data and described examples of food experimentation • Less: nothing noted	None noted
12	• More: water • Less: sweets	Chose smaller portions
13	• More: several vegetables • Less: milk	Chose smaller portions, chose overall lower carbohydrate (eg, dropped the bun), and ate a small amount of protein before bed
14	• More: nonstarchy vegetables (steamer bags), cottage cheese, and protein foods • Less: soda	Chose smaller portions, added more protein to meals, read food labels, and limited sweets and sugars
15	• More: no changes were noted; however, the participant reported confidence in using the CGM data and reported several examples of current food choices that were reinforced because of seeing CGM data • Less: cereals, pancakes, and baking with regular flour	None noted

In contrast, many participants described the CGM as finally providing them with a clear understanding of how their food choices influenced their glucose levels and diabetes, which in turn led to potentially more sustainable behavior changes. One participant described the impact of their participation in this NFA as something that helped them make changes in their diabetes management that they had not been able to do for years and another expressed excitement in seeing progress:

> *It helped me set a different pattern on when I ate, how much I ate, what I ate—those are changes I was unwilling to make until I saw the data.* [Participant #4]

> *This is the first time in 10 years that I've made progress!* [Participant #14]

Similarly, others described the CGM data as "encouraging to see how much control I had" and a way to see the impact of foods with new clarity:

> *I think focusing on nutrition is helpful for someone to get started using a CGM. It hit home that the choices I was making, like in crystal clear clarity, if I eat this, this happens, that happens. With the monitor, it showed it goes up this much.* [Participant #2]

Other participants shared special appreciation for the biofeedback following food choices, with one person describing the feedback loop as a "gamechanger" and another especially liking the immediacy of the data:

> *...many people intellectually understand nutrition, but don't comply—the sensor is an immediate and absolute reminder of the changes and differences that [foods] make.* [Participant #12]

When participants were prompted for suggestions to improve the overall NFA, 1 (7%) of the 15 participants suggested pairing the CGM with structured meal plans, such as instructions for what to try eating for a week for improved glucose. Other suggestions focused more on ideas to improve the CGM app, such as a quick and easy way to record a meal in the app or to overlay their food notes with their glucose values. A participant suggested they would have liked it if the NFA intervention materials "were built into the app" for easier reference:

> *If there was a really convenient way to record what I was eating and have that tied very directly and very visibly to what the CGM app was showing me, that would have been hugely impactful.* [Participant #3]

Discussion

Principal Findings

Through these qualitative interviews, we heard that using an NFA during CGM initiation was generally well received and perceived as helpful for people with T2D who do not use insulin. We also found that in this population of people who do not use insulin and who infrequently monitored glucose (with finger sticks), the CGM data were easily understood, regularly viewed, and often used to promote changes in food choices and behaviors during the 2-month study. The nutrition-focused intervention materials and messages were mostly described as supportive and useful for helping participants understand how to use their CGM data to guide food choices.

Relationship to Prior Work

The results of this research add to existing literature in several ways, including highlighting how the CGM device could potentially be used to specifically encourage evidence-based nutrition recommendations. Research demonstrates that choosing high-quality eating patterns (ie, adhering to evidence-based nutrition recommendations) is linked to better glycemia [26,27] and inversely associated with risk of all-cause mortality, cardiovascular disease, cancer, and neurodegenerative diseases [28]. Therefore, any diabetes technology or care approach that can integrate messages about the importance of diet quality could be of significant benefit. These interviews not only reinforced the notion that there is no one-size-fits-all diet or lifestyle plan that works for everyone with diabetes [2] but also that CGM can be used to help individuals identify which specific foods and behavior strategies work best for them. Findings from this research may also help support the conclusions of previous research, which have suggested that CGM can lead to lifestyle and behavior changes [29-31] but where objective behavior outcomes were not measured or qualitatively assessed.

In addition, this research provides context regarding opportunities for training new CGM users on optimal use of the device. The American Diabetes Association's Standards of Care recommend that education, training, and ongoing support are needed for all diabetes devices, including continuous glucose monitors [5]. Furthermore, Heinemann and Klonoff [32] expanded upon how CGM use in and of itself does not necessarily lead to better outcomes (ie, improved glucose), which may be particularly true for people with T2D who do not take insulin and are less reliant on (or familiar with) glucose testing. At the same time, lack of nutrition guidance and support has also been identified as a prominent barrier to behavior change for people with T2D [33]. Thus, education about how to optimally interpret and use CGM data, specifically to guide food choices that align with evidence-based guidance, seems of benefit. Our interviews suggest that using an NFA during CGM initiation could be a helpful way to both educate on the device and its data and empower new users to use the data to make healthful adjustments to their food choices and behaviors. With this NFA, participants seemed to have little to no difficulty interpreting CGM metrics and using them to guide food choices, which suggests that providing education on both glycemic targets and evidence-based eating principles (at the same time) during CGM initiation is reasonable.

Related to CGM support, it is important to note that this intervention provided to these new CGM users was very brief—just 1 in-person session and 1 remote follow-up session approximately 14 days later. Some participants suggested that more follow-up sessions would have been beneficial. The need for additional follow-up sessions aligns with recommendations for adequate diabetes self-management education [2] and with recent research suggesting that—based on individual circumstances and goals—evolving support is needed to sustain effective CGM use [34]. At this time, it is unclear how often CGM data reviews are needed to support glycemic goal attainment or maintenance, and therefore, further research is needed. Future research should aim to help define best practices for the ideal frequency of health care provider–led CGM data review, for the most efficient ways to systematically and effectively assess and discuss CGM data with users, and for using CGM data specifically as a tool to help sustain long-term lifestyle and behavior change.

The results of this research provide the diabetes care community with considerations for how to present or position nutrition messages when initiating CGM in people with T2D.

These interviews suggest that using a positive, respectful tone to discuss evidence-based nutrition guidance during CGM initiation was beneficial; however, we also encountered the potential for CGM data to exacerbate negative feelings about oneself or one's relationship with food. Some people described skipping or delaying meals as a means to try and stay in range, which could be acceptable or could be concerning, for example in people with a history of or potential for disordered eating [35]. Others expressed fears and frustration over thinking too much about their CGM data as it related to foods. Taken together, this underscores the importance of ensuring that CGM education includes messaging about how foods and behaviors are only part of what drives glycemia, especially for people who are not using CGM primarily to determine medication doses or adjustments. On the basis of this research, it seems important for diabetes care providers to regularly remind CGM users that sometimes even with the best adherence to nutrition or lifestyle plans, additional medication support may be needed. In other words, diabetes care providers should make it clear that the CGM device is meant to be a support (eg, for positive nutrition and lifestyle changes and medication management), and it should not contribute to negative feelings, stress, or disordered eating. These concepts can be considered further by exploring previous qualitative research describing the psychosocial outcomes [36], quality of life [37], and other attitudes and behaviors [38] of people with T2D using CGM.

Strengths and Limitations

This research has several strengths and limitations. The first strength is the qualitative assessment of people who underwent a well-defined intervention that was designed specifically for the purposes of using CGM to guide evidence-based nutrition and lifestyle choices. The second strength is the methodology used to design, conduct, and analyze these interviews. Furthermore, the third strength is that this work focused exclusively on CGM initiation in people with T2D who do not use insulin, as people with T2D who do not use insulin and who use CGM is a segment of the diabetes population that has been evaluated less frequently than others.

Regarding limitations, the first limitation is that this research did not assess the perspectives and behaviors of people with T2D who initiated CGM without an NFA (eg, with an SDA). Thus, it is unclear whether people without an NFA during CGM initiation would have similar experiences and report similar changes or whether they would consider the importance of nutrition choices for other aspects of health; future research should consider this. Second, the participants interviewed were predominantly White (13/15, 87%), food secure (14/15, 93%), and identified as males (9/15, 60%) with a lower HbA_{1c} at baseline, which may limit the generalizability of the findings because we cannot account for how the nutrition-focused intervention materials would be received by a more diverse audience (eg, food images and core messaging). It is possible the materials would be more or less applicable based on recipient characteristics, and further research in a more diverse population is needed. Third, while this research describes the participants' reports of their CGM use and their nutrition and lifestyle behaviors over a 2-month period, these behaviors were not objectively measured or connected to the participants' actual glycemic outcomes. However, these objective data will be available with the results of the larger UNITE study.

Future Research

Future research should assess the experiences and behaviors of people with diabetes who participate in an NFA intervention over a longer period and with more health care provider–led CGM data reviews or could explore factors that may contribute to negative experiences or stress around using CGM data to guide food and lifestyle changes.

Conclusions

First-line therapy for T2D management is lifestyle modification, which includes following evidence-based nutrition guidelines and increasing physical activity. CGM data can be used to promote or encourage these lifestyle changes. This qualitative study described the experiences and reported behavioral effects of using an NFA during CGM initiation in people with T2D who were not using insulin.

Approximately 2 months after initiating CGM using an NFA (which included 1 in-person and 1 remote follow-up session), participants seemed to clearly understand the meaning and application of CGM data for behavior change. They reported using their real-time and retrospective CGM data regularly, and they agreed that pairing evidence-based nutrition information with CGM initiation instructions was helpful for their diabetes care. Most participants reported making some food and behavior changes that aligned with evidence-based guidance for a healthy lifestyle, such as increasing nonstarchy vegetable intake or decreasing overall sugar intake. At the individual level, participants also noted several unique food or behavior changes, which highlights that no single eating plan works for all people with diabetes but that CGM can likely show which eating plan may work best for an individual. Opportunities exist to further explore best practices for CGM-guided nutrition interventions in people with diabetes.

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Data Availability

The datasets generated during and analyzed during this study are available from the corresponding author on reasonable request.

Authors' Contributions

HJW and MMJ designed the research, analyzed data, and wrote the first draft. LJZ and MSGH conducted the research and reviewed and edited the manuscript. HJW had primary responsibility for the final content. All authors read and approved the final manuscript.

Conflicts of Interest

HJW has received research support from, consulted with, and been on an advisory board for Abbott Diabetes Care and has received research support from and consulted with Dexcom. The employer of HJW, the nonprofit HealthPartners Institute, contracts for her services, and no personal income goes to HJW. MMJ, LJZ, and MSGH declare no potential conflicts of interest.

Multimedia Appendix 1
UNITE (Using Nutrition to Improve Time in Range) study qualitative interview guide.
[DOCX File , 27 KB - diabetes_v10i1e67636_app1.docx]

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Abbreviations

CGM: continuous glucose monitoring
COREQ: Consolidated Criteria for Reporting Qualitative Research
HbA_{1c}: hemoglobin A_{1c}
NFA: nutrition-focused approach
REDCap: Research Electronic Data Capture
SDA: self-directed approach
T2D: type 2 diabetes
TIR: time in range
UNITE: Using Nutrition to Improve Time in Range

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Toward Personalized Digital Experiences to Promote Diabetes Self-Management: Mixed Methods Social Computing Approach

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Abstract

Background: Type 2 diabetes affects nearly 34.2 million adults and is the seventh leading cause of death in the United States. Digital health communities have emerged as avenues to provide social support to individuals engaging in diabetes self-management (DSM). The analysis of digital peer interactions and social connections can improve our understanding of the factors underlying behavior change, which can inform the development of personalized DSM interventions.

Objective: Our objective is to apply our methodology using a mixed methods approach to (1) characterize the role of context-specific social influence patterns in DSM and (2) derive interventional targets that enhance individual engagement in DSM.

Methods: Using the peer messages from the American Diabetes Association support community for DSM (n=~73,000 peer interactions from 2014 to 2021), (1) a labeled set of peer interactions was generated (n=1501 for the American Diabetes Association) through manual annotation, (2) deep learning models were used to scale the qualitative codes to the entire datasets, (3) the validated model was applied to perform a retrospective analysis, and (4) social network analysis techniques were used to portray large-scale patterns and relationships among the communication dimensions (content and context) embedded in peer interactions.

Results: The affiliation exposure model showed that exposure to community users through sharing interactive communication style speech acts had a positive association with the engagement of community users. Our results also suggest that pre-existing users with type 2 diabetes were more likely to stay engaged in the community when they expressed patient-reported outcomes and progress themes (communication content) using interactive communication style speech acts (communication context). It indicates the potential for targeted social network interventions in the form of structural changes based on the user's context and content exchanges with peers, which can exert social influence to modify user engagement behaviors.

Conclusions: In this study, we characterize the role of social influence in DSM as observed in large-scale social media datasets. Implications for multicomponent digital interventions are discussed.

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KEYWORDS

digital health communities; diabetes self-management; behavior change; affiliation exposure; social networks; deep learning

Introduction

Type 2 diabetes (T2D) is responsible for affecting nearly 34.2 million adults, which accounts for 10.5% of the US population [1]. According to a recent report, about US $327 billion was spent on the treatment of diagnosed cases of T2D in the year 2017 alone [1]. In addition to its health and economic burden, T2D also increases the risk of developing other health complications such as heart disease, stroke, kidney failure, and blindness [2]. Modifiable health behaviors such as obesity, physical inactivity, unhealthy eating habits, and tobacco use are major risk factors for developing chronic health conditions such as T2D [2].

Behavior modification is a core component of diabetes self-management (DSM) programs and provides the much-needed support to improve health-related outcomes in individuals with diabetes [3]. It is a complex process, and research has shown that a range of psychological and social processes influence an individual's engagement in the sustenance of positive health behaviors [4,5]. For example, individuals are more likely to comply with health-related goals and adhere to preventive practices, provided their socially

connected peers also engage in similar behaviors by changing their intrapersonal beliefs, attitudes, or knowledge [6,7]. However, the mechanisms underlying such multilevel influences are not fully understood. Such a lack of understanding limits our capabilities to personalize support infrastructure to meet individual needs.

The widespread adoption of digital health technologies, such as mobile apps, wearables, sensors, and digital health communities (DHCs), creates opportunities to design tailored strategies for behavior change [8,9]. These technologies enable in-depth analysis of large-scale individual and population-level trends, providing valuable insights into behaviors, preferences, and social networks. [8,9]. The emergence of various peer-driven health communities has allowed health care consumers to interact with their peers and health care providers to garner social support and gather knowledge on various health-related topics, etc [10-12]. DHCs specific to T2D have been shown to enable their users to seek and receive support and obtain valuable information to improve psychosocial care and health outcomes [13]. These communities provide us with large and invaluable datasets in the form of electronic traces of peer interactions that capture the attitudes and behaviors of large populations in near real time and in natural settings [9]. Analyzing these datasets allows us to understand the individualistic and environmental factors underlying behavior change and develop effective behavior change interventions (BCIs) [14].

Several studies have leveraged peer interactions in DHCs to model human health behavior [15]. Some research studies have explicitly focused on DSM-related DHCs and have analyzed the data generated from these communities to (1) identify the content of peer interactions, such as topics or themes of conversation [16,17], and (2) understand linguistic features of expression among members of DHCs and how that influences social support [18]. However, in a social setting, the content of communication and its context can affect the cognitive state of individuals engaging in a conversation [19,20]. Still, the current research on DSM-related DHCs needs to be more integrative of these components. To develop agile, adaptive, and personalized digital experiences for individuals at risk for T2D or diagnosed with T2D, new approaches are needed that consider multilevel contexts that can influence individual adherence to DSM behaviors. In this paper, we present our methodology using a mixed methods approach that combines qualitative analysis, automated text analysis, and social network analysis (SNA) techniques to characterize the role of context-specific social influence patterns underlying peer-to-peer communication and evaluate how “membership or affiliation” in a specific context is predictive of user engagement in DSM. Such an integrative approach can help us optimize user engagement in digital settings and subsequently leverage these platforms as delivery modalities for DSM.

Methods

Ethical Considerations

This study was exempted from human participant ethics review approval by the institutional review board at the University of Texas Health Science Center at Houston (HSC-SBMI-15-0697). We extracted only the messages in the public domain, that is, peer interactions marked public by the community users. To maintain user anonymity, we deidentified the data obtained from the DHC by assigning every community user a unique user identifier. In addition, the researchers had no direct contact with the community users.

Materials

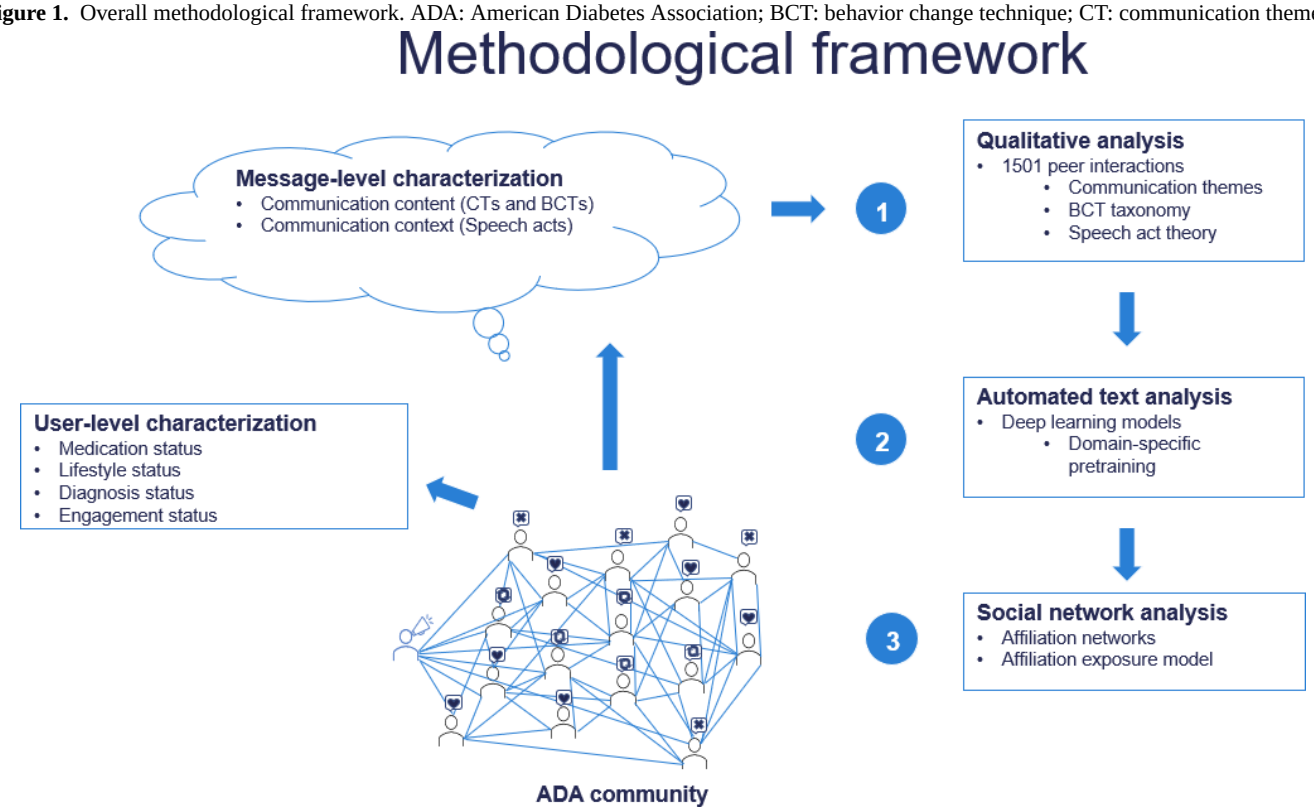
The American Diabetes Association (ADA) support community is a digital support group for individuals with diabetes (type 1, type 2, or prediabetes) to engage with their peers as well as caregivers [21]. The users of the community interact with one another on a wide variety of topics ranging from medication use, diet, physical activity, and daily monitoring of blood glucose levels. Even though the outcomes among type 1, type 2, or prediabetes are impacted by behaviors (such as lifestyle, medication use, and self-monitoring of blood glucose) that can be heavily influenced by an individual’s social infrastructure, for this research, we focused on interactions related to T2D. The dataset used in this research spanned from 2014 to 2021, consisting of 73,543 messages specific to T2D organized into 7619 unique topics posted by 2374 unique community users. The dataset characteristics across all years are presented in Table 1.

Figure 1 captures the overall methodological framework used in this study and is described in detail below.

Table . American Diabetes Association dataset characteristics.

	2014	2015	2016	2017	2018	2019	2020	2021
Total messages (n=73,543), n (%)	14,104 (19.2)	18,311 (24.9)	16,859 (22.9)	10,940 (14.9)	6379 (8.7)	3805 (5.2)	2202 (3)	922 (1.3)
Unique topics (n=7619), n (%)	1337 (17.5)	1776 (23.3)	1588 (20.8)	1028 (13.5)	746 (9.8)	587 (7.7)	501 (6.6)	234 (3.1)
Unique users (n=2374), n (%)	597 (25.1)	767 (32.3)	677 (28.5)	458 (19.3)	336 (14.2)	242 (10.2)	206 (8.7)	129 (5.4)

Figure 1. Overall methodological framework. ADA: American Diabetes Association; BCT: behavior change technique; CT: communication theme.



Characterization of Content and Context Exchanged in Social Ties

Qualitative Analysis

The objective of qualitative analysis was to characterize the nature of communication content and underlying context embedded in peer interactions of the ADA community to gain insights into the meaning of peer conversations and the choice of user expressions that affect DSM behaviors. We randomly selected a subset of 1501 forum messages from the original dataset and manually coded them using directed content analysis techniques along the following three dimensions:

1. Communication themes (CTs): Themes capture the essence or meaning of peer conversations and are derived through inductive analysis using grounded theory techniques [22]. These themes provide insights into the theory-driven behavioral constructs prevalent in digital peer interactions.
2. Behavior change techniques (BCTs): For BCTs, we used the BCT taxonomy [23] to identify manifestations of theory-linked BCTs embedded within digital peer interactions. This taxonomy provides a common vocabulary to understand how sociobehavioral and cognitive constructs of existing behavior change theories have been operationalized in BCIs.
3. Speech acts (SAs): To model the communication context underlying digital peer interactions, we used a modified version of Searle's SA theory [20] to describe how specific content is expressed in human communication using 10 categories of SAs. SA theory can be used to model digital peer interactions to recognize the general attitudes of community users and understand their state of mind by capturing implicit expressions and discourse patterns underlying such peer interactions.

Our qualitative coding schema with definitions of various categories of CTs, BCTs, and SAs can be found in Myneni et al [24] and Singh et al [25].

Automated Text Analysis

Given our initial experiments with a conventional multiclass, multilabel classification approach (which yielded poor results) and the inherently imbalanced nature of the dataset (see the Results section), we built a classification approach in which multiple models were combined in a cascading manner [26,27] for classification of the 3 communication attributes (CTs, BCTs, and SAs). We implemented the following deep learning models for performing text classification of peer interactions along the 3 dimensions: recurrent neural networks (RNNs), convolutional neural networks (CNNs), and transformer-based models. The labeled dataset was divided into 3 parts: 80% (1201/1501), 10% (150/1501), and 10% (150/1501) for training, validation, and test sets, respectively. For the implementation of RNNs and CNNs, we used the Adam optimization algorithm to find the best values for each parameter [28]. Specifically, we used the AdamW optimizer to implement the Bidirectional Encoder Representations from Transformers (BERT), set the dropout to 0.1 to avoid overfitting, and used a learning rate of 1×10^{-5}. We also computed class weights for the loss function to assign a higher weight to the loss encountered by the messages associated with infrequent label categories. To mitigate overfitting and increase the models' generalization capacity, the validation loss was monitored at every epoch. We found no further decrease in the value of validation loss after 20 epochs for all models that were trained. Therefore, the models were trained for only 20 epochs. We chose model hyperparameters based on their

optimal performance on the validation set. We converted the probabilities into label categories based on a threshold value that was calculated using the validation set. RNNs and CNNs were implemented with Keras (developed by Google LLC) [29], and BERT was implemented using PyTorch (developed by Meta Platforms, Inc) [30]. The detailed implementation methodology can be found in Singh et al [31].

Characterization of Individual Behaviors: Qualitative Analysis

We extracted DSM behavior persona for a subset of users (92 of a total of 205 unique community users) based on their self-reported forum signatures and assigned them behavior profiles based on their DSM strategies [32] and diagnostic features as follows: (1) medication status—whether or not the users take medications; we further classified the medication use to identify oral medicines only (metformin and glipizide) versus injectable only (Novolog and Lantus) versus using both; (2) diagnosis status—newly diagnosed of diabetes (2018 onward) or had pre-existing diabetes (earlier than 2018); and (3) lifestyle profile—whether the users incorporated lifestyle changes (low-carbohydrate or Mediterranean diet, treadmill, and walking) or they did not incorporate any such changes. An example of a self-reported behavior signature is "Diagnosed: February 2017, I went diet controlled with type 2 diabetes. Meds: metformin 500 mg twice a day," based on which this user was assigned the following behavior persona—medication user, a pre-existing user with T2D, and a user who incorporates lifestyle changes.

Characterization of Social Ties

Overview

Using the labeled peer interactions from the ADA dataset, we characterized the social networks of the 2 DHCs using content-sensitive user-context affiliation networks. These networks consisted of 2 modesT2D the first one being the community users and the second one being the different SA categories. The ties between them recorded the affiliation of each user with each SA in a given CT. The community users were assigned to a specific CT if they had at least exchanged 1 message belonging to the respective CT. For example, in obstacles CT–based social network (Multimedia Appendix 1), the first community user is affiliated with assertion SA, the second community user is affiliated with commissive SA, and the third community user is affiliated with both SAs, given that these users expressed themselves using these categories of SAs in the given CT. We constructed visual representations of various CT-based affiliation networks between community users and SAs. We used Gephi, an open-source network visualization tool, to create and analyze these networks [33].

Affiliation Exposure Model

We used 2-mode affiliation networks consisting of 2 distinct sets of nodes—the first set of nodes represents the ADA community users (total n=360 - 529, varies by CT), and the second set of nodes represents the various SA categories (k=8). We used CT-based social networks, where SAs were further categorized based on community user's communication styles. The two broad communication styles were as follows: (1) the sender of the message has an intention to "push-in" information to the receiver (using SAs—assertion, stance, declarative, directive, and statement) and (2) "interactive turn-taking," where the sender might try to engage their peers by pulling out and pushing in information in the form of question, expressive, or emotion. A community user was considered affiliated with a specific SA category only if that user had exchanged a message with that specific underlying context or SA. The affiliation exposure model (AEM) was used to understand if the affiliation to common SA categories (ie, peers who share similar contexts) within a specific CT is associated with user engagement levels in the ADA community. Affiliation exposure measures the percentage of events in the community, where users coparticipate with other users while embracing a specific behavior [34]. This allows characterization of the role of context-specific social influence patterns underlying peer-to-peer communication in digital communities and simultaneously evaluates the extent to which "membership or affiliation" in a specific SA category is associated with user engagement levels.

In this context, we used the network exposure model [34-37] that assumes that social influence occurs when community users are exposed to a specific behavior by their social network contacts. The 2-mode affiliation networks represented a user (row)-by-SA (column) matrix, where each cell entry recorded the number of times a particular SA (k) was expressed by the user (n; ie, n × k 2-mode valued matrix) in a given CT. This network was binarized using the median of the counts of SA expressed by all community users in a given theme as a threshold and used for further analysis (A_{ij})=1or 0 for i=1, … , 529, and k=1, … ,8. By multiplying this dichotomized 2-mode affiliation matrix (A_{ij}) with its transpose ($A_{ij'}$), the resulting coaffiliation matrix C (=$A_{ij}A_{ij}$) is a symmetric matrix where off-diagonal entries represent the pair of user's coexpression of SAs during peer conversations. The diagonal entries represent the number of SAs expressed by a specific ADA community user (diagonal vector of C_{ij}).

The computation of affiliation exposure uses the coaffiliation matrix (C_{ij}) and multiplies C_{ij} by each user's attribute y_j (ie, engagement level, which corresponds to the posting frequency of the ADA users). In this scenario, given that y_j represents a continuous variable, affiliation exposure measures the mean y value of all ADA users with whom the ADA user is affiliated through the expression of the same SAs weighted by the shared SAs. The diagonal values of C_{ij}; i=j were not included in this computation but are included as a control variable for later regression analysis to alleviate the potential underestimation of autocorrelation parameter estimates [34]. The formula used to compute 2-mode affiliation exposure is as follows:

$$F\_=\sum j=1Cij\ yj\sum j=1Cij \text{ for } i,j=1,\ldots,N\ i\neq j$$

where F is the affiliation exposure vector, C_{ij} is the coaffiliation matrix that represents a symmetric matrix of community users (user-by-user) with every off-diagonal cell entry recording the number of SAs shared between a pair of ADA users in their peer conversations, and y_j is a vector of user's behavioral attribute (user's posting frequency). In this work, affiliation exposure measures the percentage of SAs that ADA users

coexpress while engaging with other community users in a given CT. To account for network autocorrelation, we used the 2-mode version of the network autocorrelation model, which is defined as:

$$y=\rho Wy+X\beta+\gamma D+ \text{ for } \sim n(0,\sigma 2I)$$

where y is the vector of the user's behavioral attribute (user's posting frequency), Wy equivalent to affiliation exposure term F with W being (n×n) coexpression matrix C, $X(n\times h)$ is a matrix of values for the n community users on h independent variables with unit row vector for the intercept term, β(n × h) is a vector of regression coefficients, ρ is a scalar estimate of autocorrelation parameter, D represents the number of SAs expressed by each community user, and γ is the corresponding parameter. The covariates were the number of SAs each user expressed (diagonal vector of C_{ij}), medication status, diagnosis status, and lifestyle status (Xs). We used the lnam function from the statnet library in R (R Foundation for Statistical Computing), open-source statistical analysis software for this purpose [38].

Results

Characterization of Content and Context Exchanged in Social Ties

Qualitative Analysis

Regarding the thematic interests of the ADA community users, social support (1128/1501, 75.1%) was the most communicated theme among users. Teachable moments (357/1501, 23.8%) was the second most prevalent theme among ADA community users, using which the users described how positive behavior changes impacted their blood glucose levels. The medication-related conversations centered around insulin, Lantus, metformin, etc, were quite prevalent (pharmacotherapy: 310/1501, 20.7%). Anxiety issues or the inability to manage blood glucose numbers within the desired range were the most commonly expressed obstacles among ADA community users (obstacles: 262/1501, 17.5%). ADA community users shared patient-reported outcomes (232/1501, 15.5%), for example, the impact of β-blockers on blood glucose readings (Multimedia Appendix 2).

For BCTs, feedback and monitoring (659/1501, 43.9%) was the most frequently used among the community users, followed by social support (565/1501, 37.6%), shaping knowledge (518/1501, 34.5%), antecedents (420/1501, 28%), regulation (323/1501, 21.5%), natural consequences (294/1501, 19.6%), goals and planning (246/1501, 16.4%), and comparison of outcomes (185/1501, 12.3%). Community users provided feedback to one another regarding their self-management behaviors toward diabetes. Users also provided support to one another through emotional support or practical guidance. DHC users guide their peers through information on how behavior can be changed or how to restructure or organize physical or social environments to support positive behavior changes. Discussions on regulating positive behavior through medication options such as insulin and metformin were also present. The community users provided examples of social, emotional, and health consequences of changing their behaviors.

Assertion SA (845/1501, 56.3%) was the most prevalent SA embedded within the ADA messages, such as "consider blurry vision as a sign of high blood sugar" or "diet and exercise are the primary tools of defense against diabetes." There was also a high prevalence of statement SA (555/1501, 37%) highlighting health-related practices of community users, such as "since my diagnosis I have cut down carbs, started exercising and taking metformin with the goal of keeping A1C values close to normal." Directive SA (392/1501, 26.1%) highlighting the presence of peer guidance within the community was also prevalent, such as "follow up with your primary care physician to get the medications checked" or "check your blood glucose values at least before every meal in the beginning." Many community ADA users seeking guidance from their peers posted their queries or questions (304/1501, 20.3%) in the forums. Stance SA (260/1501, 17.3%) in the form of "I agree, meds are a source of consternation" or "I disagree with your point" was also prevalent in ADA peer interactions.

Automated Text Analysis

For the classification of CTs, the performance of BERT (ADA-trained) and BERT-base was comparable for all the categories. For progress CT, BERT (ADA-trained) had a higher F_1-score compared to BERT-base, and for obstacles CT, BERT-base had a higher F_1-score compared to BERT (ADA-trained; Table 2). RNNs and CNNs performed comparably to BERT models for determining social support and patient-reported outcomes CTs. The average performance of RNNs and CNNs was comparable, while the average performance of BERT (ADA-trained) and BERT-base was the same. BERT (ADA-trained) outperformed all other models when predicting community-specific pharmacotherapy and progress CTs within ADA peer interactions. It could be because further pretraining on the ADA corpus helped the model to understand the context of words that pertain to medication uses, such as sugar, swings, insulin, and metformin, as well as understand the context of how these community users report their behavioral progress in terms of A_{1c} values over time, etc.

Table . Category-wise F_1-scores of deep learning models for classification of communication attributes in the American Diabetes Association (ADA) dataset.

Category		RNN[a]	LSTM[b]	BiLSTM[c]	GRU[d]	CNN[e]	BERT[f]-base	BERT (ADA-trained)
Communication themes								
	Social support	0.91	0.91	0.88	0.91	0.91	0.91	0.91
	Readiness regulators	0.70	0.76	0.79	0.72	0.78	0.81	0.80
	Pharmacotherapy	0.62	0.67	0.53	0.66	0.68	0.79	0.78
	Obstacles	0.71	0.65	0.69	0.68	0.74	0.75	0.73
	Patient-reported outcomes	0.81	0.81	0.82	0.79	0.79	0.81	0.81
	Progress	0.62	0.69	0.68	0.64	0.56	0.74	0.76
	Average performance (SD)	0.73 (0.11)	0.75 (0.10)	0.73 (0.13)	0.73 (0.10)	0.74 (0.12)	0.80 (0.06)	0.80 (0.06)
Behavior change techniques								
	Feedback and monitoring	0.66	0.66	0.59	0.64	0.71	0.72	0.72
	Social support	0.59	0.61	0.55	0.65	0.63	0.71	0.71
	Shaping knowledge	0.60	0.64	0.71	0.66	0.67	0.75	0.78
	Antecedents	0.63	0.68	0.68	0.67	0.70	0.73	0.71
	Regulation	0.66	0.67	0.81	0.62	0.76	0.81	0.86
	Natural consequences	0.68	0.70	0.73	0.72	0.76	0.71	0.74
	Goals and planning	0.78	0.73	0.78	0.76	0.79	0.79	0.79
	Comparison of outcomes	0.57	0.67	0.67	0.58	0.67	0.73	0.76
	Average performance (SD)	0.65 (0.07)	0.67 (0.04)	0.69 (0.09)	0.66 (0.06)	0.71 (0.05)	0.74 (0.04)	0.76 (0.05)
Speech acts								
	Assertion	0.71	0.70	0.73	0.68	0.70	0.74	0.76
	Statement	0.49	0.53	0.54	0.47	0.60	0.69	0.71
	Directive	0.38	0.51	0.54	0.49	0.51	0.62	0.67
	Question	0.27	0.45	0.45	0.53	0.54	0.72	0.75
	Emotion	0.62	0.60	0.65	0.68	0.63	0.63	0.72
	Stance	0.53	0.60	0.64	0.56	0.58	0.67	0.71
	Declarative	0.69	0.70	0.71	0.59	0.72	0.67	0.76
	Expressive	0.67	0.68	0.63	0.62	0.68	0.71	0.75
	Average performance (SD)	0.55 (0.16)	0.60 (0.09)	0.61 (0.09)	0.58 (0.08)	0.62 (0.08)	0.68 (0.04)	0.73 (0.03)

[a]RNN: recurrent neural network.

[b]LSTM: long short-term memory.

[c]BiLSTM: bidirectional long-short-term memory.

[d]GRU: gated recurrent unit.

[e]CNN: convolutional neural network.

[f]BERT: Bidirectional Encoder Representations from Transformers.

For BCT classification, BERT (ADA-trained) was better than all other models for classifying various BCT categories, except for the antecedents and natural consequences, for which the BERT-base and CNN had higher predictive performance, respectively. However, the average performance of BERT (ADA-trained) was higher than all other models. The BERT-base model's performance was comparable to that of BERT (ADA-trained) in predicting feedback and monitoring, social support, and goals and planning BCTs. The BERT-based model's average performance was comparable to that of BERT (ADA-trained) in classifying various BCT categories.

In the case of SAs, BERT (ADA-trained) achieved the highest F_1-scores for all the categories, ranging from 0.67 to 0.76 (Table 2). The average performance of the model was much higher than that of the other models—BERT-base, CNNs, and RNNs. The F_1-score was lowest for identifying directive SA in the ADA dataset, while assertion, declarative, question, and expressive had the highest F_1-scores (0.76, 0.76, 0.75, and 0.75, respectively).

Characterization of Individual Behaviors: Qualitative Analysis

We extracted the behavior persona for 529 (~22.3%) ADA community users (from 2374 community users) who had provided their self-reported behavior signatures. The distribution of different statuses is provided in Table 3; as can be seen, most of the users interacting within the ADA forum used oral medications (237/529, 44.8%), had a long history of diabetes (428/529, 80.9%), and did not provide any information about lifestyle changes (378/529, 71.5%).

Table . User-level behavior persona extracted from the American Diabetes Association dataset.

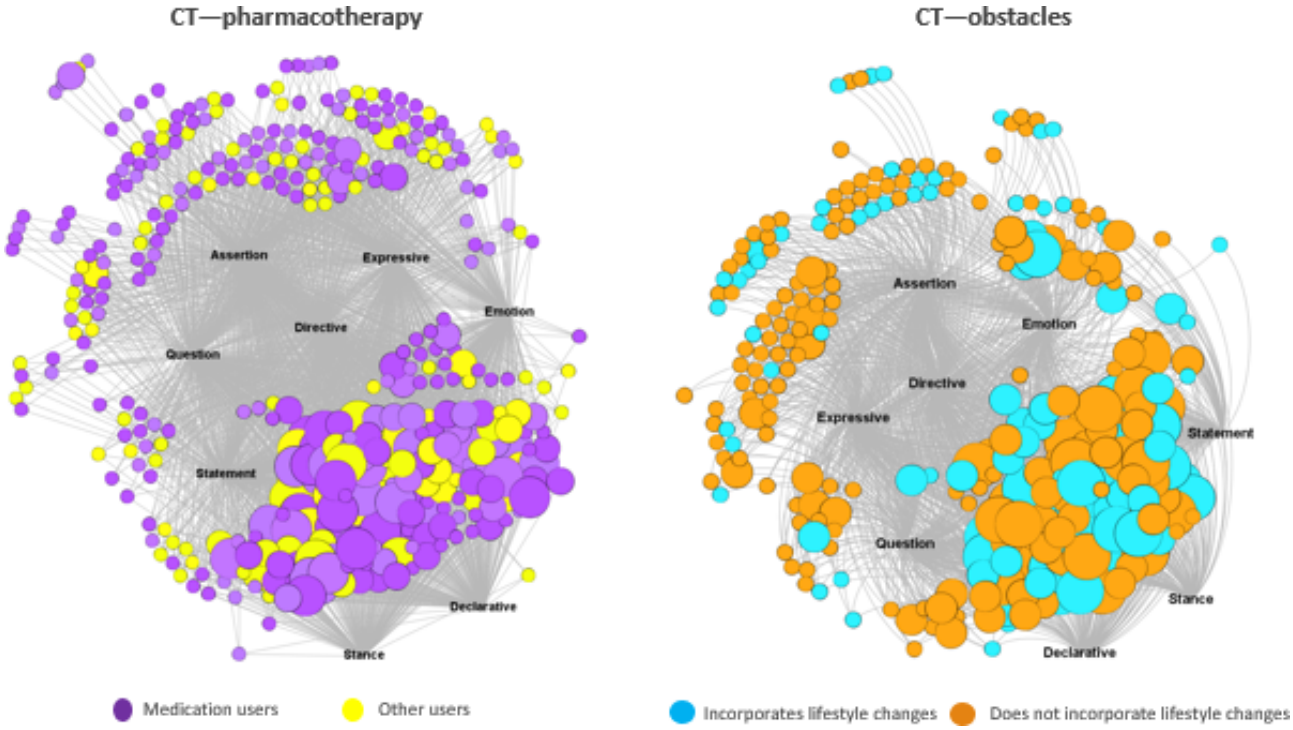
		Users (n=529), n (%)
Medication profile		
	Oral only	237 (44.8)
	Injectable only	63 (11.9)
	Both (oral+injectable)	77 (14.6)
	No medications	52 (9.8)
	No information	102 (19.3)
Diagnosis profile		
	Pre-existing diabetes	428 (80.9)
	Newly diagnosed	4 (0.8)
	No information	99 (18.7)
Lifestyle profile		
	Yes	153 (28.9)
	No	378 (71.5)

Characterization of Social Ties

Overview

For illustration purposes, Figure 2 presents the users-by-SA affiliation networks for ADA community users for the 2 CTs—pharmacotherapy and obstacles. In the pharmacotherapy CT–based network, the purple nodes represent the medication users, and the yellow nodes represent the other users. In the obstacles CT–based network, the blue color nodes represent the users who incorporate lifestyle changes, and the orange nodes represent users who did not incorporate lifestyle changes. In both networks, the size of the nodes represents the engagement of the users, where the large-sized nodes represent the power engagement users, medium-sized ones represent the sustained engagement users, and small-sized nodes represent the infrequent engagement users. The different SA categories are represented by their labels, and the affiliation ties represent the SAs the users expressed in their communication using the 2 CTs. These data represent all users' communications from 2012 to 2021, in which the ADA users expressed the 2 CTs given. As seen in the figure, stance and declarative are popular SAs among power engagement users in the pharmacotherapy CT–based network.

Figure 2. Two-mode affiliation networks for American Diabetes Association community users. CT: communication theme.



Affiliation Exposure Model

The overall ADA dataset used for AEM spanned from 2014 to 2021, consisting of 56,993 messages organized into 7232 unique topics posted by 529 community users with self-reported signatures. The distribution of messages by themes is provided in Table 4.

Table . Theme-specific affiliation exposure model dataset characteristics.

Communication themes	Messages (n=56,993), n (%)	Topics (n=7232), n (%)	Users (n=529), n (%)
Social support	56,952 (99.9)	7232 (100)	529 (100)
Readiness regulators	40,233 (70.6)	6726 (93)	505 (95.5)
Pharmacotherapy	20,722 (36.4)	4333 (59.9)	471 (89)
Obstacles	8204 (14.4)	2635 (36.4)	360 (68.1)
Patient-reported outcomes	19,230 (33.7)	3033 (41.9)	391 (73.9)
Progress	18,205 (31.9)	2869 (39.7)	378 (71.5)

The effect of affiliation exposure on user engagement was statistically significant for all CTs (ie, social support, readiness regulators, pharmacotherapy, obstacles, patient-reported outcomes, and progress; communication content). The autocorrelation parameter estimates indicated a positive association between exposure to community users through interactive communication style SAs and user engagement. Specifically, community users affiliating with interactive turn-taking communication styles, such as questions, emotions, or expressive statements, were positively linked to higher engagement levels among ADA community users. For example, when a user with a question about morning glucose levels (communication context) interacts with others sharing a similar DSM context within a readiness-regulators–specific network, they are more likely to remain engaged in the digital community. This engagement is reflected in their posting frequency. On the other hand, exposure to community users affiliating with push-in communication style SAs, such as assertions, declaratives, directives, stances, or statements (communication context), was negatively associated with user engagement in the community (Table 5).

The pre-existing users with T2D were more likely to stay engaged in the community when they expressed patient-reported outcomes and progress CTs (communication content) using interactive communication style SAs (questions, emotion, or expressive; communication context). The number of common SAs as manifested in the interactions exchanged between ADA users were significant across all CTs. It indicated that the more SAs a user expressed through peer interactions within the community, the more likely the user would remain engaged with the community for self-managing diabetes-related behaviors (Table 5).

Table . Affiliation exposure among American Diabetes Association users derived from the network autocorrelation model.

Type of CTs[a] and type of SAs[b] (communication styles)	Affiliation exposure, b (SE)	Medication status, b (SE)	Diagnosis status, b (SE)	Lifestyle status, b (SE)	SAs affiliated, b (SE)
Social support (n=529)					
Push-in CS[c]	−0.012[d] (0.004)	−0.790 (1.415)	1.682 (1.516)	−1.500 (2.068)	0.758[d] (0.002)
Interactive turn-taking CS	0.068[d] (0.006)	−0.758 (2.560)	0.885 (2.747)	1.787 (3.753)	0.929[d] (0.004)
Readiness regulators (n=505)					
Push-in CS	−0.023[d] (0.003)	−0.546 (0.812)	0.837 (0.865)	−1.222 (1.167)	0.731[d] (0.001)
Interactive turn-taking CS	0.067[d] (0.006)	−0.825 (1.884)	0.660 (2.008)	3.200 (2.707)	0.885[d] (0.004)
Pharmacotherapy (n=471)					
Push-in CS	−0.012[e] (0.004)	0.160 (0.474)	0.500 (0.504)	−1.003 (0.688)	0.690[d] (0.002)
Interactive turn-taking CS	0.074[d] (0.007)	−0.391 (1.000)	0.212 (1.064)	1.080 (1.452)	0.871[d] (0.005)
Obstacles (n=360)					
Push-in CS	−0.017[d] (0.003)	−0.209 (0.147)	0.049 (0.162)	0.102 (0.222)	0.735[d] (0.002)
Interactive turn-taking CS	0.070[d] (0.008)	−0.265 (0.441)	0.663 (0.488)	0.164 (0.668)	0.839[d] (0.006)
Patient-reported outcomes (n=391)					
Push-in CS	−0.008[e] (0.003)	−0.246 (0.312)	0.516 (0.340)	−0.313 (0.453)	0.707[d] (0.001)
Interactive turn-taking CS	0.080[d] (0.006)	−0.590 (0.754)	1.854[f] (0.823)	1.208 (1.094)	0.821[d] (0.004)
Progress (n=378)					
Push-in CS	−0.009[d] (0.003)	−0.258 (0.313)	0.512 (0.343)	−0.279 (0.456)	0.708[d] (0.002)
Interactive turn-taking CS	0.082[d] (0.006)	−0.421 (0.752)	1.944[f] (0.823)	0.822 (1.092)	0.820[d] (0.004)

[a]CT: communication theme.

[b]SA: speech act.

[c]CS: communication style.

[d]$P<.001$.

[e]$P<.01$.

[f]$P<.05$.

Discussion

Principal Findings

Overview

Studies on social diffusion research underscore social relationships' role in the adoption and spread of behaviors [39]. Ideological proximity increases the likelihood of individuals becoming friends and influences the dynamic of social interactions [40-43]. Characterizing the communication content and context embedded in these social exchanges helps capture the proximity of such ideas. Communication attributes captured via CTs, BCTs, and SAs, along with the structure of social ties in a DHC, can provide us with insights into mechanisms of how communication events lead to specific social actions. One study showed that highly engaged individuals with the diabetes digital community achieve better health outcomes, such as improved glycemic levels, than those who do not engage with such digital platforms [44].

In this paper, we described our attempts to adapt the existing advances in natural language processing techniques and social network modeling approaches to incorporate communication-level attributes (content and context) and individual-level attributes to understand the social influence mechanisms that drive user DSM behaviors from large-scale social media datasets. This study takes an empirically grounded approach to derive communication content- and context-driven network patterns of behavior change that can be translated into the design of adaptive BCIs. The 2-mode affiliation networks allowed us to visualize distinctive patterns of clustering within CT- and BCT-specific networks. The community users in these affiliation networks are interconnected by different SAs, with certain SAs being more popular than others as per user's engagement status, and it also varies by various kinds of CTs

or BCTs. Another study used affiliation networks to study the impact of affiliation on alcohol use behaviors among adolescents [45]. Young et al [46] investigated how affiliation to certain digital groups within a social network can influence sexual behaviors. Overall, the results from content-sensitive and context-aware SNA conducted in our work reveal multiple significant patterns of expression of specific content and context that can influence users' DSM behaviors.

Implications for Design of Digital DSM Interventions

The results from this study indicate that capturing various communication attributes from digital peer conversations can help us understand users' implicit needs and how providing users with their requirements can positively impact their DSM behaviors. For example, users expressing themselves with specific communication attributes (eg, interactive turn-taking SAs) can form better connections with other community users, which was shown to improve engagement in DSM behaviors [47]. Our results from AEMs show that specific patterns of content and context can exert social influence—for example, ADA community users affiliating with peers who express with interactive turn-taking communication style SAs in the form of question, expressive, or emotion tend to stay engaged in the community. In another study, the AEM was used to understand how affiliation-based peer influence affects alcohol use behaviors in adolescents [48]. Previous studies have shown how user engagement in social media can influence their health-related outcomes [49,50]. Social network interventions using the use of such networks have already been proposed by researchers in the domain of HIV prevention [51] and tackling COVID-19 misinformation spread [52]. The findings from this study suggest new directions in developing network interventions that focus on incorporating communication attributes that are personalized to individuals' latent needs. For example, an intervention in the form of an artificial intelligence Bot Moderator can recommend connections to make structural changes to the existing networks, such as connecting users with similar contexts, for example, a community user asking questions about pharmacological support can be recommended to communicate with other users who have similar questions.

Limitations

First, in the qualitative analysis, the relatively small sample size was selected for manual annotation, which may have resulted in inaccurate representations of the overall prevalence of different communication attributes. However, the sample of 1501 messages using qualitative research methods was appropriate for the research objectives. For this research, we extracted messages about topics related to T2D, and the extractions were done in 2018 and 2021. While there was a reduction in the number of messages in our dataset between 2018 and 2021, several external factors must be considered, notably the community's transition to a new technology platform and the impact of the COVID-19 pandemic. Research during the pandemic has shown that DSM behaviors were significantly impacted, with many individuals experiencing both positive (adopting healthier eating habits) and negative (decreased physical activity) changes in their management routines due to social isolation, stress, and disruptions in health care access [53,54]. It aligns with what may have occurred within our study community, as they faced the dual challenge of adapting to a new platform and managing the broader societal disruptions caused by the pandemic. Despite these challenges, the dataset remains highly relevant to understanding DSM, as peer interactions are a cornerstone of diabetes self-care. The insights from this dataset contribute to a broader understanding of how peer support can enhance patient engagement in DSM. Thus, while the reduction in message volume is a limitation, the remaining interactions continue to provide valuable insights into the adaptation and resilience of individuals managing diabetes in digital social environments. Second, we only considered some categories of BCTs and SAs for automated text analysis, given the imbalanced nature of the manually annotated dataset. In addition, while applying the finalized model to the unlabeled dataset, we used the threshold values for assigning a particular category of CTs, BCTs, or SAs to the peer messages, which reduced the total number of labeled messages, which might have resulted in missed network ties during our retrospective and SNA. Finally, the AEM analysis was based on the cross-sectional affiliation data obtained from the ADA dataset, which limits our understanding of the potential causality of SA affiliation and dynamic patterns of SA affiliation in various CT-based social networks. Despite this limitation, this work offers empirical insights into users' affiliation to SAs using certain themes or theoretical constructs. Another critical limitation of this study is the potential for bias arising from affiliation exposure, particularly selection bias, autocorrelation bias, and the challenge of distinguishing between causality and correlation [34]. Selection bias may occur if the dataset overrepresents certain affiliations, leading to results that are not fully generalizable. Our methods attempt to address this by ensuring random harvesting of digital interactions. However, our data are limited to individuals participating in these networks. Future works should attempt to include mixed methods recruitment strategies to ensure broader population-level data capture. Autocorrelation bias can inflate behavioral similarities within networks, making it appear that behaviors spread more widely due to social connections rather than inherent trends [34]. Although our AEM helps mitigate these biases by segregating peer and group influences, the difficulty in separating correlation from causality remains. While individuals within certain affiliations may exhibit similar behaviors, it is often unclear whether these behaviors are driven by the affiliation itself or by pre-existing characteristics that led individuals to join those groups. Future research should aim to diversify affiliations in the dataset and incorporate longitudinal data to address these biases better and distinguish between correlation and causality.

We extracted behavioral profiles for only a subset of the community users with self-reported behavior persona; thus, such behavior profiles may not represent the entire community user population. Moreover, this analysis does not consider sociodemographic and cultural factors, which can also result in differences in the expression of various communication attributes. Future work should focus on complementing the current efforts by biobehavioral sensing using commercial wearables (such as continuous glucose monitors), collaborating with community partners, and using data obtained from multiple

communities for each application domain as has been used by other studies [55]. Such insights will help us understand users' needs and triggers surrounding certain behavioral events (such as fluctuations in blood glucose values) so that the interventions can be customized for that specific behavioral stage of change.

Conclusions

Ubiquitous internet connectivity has led to the onset of digital health platforms where more and more individuals are engaging with their peers to manage their health-related conditions. Our study demonstrates that real-time digital interactions effectively capture the complexities of DSM-related behaviors and reveal how self-expression within specific contexts influences engagement with digital peers, ultimately affecting DSM. A theory-driven, large-scale analysis of such datasets can provide valuable insights into the underlying processes of DSM, informing the design of highly effective BCIs.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Example of affiliation ties in the American Diabetes Association community.
[PNG File, 7 KB - diabetes_v10i1e60109_app1.png]

Multimedia Appendix 2
Distribution of (A) communication themes, (B) behavior change techniques, and (C) speech acts in the American Diabetes Association community.
[PNG File, 101 KB - diabetes_v10i1e60109_app2.png]

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Abbreviations

ADA: American Diabetes Association
AEM: affiliation exposure model
BCI: behavior change intervention
BCT: behavior change technique
BERT: Bidirectional Encoder Representations from Transformers
CNN: convolutional neural network
CT: communication theme
DHC: digital health community
DSM: diabetes self-management
RNN: recurrent neural network
SA: speech act
SNA: social network analysis
T2D: type 2 diabetes

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Original Paper

School-Partnered Collaborative Care (SPACE) for Pediatric Type 1 Diabetes: Development and Usability Study of a Virtual Intervention With Multisystem Community Partners

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Abstract

Background: School-partnered interventions may improve health outcomes for children with type 1 diabetes, though there is limited evidence to support their effectiveness and sustainability. Family, school, or health system factors may interfere with intervention usability and implementation.

Objective: To identify and address potential implementation barriers during intervention development, we combined methods in user-centered design and implementation science to adapt an evidence-based psychosocial intervention, the collaborative care model, to a virtual school-partnered collaborative care (SPACE) model for type 1 diabetes between schools and diabetes medical teams.

Methods: We recruited patient, family, school, and health system partners (n=20) to cocreate SPACE through iterative, web-based design sessions using a digital whiteboard (phase 1). User-centered design methods included independent and group activities for idea generation, visual voting, and structured critique of the evolving SPACE prototype. In phase 2, the prototype was evaluated with the usability evaluation for evidence-based psychosocial interventions methods. School nurses reviewed the prototype and tasks in cognitive walkthroughs and completed the Intervention Usability Scale (IUS). Two members of the research team independently identified and prioritized (1-3 rating) discrete usability concerns. We evaluated the relationship between prioritization and the percentage of nurses reporting each usability issue with Spearman correlation. Differences in IUS scores by school nurse characteristics were assessed with ANOVA.

Results: In the design phase, the partners generated over 90 unique ideas for SPACE, prioritizing elements pertaining to intervention adaptability, team-based communication, and multidimensional outcome tracking. Following three iterations of prototype development, cognitive walkthroughs were completed with 10 school nurses (n=10, 100% female; mean age 48.5, SD 9.5 years) representing different districts and years of experience. Nurses identified 16 discrete usability issues (each reported by 10%-60% of participants). Two issues receiving the highest priority (3.0): ability to access a virtual platform (n=3, 30% of participants) and data-sharing mechanisms between nurses and providers (n=6, 60% of participants). There was a moderate correlation between priority rating and the percentage of nurses reporting each issue (ρ=0.63; *P*=.01). Average IUS ratings (77.8, SD 11.1; 100-point scale) indicated appropriate usability. There was no difference in IUS ratings by school nurse experience (*P*=.54), student caseload (*P*=.12), number of schools covered (*P*=.90), or prior experience with type 1 diabetes (*P*=.83), suggesting

that other factors may influence usability. The design team recommended strategies for SPACE implementation to overcome high-priority issues, including training users on videoconferencing applications, establishing secure forms for school data reporting, and sharing glucose data in real-time during SPACE meetings.

Conclusions: Cross-sector interventions are complex, and perceived usability is a potential barrier to implementation. Using web-based cocreation methods with community partners promoted high-quality intervention design that is aligned with end-user priorities. Quantitative and qualitative assessments indicated appropriate degree of usability to move forward with pilot-testing.

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KEYWORDS

type 1 diabetes; user-centered design; school health; collaborative care model; implementation research; pediatric; usability testing; virtual intervention; multisystem community partners; children; youth; diabetes management support; health system partners; psychosocial interventions; quantitative assessments; qualitative assessments

Introduction

Supportive parent and peer relationships can have a significant impact on diabetes-related behaviors, glycemia, and psychosocial outcomes of children and adolescents with type 1 diabetes [1-4]. For this reason, parent and peer interactions have been the target of numerous community-based interventions [5-7]. There are other natural support systems in the community for children with type 1 diabetes and their families. In particular, schools serve a critical role in the development of children. School success is linked to professional attainment and health in adulthood, making education an important social determinant of health [8]. For children with type 1 diabetes, attendance at in-person schools may benefit diabetes management practices through establishing routines for meal timing and physical activity [9,10]. Children with diabetes are also supported by numerous legal protections to ensure they have appropriate medical care in school and a safe learning environment [11].

Despite the role of schools, there are ongoing challenges with diabetes care there. School nurses have identified gaps in their diabetes training, particularly related to new diabetes technologies [12,13]. This can adversely affect both student and parent experiences with school care [14-16] and may impact health outcomes, as young children with type 1 diabetes have higher blood glucose on average during school as compared to weekends or virtual school days [17]. School nurses have also endorsed difficulty coordinating care with students' medical teams, which can lead to gaps in care [12]. Pediatric diabetes providers understand the importance of school-based diabetes care, though they have similarly reported challenges interfacing with schools due to gaps in school staff education, lack of awareness of specific policies, and poor systems for communication [18]. Interventions to address these challenges in the school setting have been limited in scope and impact [19], and different barriers may hamper joint interventions. At the school level, there may be competing priorities between health and educational initiatives, the confines of the school day, and staffing or resource limitations, driven by state-level policies and funding. Health systems similarly encounter challenges with staffing and resources, which impair the ability to communicate with and train school health staff [18]. Enhancing partnerships through collaborative health service interventions may improve diabetes care in the school setting [20].

To bridge the school-provider practice gap, the objective of this study was to develop a school-partnered collaborative care (SPACE) model for pediatric type 1 diabetes to bring together schools, health care providers, and families into a comprehensive diabetes care team using digital technologies. SPACE was modified from the collaborative care model (CCM), an evidenced-based, integrated care model for pediatric and adult mental health care with several core components [21]. A CCM classically partners multidisciplinary teams with a care manager (core component: patient-centered care team). The team regularly screens candidates for the program (core component: population-based care), develops a shared treatment plan, tracks progress with valid measures (core component: measurement-based treatments to target), and makes treatment recommendations in a stepwise approach (core component: evidence-based care). Originally used in the primary care setting, the CCM has been associated with improved outcomes in youth with depression [22] and in adults with combined depression and chronic illness, including poorly controlled diabetes [23]. The CCM has been adapted for the school setting, as schools are uniquely positioned to identify at-risk students, offer services, and treat co-occurring academic problems [24,25]. The CCM is well-suited for school-based diabetes care, as it could be used to better connect school personnel with diabetes medical teams to overcome barriers in communication and identify and address opportunities to improve diabetes management by integrating a diabetes expert into the school health team.

Translating the CCM to type 1 diabetes required modifications to both content (related to the diagnosis) and contextual factors (local school setting). To accomplish this, we relied on user-centered design (UCD), a field that is relatively new to the health sciences [26], in combination with concepts from implementation science (IS) [27]. The goals of UCD are to promote the development of interventions that are easy to learn, efficient, acceptable, sustainable, and most importantly, fit to the local context [28]. UCD draws from a multidisciplinary background in human-computer interaction, industrial design practices, cognitive psychology, and participatory research [28]. In this application, UCD involves a set of procedures to cocreate interventions with the individuals who will ultimately use them [29]. UCD can be strengthened by combining it with theories, frameworks, and models drawn from IS [27]. Merging methods from UCD and IS can enable investigators to simultaneously

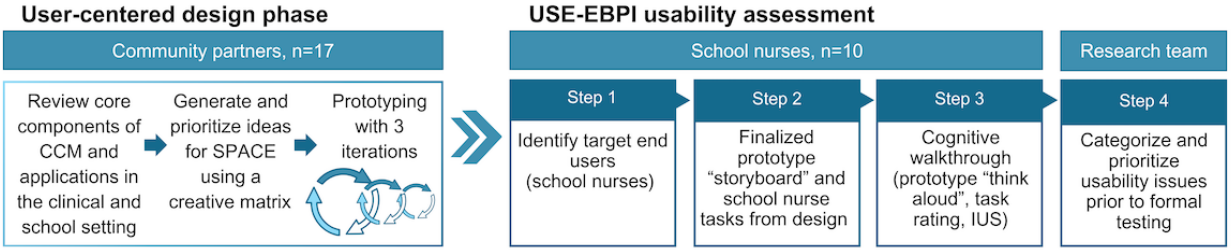
assess multilevel barriers and facilitators which may influence implementation during intervention development. Investigators may also work with design teams to select implementation strategies for future testing or incorporation into clinical practice. In this study, integrating UCD and IS strategies was innovative and essential, as the modifications required navigation of two complex ecosystems, schools, and an academic diabetes medical center. In this paper, we present SPACE design activities and assessments of usability, an indicator of design quality [30], and a determinant affecting intervention feasibility and acceptability [30,31], with target end users (school nurses).

Methods

Study Design

We used cocreation methods to design SPACE and assess preliminary usability prior to full-scale implementation [32]. The goal of the SPACE adaptation was to maintain fidelity to the core components of the CCM with the addition and removal of some elements to accommodate the differing content and contextual factors [33]. All modifications were proactive and preplanned prior to full-scale implementation. A summary of processes is depicted in Figure 1. The research team overseeing all activities was comprised of four physicians, a nurse, a psychologist, and a UCD consultant. Together, this team had expertise in type 1 diabetes clinical care, type 1 diabetes school care, school-based health services and research, UCD methods, and IS. All UCD activities were facilitated by a trained investigator in UCD (CAM) with input from other team members. No member of the research team had a diagnosis of or child with type 1 diabetes, though one physician (EM) had a role as the medical doctor for a local school district.

Figure 1. Overview of the cocreation methods and usability testing to design the SPACE intervention. In the first phase, we used user-centered design strategies to generate iterative prototypes of the intervention with multisystem community partners. In the second phase, we adopted the USE-EBPI methods to assess usability with target end users (school nurses). CCM: collaborative care model; SPACE: school-partnered collaborative care; IUS: Intervention Usability Scale; USE-EPBI: usability evaluation for evidence-based psychosocial interventions.



Design Strategies

We iteratively adapted the CCM to create SPACE with a design team of community partners with a vested interest in school-based diabetes care. Roles were identified through stakeholder mapping with an established research advisory board [34]. We recruited partners from three primary groups to represent schools, patients and families, and health systems. School partners included school nurses, educators, and administrators with current working experience with children with type 1 diabetes. Patient and family partners included individuals with type 1 diabetes for ≥6 months, parents of children with type 1 diabetes for ≥6 months, and community advocates. Health system partners included specialists who manage children with type 1 diabetes and paraprofessionals who interact with school systems (eg, nurses, diabetes care and education specialists, and social workers). Partners could identify with more than one role. All partners were required to reside or be employed in our geographic region (Pennsylvania) and participate in English. An established research advisory board served as the foundation for the design team; additional members were recruited through the research team's existing relationships with the Pennsylvania Association of Nurses and Practitioners, our diabetes center, and local branches of national diabetes advocacy organizations. To manage potential power differentials that can exist between these roles [35], we used three strategies: (1) participants completed basic training in ethical research [36], (2) design meetings began by recognizing the importance of each role's unique contributions, and (3) meetings involved a combination of individual and group activities to limit influence from any one person's ideas.

The research team held a series of three monthly 90-minute design meetings. Design meetings were web-based using a videoconferencing platform, Zoom (Zoom Video Communications), which could be accessed by phone, tablet, or computer. The research team met with each community partner either individually or in a group setting to ensure they had access to the videoconferencing platform. All partners were trained on a shared digital whiteboard (Mural Visual Collaboration) to enable active participation in meetings. Two meeting time options were offered each month to increase flexibility and maximize the involvement of all community partners. Partners were provided with meeting agendas in advance, as well as relevant materials to review if able.

Each meeting served as an iterative design cycle for a total of three cycles [37]. The activities generated an intervention prototype and potential strategies for future implementation. The research team provided three assumptions to ground group ideation: (1) the SPACE team must include the school nurse, family, and diabetes medical team at a minimum, (2) the intervention will be geared toward younger children (6 to 13 years of age) who are more likely to rely on a school nurse, and (3) all SPACE activities would be virtual to engage school districts within our broader region and fit within the diabetes medical team's workflow. Each cycle included bidirectional sharing of information between the research team and partners. In the first meeting, we reviewed the core components and

evidence for the CCM with examples from the literature of the CCM being used in clinical and school settings. Partners independently generated ideas for the adaptation based on the CCM components and roles involved using a creative matrix [38]. In the matrix, the column headings identified the participating role (eg, student, parent, school nurse, diabetes medical team, or other), and the row headings identified important features of SPACE (engagement, structure and content, outcomes, supports and policies, or other). Partners categorized ideas by where they best fit, acknowledging some ideas may bridge between multiple roles or concepts. Following a brief discussion of each idea, partners used a visual voting system to identify first and secondary priorities for the CCM, generating a semiquantitative indicator for each idea. The research team assigned two points for each first-priority vote and one point for each second-priority vote. The total points for each idea were summed.

In the subsequent two cycles, the research team presented increasingly detailed versions of the prototype, with the end goal being a narrative storyboard representing the SPACE intervention. At each stage, the facilitator asked partners to reflect on SPACE to identify strengths, limitations, opportunities for refinement, and areas in need of further clarity. In the final session, partners also discussed the individual tasks school nurses would be responsible for in SPACE to identify which tasks should be targeted for user testing.

Usability Assessment

We adopted the usability evaluation for evidenced-based psychosocial interventions (USE-EBPI) to evaluate usability, which allows for the discovery and organization of potential barriers and planning for strategies to overcome them [39]. Usability was assessed both quantitatively and qualitatively through cognitive walkthroughs with school nurses (n=10). The USE-EBPI methods outline four steps, including identifying users for testing, defining EBPI tasks, conducting the evaluation, and organizing and prioritizing usability issues. First, we identified that school nurses were appropriate end users for testing (step 1), with the sample size determination based on usability modeling [40,41]. School nurses were recruited through the email listserv of the Pennsylvania Association of School Nurses and Practitioners, which is the state branch of the National Association of School Nurses. School nurses in Western Pennsylvania, where this intervention will be formally pilot-tested, were preferentially recruited. School nurses who participated in the original SPACE design were excluded to allow for a more objective assessment. The prototype and associated tasks for testing were identified through the design process with community partners (step 2). Cognitive walkthroughs were conducted using a videoconferencing platform (step 3). Each session lasted approximately 45 minutes and was attended by two members (CAM and EN) of the research team for facilitation and detailed note-taking. All sessions were audio-recorded to allow for review to ensure all ideas were captured.

Each cognitive walkthrough had two components. First, school nurses were led sequentially through each step of SPACE using the storyboard prototype and asked to think aloud about the intervention. Subsequently, we presented the school nurses with nine case scenarios describing intervention tasks. For each case scenario, school nurses were asked to provide a rating for how likely they would be able to do the task and a justification. Ratings used a 5-point Likert-type response scale with 1 indicating no or very small chance of success and 5 indicating a very good chance of success. Detailed notes were taken throughout the cognitive walkthrough. Subsequently, school nurses completed the Intervention Usability Scale (IUS), a 10-item, validated survey that is used as a benchmark in intervention redesign [42]. The IUS has strong psychometric properties including a two-factor solution (“usable” and “learnable”) and a Cronbach α of 0.83 in a sample of medical professionals [42]. A benchmark IUS score of >70 (range 0-100) corresponds to an acceptable level of usability [43].

Data Management and Analysis

Qualitative notes from the cognitive walkthroughs were typed, deidentified, and reviewed weekly by two members of the research team (EN and CAM). Usability issues captured from the notes related to both the intervention generally and its specific components, as elicited by the scenarios. The reviewers tallied the number of participants who identified the same issue, adding new usability issues as needed as cognitive walkthroughs continued. Once completed, the reviewers organized the usability issues by type using 13 categories in the UCD literature (step 4) [30]. Two investigators assigned a priority score (1=not important, 2=somewhat important, and 3=very important) for additional adaptations needed to generate a workable intervention. Priority scores were based on the perceived likely impact on future end users, the likelihood that this would be experienced by users, and how critical it is for the success of SPACE [39]. Independent scores were then averaged and sorted from highest to lowest priority. We examined the correlation between the priority rating and the percentage of school nurse participants identifying the issue using Spearman’s correlation. The usability issues and priority rankings were shared with the design team to determine any additional refinements to SPACE.

Quantitative data included case scenario ratings and IUS scores. Ratings for each case scenario and the IUS scores were averaged across participants and presented as a mean and SD. We explored differences in IUS scores using one-way ANOVA among groups with differing characteristics perceived to influence school nurse workload and skill level, including school nursing experience (<10 years vs ≥10 years), caseload (<750, 750-1000, or 1001-1500 students), number of schools covered (1, 2, and more than 2), and students with type 1 diabetes in the past 5 years (<5, 5-10, or >10 students) [44]. A *P* value of <.05 was considered significant. All statistical analyses were completed using StataSE (version 17; StataCorp).

Ethical Considerations

All design and research activities were deemed exempt by the University of Pittsburgh Institutional Review Board (PRO 23110009). As the study was exempt, we were not required to document written informed consent. All research participants were presented with a consent script describing the purpose of the study, study activities, compensation, risks, and benefits. Verbal consent was obtained. All study data were deidentified

and linked to private identifiable information using a unique code. Community partners were compensated US $25 per hour (US $37.50 per 90-minute meeting), for a total of US $150. Compensation was provided for partners who could not attend a meeting if they reviewed materials and provided feedback via phone or email. School nurses participating in usability tests were compensated US $30.

Results

Overview

We recruited 20 community partners for the design team. Three community partners were unable to attend the meetings due to changes in their family circumstances. The remaining 17 community partners reflected all intended roles (Table 1). The school nurses were employed in rural, urban, and suburban school districts of different sizes. A total of 3 (18%) partners had a personal diagnosis of type 1 diabetes, giving them the additional role as a patient. Monthly attendance ranged from 15 (88%) to 17 (100%) participants. Personal communications were used to follow up with any partner who could not attend a scheduled meeting.

Table 1. SPACE[a] design team community partner roles (n=17).

Type of partner	Value[b], n (%)
School	8 (47)
School nurse	4 (24)
Administrator or educator	4 (24)
Patient or family	8 (47)
Individual with diabetes	3 (18)
Parents	4 (24)
Community advocate	1 (6)
Health system	6 (35)
Diabetes specialists	2 (12)
Diabetes care and education specialist	1 (6)
Social workers	2 (12)
School nurse navigator	1 (6)

[a]SPACE: school-partnered collaborative care.

[b]Numbers add to more than 17 as partners could identify with more than one role.

Intervention Design

At the initial design meeting, participants generated 141 ideas for the SPACE redesign, of which 94 were unique. Partners assigned a numeric prioritization to ideas, which were then condensed to create a list of unique ideas (Multimedia Appendix 1). Higher prioritized design ideas by SPACE category and role from the creative matrix are summarized in Table 2. Many focused on flexibility in scheduling, data sharing and communication during and between meetings, multidimensional outcome tracking, and the team approach with other vested stakeholders. Other ideas included having students lead the SPACE discussions if developmentally appropriate (9 points) and having the school nurse identify barriers to the student's diabetes management in school (8 points).

The research team used these ideas to generate an initial concept, functioning as a low-fidelity prototype, summarizing the SPACE intervention (Multimedia Appendix 2). The concept poster summarized the team members and roles, the structure of and topics addressed during SPACE meetings, and potential outcomes to track for the students. Partners provided a critique using individual text responses on the shared whiteboard, followed by group discussion, aligned with four categories in a feedback capture grid (strengths, limitations, opportunities, and questions; Textbox 1). Identified strengths focused on the ability for "everyone to share ideas at the same time" to streamline communication, give the school nurse personalized diabetes advice, and offer the family a team outside of the hospital. Partners also appreciated the flexibility of meeting scheduling and the emphasis on identifying specific goals that are measurable to help the student "feel good and motivated to move forward." Constructive feedback identified potential challenges at the student, school nurse, and parent levels. For students, these may include the impact of meeting attendance on class time and the willingness to share if the team has too many members. For nurses and parents, these included finding a common time for both meetings and communication between meetings. Additional parent challenges included the financial burden of any recommended referrals and the reliance on disclosure to offer resources. To overcome these, the partners suggested maximizing flexibility in scheduling, offering resources to all parents regardless of disclosure, and determining team size based on student comfort level. Partners also suggested the SPACE intervention consider strategies to incentivize less engaged students and reach out to other school staff with educational activities about diabetes. Questions included how

meetings would be conducted (eg, the virtual platform), follow-up documentation for team members, what to do if the parent or nurse does not come to the meeting, and what if any communication between visits should be required.

Table 2. Representative design ideas from the creative matrix exercise for the SPACE[a] adaptation with associated point totals indicating prioritization[b].

	Student	Parent	School nurse	Medical team
Engagement	• Offer the student incentives (n=8) • Establish criteria for student considered high risk and in need of more support (n=2)	• Flexible scheduling (n=8) • Review different parent motivations to participate (n=2)	• Include a school administrator (n=4) • Identify daytime coverage or availability (n=1)	• Screen for social determinants of health (n=2) • Identify patients at medical appointments (n=2)
Structure and content	• Choose one thing to work on at a time (n=4) • Address consistent topics (n=2)	• Parent and school nurse communication plan (n=7)	• Check in with student between meetings (n=8) • School nurse contributes data (n=2)	• Identify education needs of the parent, student, and nurse (n=8) • Adjust written care plans (n=3) • Referrals to other services (2)
Outcomes	• Time in the classroom (n=11) • Confidence in skills (n=8)	• Communication with school nurse (n=2)	• Assessment of self-management skills (n=7) • Attendance (n=4)	• Glycemia (n=14)
Supports and policies	• Cooperation from peers (n=4)	• Family support and collaboration (n=8) • Person-friendly language (n=1)	• Cooperation from teachers (4) • Support from school administration (n=2)	• Diabetes Medical Management Plan (n=6)

[a]SPACE: school-partnered collaborative care.

[b]Higher numbers indicate greater prioritization from the study team.

Textbox 1. Summary of partner critique to the school-partnered collaborative care (SPACE) concept or low-fidelity prototype.

Strengths

- Multidisciplinary approach between school, family, and health care system
- Flexibility in scheduling for school and parent
- Focus on tangible outcomes for the student

Limitations

- Student concerns: missed class time, comfort with discussing diabetes in the group setting
- Parents: scheduling, reliance on disclosure to identify supportive resources, financial burden of referrals
- School nurses: scheduling, bandwidth to communicate with parents between meetings

Opportunities

- Strategies to incentivize students who are less engaged or experiencing burnout
- Parallel education programs for school staff

Questions

- Technical aspects (eg, What platform will be used to share information?)
- Follow-up documentation (eg, Who provides the follow-up calls or evaluation?)
- Meeting no-shows (eg, If key members cannot be at meetings, how will the info be communicated?)

We then generated a more detailed prototype of SPACE using a storyboard, narrating the intervention from the initial recruitment of a student through the first SPACE meeting. Partners were given an opportunity to review the prototype independently. During the meeting, partners were split into small groups to go through the prototype together. In addition to minor changes in word choice, this second review generated six areas in need of clarity: a reference to obtaining parental

permission, the inclusion of teacher support when applicable, clarifying expectations for parental involvement, giving multiple examples for student diabetes goals, modifying language from barriers to factors which may positively or negatively influence diabetes goal attainment, and promoting changes to a 504 or other written accommodations plan. The final storyboard is included in Multimedia Appendix 3.

Partners identified nine scenarios or tasks for school nurse user testing, including securing protected time to participate, identifying candidate students, approaching families about participation, naming potential diabetes-related issues in school and factors contributing to these, selecting and recruiting additional team members, addressing mental health concerns, and listing activities that they can do with the student to work on diabetes habits between meetings. Recommended strategies to foster implementation in schools included leaning on existing programs (eg, the student assistance team in Pennsylvania) and offering incentives to the school district (designation or certification as a "SPACE" school) or school nurse (continuing education credits for participation).

Usability Testing

We recruited ten school nurses, each from a different school district in Western Pennsylvania, reflecting diverse experiences with diabetes care and school health (Table 3). School nurses identified many positive aspects of the SPACE model and 16 unique usability concerns. School nurses liked that the intervention offered a streamlined process to communicate with parents and health care providers and often found the time commitment to be realistic and manageable. Each usability issue was identified by between 10% and 60% of testers. The issues aligned with eight categories from Munson et al [30] related to intervention complexity, available time, workflow, existing infrastructure and resources, perceived value, trust between families and school nurses, and reliance on technology. Priority scores ranged from 1.0=lowest priority to 3.0=highest priority. Figure 2 visually displays the relationship between priority ratings and the frequency each issue is reported. There was a moderate correlation (ρ=0.63; *P*=.01) between priority rating and the percentage of school nurses reporting the issue. Two usability issues had the highest priority (3.0), including accessing the virtual platform and establishing a secure mechanism for data sharing between the school and health care provider (Table 4). Other higher-priority issues included coordinating meetings, nurse availability or health office coverage, and parent engagement. One issue, teacher or other staff engagement, was frequently reported but was deprioritized by the research team as it was less critical to the success of SPACE.

Table 3. Characteristics of school nurse participants (n=10) for usability tests.

Characteristic	Value
Female gender identity, n (%)	10 (100)
Age (years), mean (SD)	48.5 (9.5)
Highest nursing degree, n (%)	
Bachelor's degree	5 (50)
Master's degree or above	5 (50)
School nursing experience (years), n (%)	
<10 years	3 (30)
≥ 10 years	7 (70)
Number of schools covered, n (%)	
1	4 (40)
2	3 (30)
More than 2	3 (30)
Geographic setting, n (%)	
Rural	2 (20)
Suburban	7 (70)
Urban	1 (10)
Grades covered[a], n (%)	
Elementary school	7 (70)
Middle school	6 (60)
High school	8 (80)
Student caseload, n (%)	
<750 students	3 (30)
750-1000 students	2 (20)
1001-1500 students	5 (50)
Students with diabetes in the past 5 years, n (%)	
<5 students	4 (40)
5-10 students	4 (40)
>10 students	2 (20)

[a]School nurses could select more than one choice, so numbers total to greater than 100%.

Figure 2. Relationship between the percentage of school nurses reporting each usability issue (bar chart) and priority ratings from the research team (line).

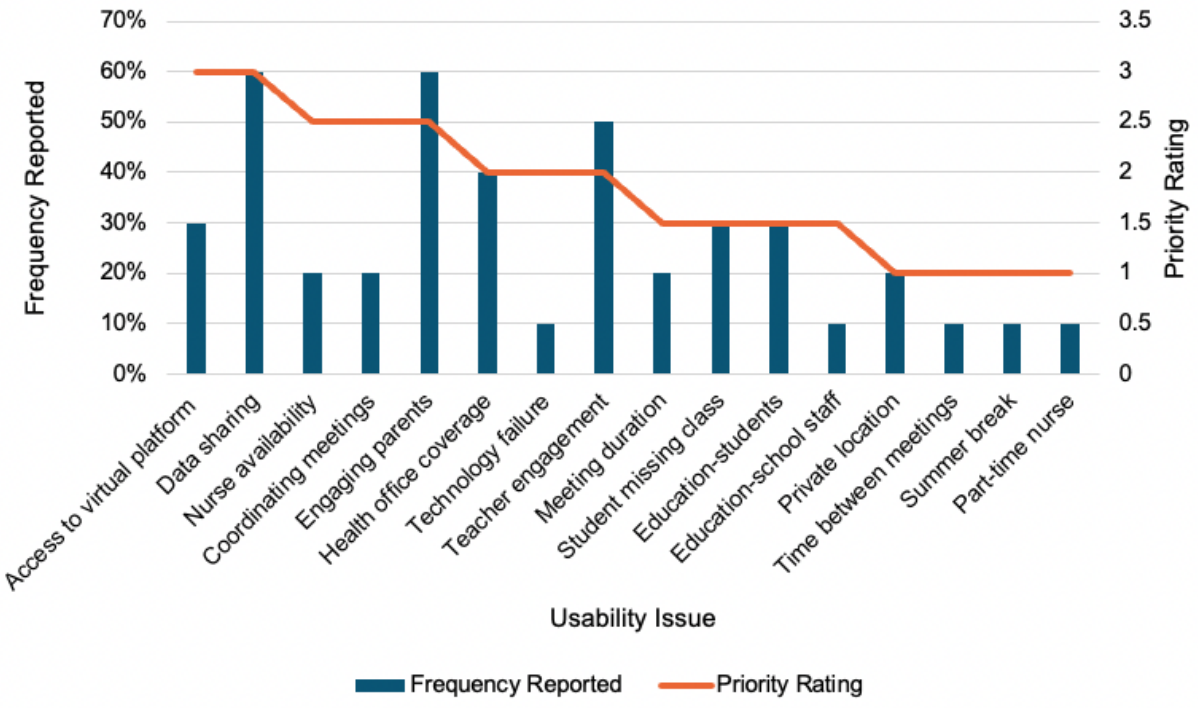


Table 4. Summary of case scenario ratings and justifications.

Scenario	Scenario topic	Rating, mean (SD)	Example comments
1	Accommodate SPACE[a] visits in nurse schedule	4.35 (0.67)	"I can block out time since this would be for a student, so the staff will cover me. The secretary might help with triage and will let teachers know I am busy. The only interruption would be in acute emergencies ... I've done this for students before." [Nurse 1]
2	Identify students for SPACE	4.90 (0.32)	"We know our students and can identify who's in need." [Nurse 6]
3	Discuss SPACE with parents	4.55 (0.76)	"It's still so new; I need to learn and experience it more to feel comfortable enough to explain it to parents and five all its benefits and value to engage them." [Nurse 7]
4	Name diabetes-related goals for SPACE	4.65 (0.47)	"The school nurse is able to look at the medical aspect of blood glucoses, how they're doing, treating, interacting with others, doing at school ... we can look at these areas and set a goal." [Nurse 3]
5	Identify other school staff to participate	4.45 (0.69)	"I can look up their schedules and see who teaches the child, who they spend the most time with. I can also check in with the counselors; sometimes they may have a good rapport with the child and their presence would help." [Nurse 2]
6	Approach other school staff to participate	4.50 (0.58)	"We're doing it already with 504 plans." [Nurse 9]
7	Discuss mental health concerns	4.60 (0.52)	"I'd do it. Mental health is essential." [Nurse 10]
8	Identify barriers affecting goal attainment	4.58 (0.55)	"I'd put on a detective hat and go look!" [Nurse 5]
9	Develop strategies to coach student	4.38 (0.72)	"That's what I do! This is where I can help educate families about how we do this." [Nurse 4]

[a]SPACE: school-partnered collaborative care.

School nurses generally indicated a high likelihood of success in the nine case scenarios, with mean Likert scale scores ranging from 4.35 to 4.90 (Table 4). The scenario with the lowest score, scenario 1, related to accommodating the SPACE visits during the school day. Acknowledging the challenge of blocking time for meetings, school nurses identified different workarounds to make time for these meetings, which they commonly use for other types of meetings (eg, for 504 plans). Some suggested having the meeting immediately before or after school, arranging coverage with an administrative assistant or other staff, or

spacing out visits for different students so they are not on the same day.

IUS scores ranged from 65.0 to 92.5, with an average score of 77.8 (SD 11.1), meeting our predetermined benchmark for acceptable usability [43]. In exploratory analyses, there was no relationship between IUS score and any school nurse characteristics, including years of school nursing experience, student caseload, number of schools covered, or number of students with diabetes in the past five years (Table 5).

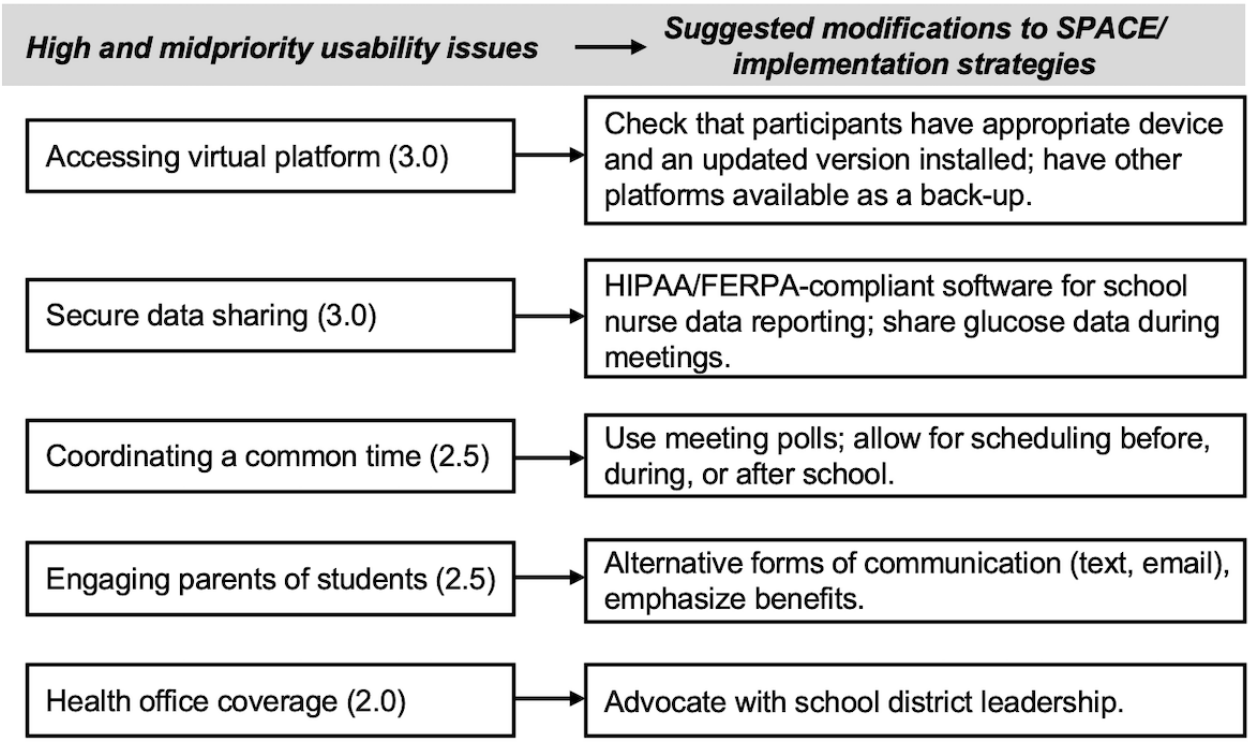
Table 5. IUS[a] scores by school nurse characteristics.

Characteristic	IUS score, mean (SD)	*P* value
School nursing experience		.54
<10 years (n=3)	74.2 (15.9)	
≥10 years (n=7)	79.3 (9.5)	
Caseload		.12
<750 students (n=3)	83.3 (15.9)	
750-1000 students (n=2)	86.3 (1.8)	
1001-1500 students (n=5)	71.0 (5.8)	
Number of schools		.90
1 (n=4)	79.4 (12.0)	
2 (n=3)	75.0 (11.5)	
More than 2 (n=3)	78.3 (13.8)	
Students with diabetes in the past 5 years		.83
<5 students (n=4)	76.3 (9.2)	
5-10 students (n=4)	80.6 (14.0)	
>10 students (n=2)	75.0 (14.1)	

[a]IUS: Intervention Usability Scale.

The usability issues were reviewed by the design team prior to implementation of the SPACE pilot, including high-priority issues (accessing the virtual platform, sharing data) and midpriority issues (coordinating a common time, ensuring health office coverage, and engaging parents). Several suggestions were made by the design team and subsequently implemented in the pilot, including both modifications to the intervention and strategies to implement it. A summary of specific strategies by usability issue is included in Figure 3.

Figure 3. Design team recommendations for SPACE implementation based on high- and midpriority usability issues. FERPA: Family Educational Rights and Privacy Act; HIPAA: Health Insurance Portability and Accountability Act; SPACE: school-partnered collaborative care.



Discussion

Principal Findings

School management of diabetes is highly important to the overall care of children with type 1 diabetes, yet school-based or school-partnered interventions remain understudied and underused. Interventions bridging the school and health systems are inherently complex, which may complicate their long-term use [45]. Our proposed modifications exhibited similar complexity, with multiple interacting components that may require organizational or workforce accommodations for implementation [46]. Our process was intended to overcome potential barriers using best practices in UCD [37]. The combination of UCD methods and usability testing with target end users enabled key stakeholders to guide all aspects of intervention design, promoting fitness for the school setting and establishing credibility and trust [27]. Furthermore, our web-based approach, including a shared whiteboard, enabled us to iteratively develop SPACE in a relatively short time with a diverse group of people who often have severe constraints on their time (eg, hospital and school staff). Finally, reviewing the potential usability issues during the design phase helped to refine the prototype in preparation for implementation.

The SPACE model is a fully developed intervention prototype that will bring together the school nurse, parent, and health care provider into a multidisciplinary care team to support students with type 1 diabetes in a structured way. SPACE is based on the CCM for psychosocial interventions, and core components were maintained to the fullest extent possible in the redesign. Patient-centered care was achieved with individualized teams composed of family, diabetes, and school supports. SPACE will allow for multiple referral reasons and sources, in line with population-based care. Measurement-based treatments focused on the evaluation of glycemia, quality of life, self-management skills, and time spent out of class for diabetes management. Finally, evidence-based care was translated to diabetes self-management and education practices.

SPACE is also distinctly unique from the original CCM in the extent to which it accommodates the differing environment (clinic vs school) and diagnosis (depression vs type 1 diabetes). Integrating a CCM into school poses new opportunities to reach a broader network of youth who may be underserved by the health care system. At the same time, there are inherent challenges to medical interventions in school. School health interventions need to consider the educational mission and pertinent outcomes, what medical services may or may not already be in place, and the different needs and wants of students and their parents [24]. Lyon et al [25] proposed key modifications to fit a CCM for the school setting for mental health care, including basing a care manager in school, allowing for flexible entry and treatments for a variety of mental health diagnoses, defining success both academically and medically, and incorporating school-wide supports. We carried these ideas forward to our school adaptation for type 1 diabetes.

Additional modifications to the intervention related to the more "physical" diagnosis of type 1 diabetes, rather than mental health care, though the framework for a school-based CCM nicely aligns with diabetes management. School nurses have frequent contact with these students for day-to-day and emergent care and can easily identify students who may benefit from this additional team support to help them achieve individualized goals [12]. Case management for youth with chronic disease is

already considered one of the responsibilities of school nursing [47]. In some contrast to the original CCM, we planned for family engagement in SPACE. Parents may be highly involved in diabetes management both at home and at school, particularly for young children. We also allowed for flexible goal identification within SPACE, not solely focused on glycemia. Diabetes treatment is multifaceted, encompassing medication, nutrition, activity, and psychosocial aspects. This lends itself to measuring a variety of school and health-related outcomes to evaluate effectiveness. Our partners felt strongly that diabetes outcomes should include indicators of glycemia, self-management, quality of life, and academics.

The strengths of the SPACE model, identified by the design team and usability tests, focused on the core function of the multidisciplinary team. Having a common space for the student, school nurse, parent, and health care provider to meet was viewed as streamlining communication, giving personalized training to the school nurse, and building trust among all parties. The entirely technology-based SPACE intervention also heightened the perceived usability among school nurses and our design team. With increasing comfort with digital platforms generally, this condition was seen as more feasible for working parents and less intrusive to the school day. The design team had several unexpected suggestions. Some felt strongly the SPACE team should regularly include other school supports, including administrators, who may be less involved in day-to-day care. Others highlighted the role of school nurses to screen for social determinants of health that may influence diabetes management and offer universal resources to families to promote health equity. In usability testing, the SPACE model resonated with school nurses, who frequently described the activities as being within the scope of their role as a medical professional.

Despite the perceived advantages of the SPACE model, our usability testing did identify potential issues to be addressed prior to pilot-testing. The highest priority issues were feasible to address, including preparing school nurses and families to access the virtual platform and organizing secure tools for school nurses to share data with the research team. Other less pressing feedback related to intervention complexity includes coordinating a common time, engaging parents, and ensuring health office coverage. Solutions for these usability issues may need to be customized for different schools to carry out the core components of SPACE. Such an approach is acceptable and often necessary to promote the adoption and sustainability of complex interventions that are appropriately fit to the local context [46]. Though this may result in a tailoring of implementation strategies, adjusting features such as the virtual platform and processes for data collection will not alter the core functions of the intervention.

The iterative design cycles conducted over Zoom contributed to an efficient process, with all activities concluding within 6 months. We used several strategies to promote equitable cocreation practices and foster mutual trust and empathy among the community partners despite the web-based setting [48,49]. We demonstrated equity by including representation from different roles in the school and health system, as well as parents and individuals with type 1 diabetes, and compensating partners for their time and contributions. We addressed potential power imbalances by offering individual and group activities, including asking all parties to vote on ideas to limit the influence of any dominant voices. Applying a web-based format with two meeting options per month lowered barriers to participation like finding childcare, transportation costs, and time needed to participate. We emphasized reciprocity by summarizing and sharing back their comments and how these changed the prototype over time. We hoped to create a personalized and transformative experience by equipping them to participate in research in the future with research ethics training. Among the partners, many agreed to continue serving on a community advisory board, one school nurse volunteered her district to pilot-test SPACE, and a diabetes health care provider agreed to serve as an ongoing study consultant. Finally, we facilitated relationships by learning each other's stories and personal motivations for joining this team.

Limitations

The SPACE intervention was designed with community partners in a specific geographic area affiliated with our health system. Though this was intentional to ensure fit to our context, this may limit the generalizability of SPACE to other settings where there may be differences in school systems (eg, school health policy, ability to delegate insulin and glucagon, and school health staffing) or health systems (eg, size and resources of the diabetes center). We sought perspectives from nurses in different school districts to get broad representation from our region, though this is still reflective of Pennsylvania, specifically, and state laws may vary. Pennsylvania is one of 35 states with school nursing requirements, and like most states, the delegation of insulin and glucagon to trained lay staff is permitted. Depending on laws in other states, translation of SPACE may require an initial evaluation of the local policy, perceived barriers, and necessary modifications prior to implementation.

A second limitation relates to the composition of our design team. Though we included young adults with type 1 diabetes, we did not rigorously incorporate perspectives of youth with diabetes. Our parent participants did informally discuss the intervention with their children between design meetings, which they shared with us. The SPACE intervention will be piloted with elementary and middle school–aged children (12 years of age or younger), and children in this age group may not have been able to participate in our activities as designed. Older teens were not included as developmentally, their priorities for diabetes management in school will differ from those of younger children who are more reliant on their parents and school nurses.

Finally, the identification of usability issues is inherently a subjective process. It is possible that additional usability issues will arise in future testing. However, a strength of this study was the inclusion of school nurses and other roles from different school districts in our state.

Comparison With Prior Work

SPACE represents a shift from other school-based diabetes interventions by integrating school nurses into the diabetes medical team with parental support and establishing continuity in that relationship. Prior interventions have focused on school

nurses alone, including delivering educational tools and curricula, case management, or engaging school nurses to deliver some diabetes tasks (downloading devices and giving long-acting insulin) [50-53]. Other interventions offer visits from diabetes providers in the school setting, such as self-management education and telemedicine [54,55]. Generally, these interventions have improved school nurse's knowledge of diabetes, and some have demonstrated a small improvement in hemoglobin A_{1c} [53,55]. To date, there is limited data on the sustainability or impact of prior interventions, and none are endorsed by leading diabetes organizations as best practices. In contrast, school-based asthma interventions are better studied. Asthma interventions that emphasize care coordination and parent engagement have demonstrated a reduction in hospital admissions and improvements in asthma-related quality of life [56]. A core pillar of the Centers for Disease Control and Prevention–sponsored asthma-friendly schools program is the coordination of school, family, and community efforts to better manage symptoms and reduce absenteeism. The use of UCD methods for co-design, paired with the USE-EBPI, will hopefully enhance the potential reach and impact of SPACE in future testing.

Conclusions

We present the iterative cocreation of SPACE, a multidisciplinary, goal-directed, school-partnered diabetes intervention based on the evidenced-based CCM for depression management. Relying on UCD methodology, we involved diverse community partners at all phases of the intervention design with the consolidation of ideas on a final prototype that is ready for formal testing. Our use of videoconferencing and shared digital whiteboards enabled diverse participation in a relatively short time interval. The USE-EBPI methods for usability testing helped to evaluate the quality of our design process, establishing a bridge between UCD and IS research. The quantitative indicators suggested a high degree of usability among school nurses of different backgrounds, which was reflected in their comments about how they would operationalize SPACE in their school district. Though cross-sector interventions are by their nature complex, this staged approach to intervention adaptation and preliminary testing may help to overcome barriers and establish a strong foundation for future implementation.

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Data Availability

The datasets generated or analyzed during this study are available from the corresponding author upon reasonable request.

Authors' Contributions

CAM was responsible for the conceptualization of the study, methodology, software, formal analysis, investigation, writing (original draft), and funding acquisition. EN was responsible for methodology, investigation, and writing (review and editing). IL, EM, and ARL were responsible for conceptualization, supervision, and writing (reviewing and editing). LS was responsible for supervision and writing (reviewing and editing). CNP was responsible for methodology and writing (reviewing and editing).

Conflicts of Interest

None declared.

Multimedia Appendix 1
Images representing Mural design activities in session/cycle 1. The first image displays a sample creative matrix with design ideas; the second image adds the priority ranking, represented by the red and blue dots to indicate first and second priority, respectively.
[PNG File , 346 KB - diabetes_v10i1e64096_app1.png]

Multimedia Appendix 2
Low-fidelity prototype (concept poster) of the SPACE intervention for critique in session/cycle 2. SPACE: school-partnered collaborative care.
[PDF File (Adobe PDF File), 9693 KB - diabetes_v10i1e64096_app2.pdf]

Multimedia Appendix 3
Narrative storyboard of the "SPACE for type 1 diabetes" prototype used for cognitive walkthroughs to assess usability with school nurses. SPACE: school-partnered collaborative care.
[PDF File (Adobe PDF File), 5077 KB - diabetes_v10i1e64096_app3.pdf]

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Abbreviations

CCM: collaborative care model
IS: implementation science
IUS: intervention usability scale
SPACE: school-partnered collaborative care
UCD: user-centered design

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Corrigenda and Addenda

Correction: Glycemic Control, Renal Progression, and Use of Telemedicine Phone Consultations Among Japanese Patients With Type 2 Diabetes Mellitus During the COVID-19 Pandemic: Retrospective Cohort Study

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In "Glycemic Control, Renal Progression, and Use of Telemedicine Phone Consultations Among Japanese Patients With Type 2 Diabetes Mellitus During the COVID-19 Pandemic: Retrospective Cohort Study" (JMIR Diabetes 2023;8:e42607) the authors made one addition.

The equal contribution footnote (marked by *) was added for the authors Akiko Sankoda and Yugo Nagae. The final authorship list appears as follows:

Akiko Sankoda[1], Yugo Nagae[1*], Kayo Waki[1,2,3], Wei Thing Sze[2], Koji Oba[4], Makiko Mieno[5], Masaomi Nangaku[6], Toshimasa Yamauchi[3], Kazuhiko Ohe[1,2]*

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The correction will appear in the online version of the paper on the JMIR Publications website on March 6, 2025, together with the publication of this correction notice. Because this was made after submission to PubMed, PubMed Central, and other full-text repositories, the corrected article has also been resubmitted to those repositories.

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Corrigenda and Addenda

Correction: Enhancing Health Equity and Patient Engagement in Diabetes Care: Technology-Aided Continuous Glucose Monitoring Pilot Implementation Project

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In Enhancing Health Equity and Patient Engagement in Diabetes Care: Technology-Aided Continuous Glucose Monitoring Pilot Implementation Project" ([JMIR Diabetes 2025;10:e68324]) the authors noted two errors.

In the Ethical Considerations section, the sentence:

> *Patients who were not able to afford the CGM sensor were provided with Libre Pro CGM sensors, which were donated to the CUHCC by the Abbott Fund.*

Has been revised to:

> *Patients who were not able to afford the CGM sensor were provided with Libre Pro CGM sensors, which were donated to the CUHCC by Abbott.*

In the Acknowledgement section, the sentence:

> *The authors express their gratitude to Abbott Fund for donating the Libre Pro sensors for participants, as well as the Abbott Fund's ongoing support of digital health programs at the Community-University Health Care Center (CUHCC).*

Has been revised to

> *The authors express their gratitude to Abbott for donating the Libre Pro sensors for participants, as well as the Abbott Fund's ongoing support of digital health programs at the Community-University Health Care Center (CUHCC).*

The correction will appear in the online version of the paper on the JMIR Publications website on March 20, 2025, together with the publication of this correction notice. Because this was made after submission to PubMed, PubMed Central, and other full-text repositories, the corrected article has also been resubmitted to those repositories.

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