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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

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

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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].

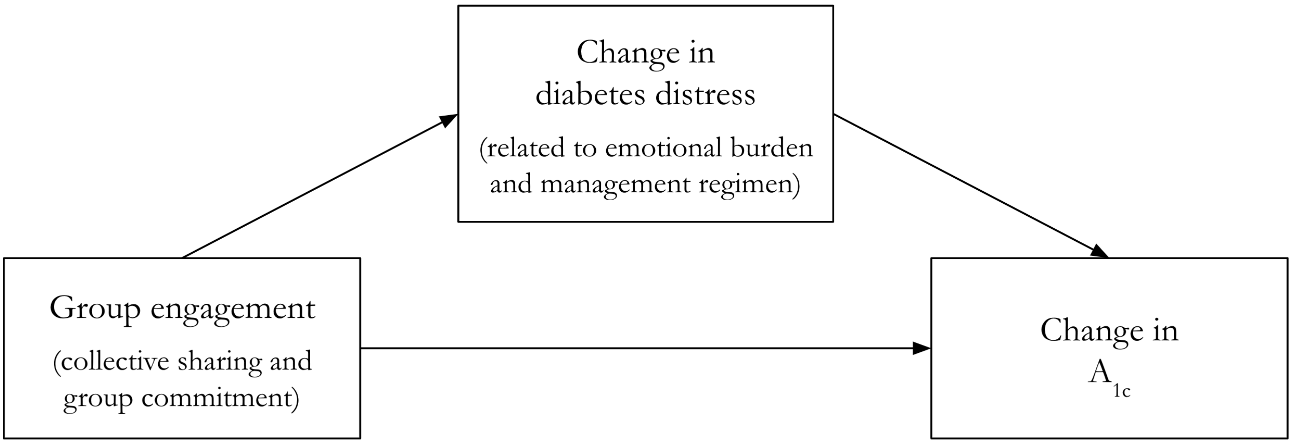
The overwhelming stress of diabetes self-management can produce an emotional response characterized as diabetes distress (DD). A distinct psychological consequence of living with T2DM, DD is more common than comorbid depression and anxiety, with prevalence estimates ranging from 36% to 45% [9-11]. It 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.

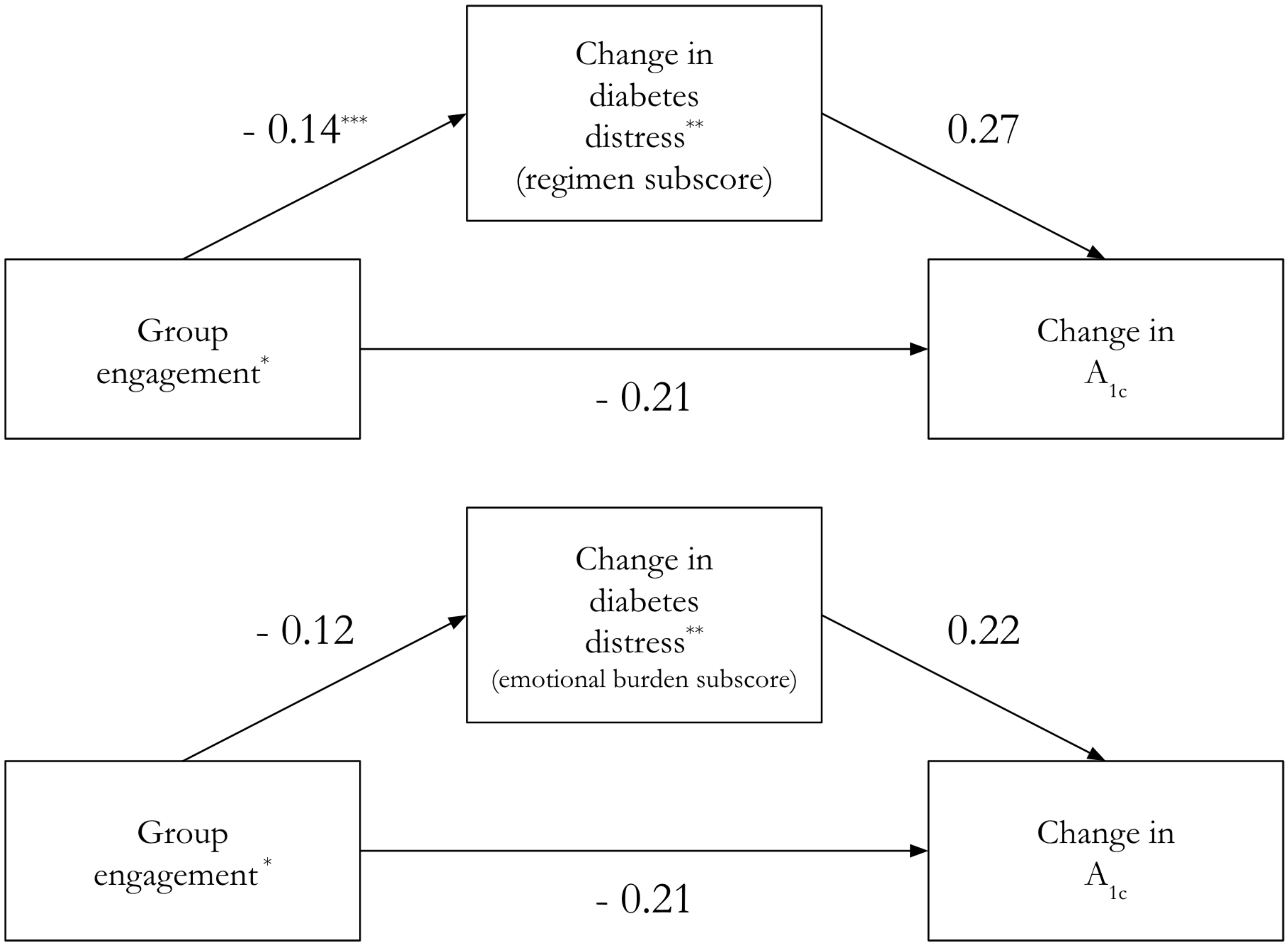
[b] Ordinary least square regression, controlling for study arm and with cohort fixed effects, described in left-hand column.

[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).

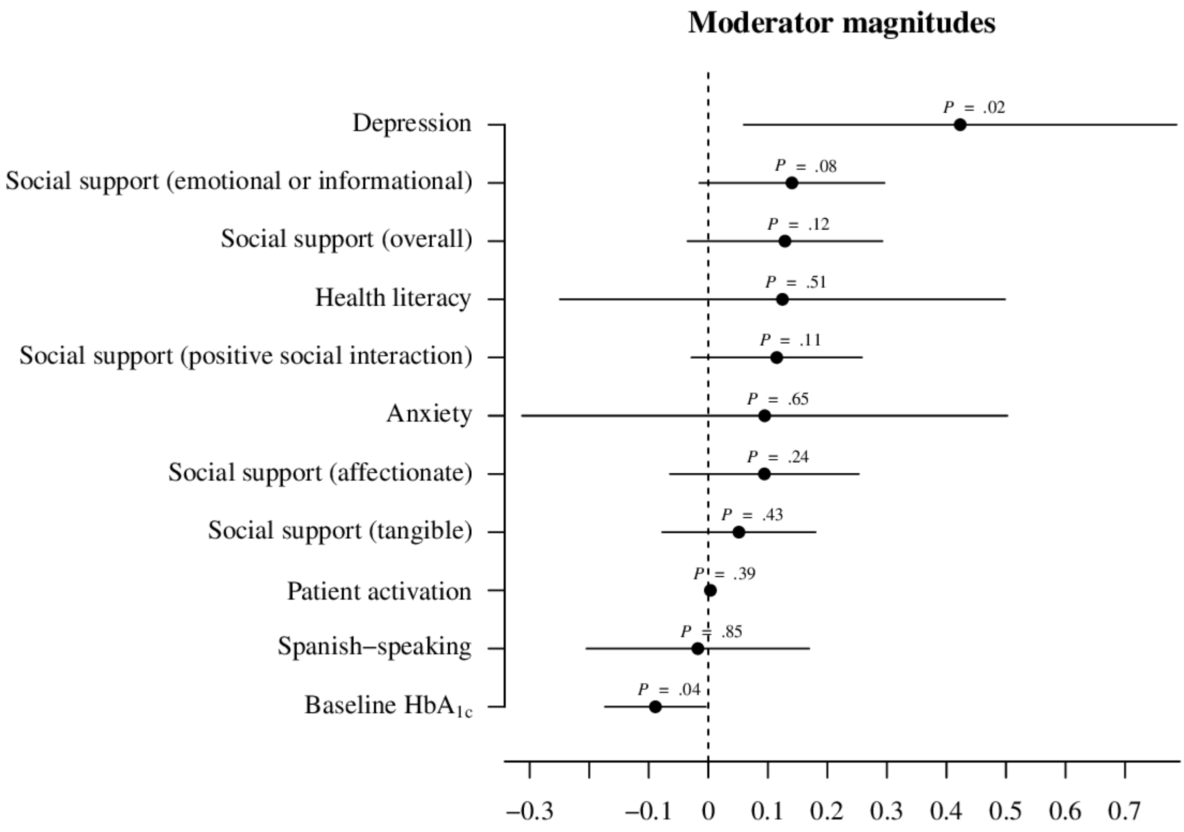
An average causally mediated effect of group engagement on 6-month change in HbA_{1c} was detected that runs through the regimen (*P*=.04) of DD. An average causally mediated effect of group engagement on 6-month change in HbA_{1c} may also run through the emotional burden of DD (*P*=.094).

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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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

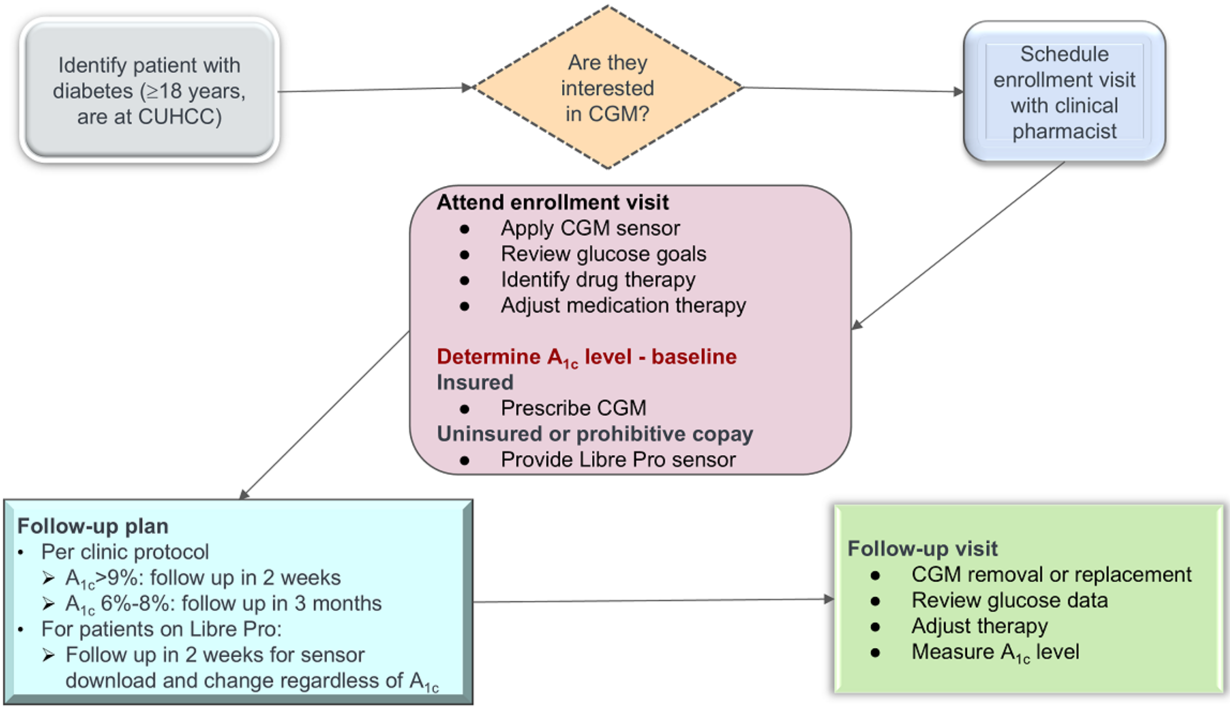
Study Eligibility Criteria and Approach

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 the Abbott Fund.

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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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

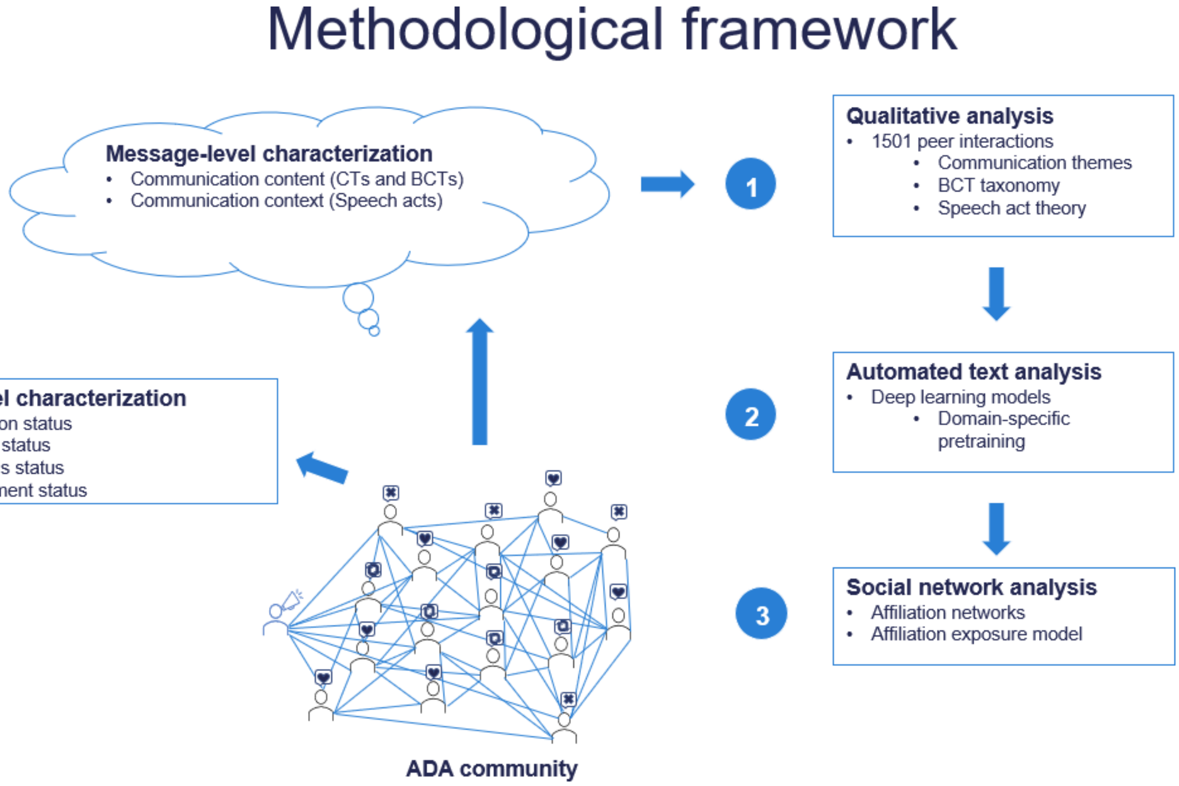
The American Diabetes Association (ADA) support community is a digital support group for individuals with diabetes (type 1, type 2, or prediabetes) to engage with their peers as well as caregivers [21]. The users of the community interact with one another on a wide variety of topics ranging from medication 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 $\times 10^{-5}$. 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 ($n\times n$) 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, $\beta(n \times h)$ 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.

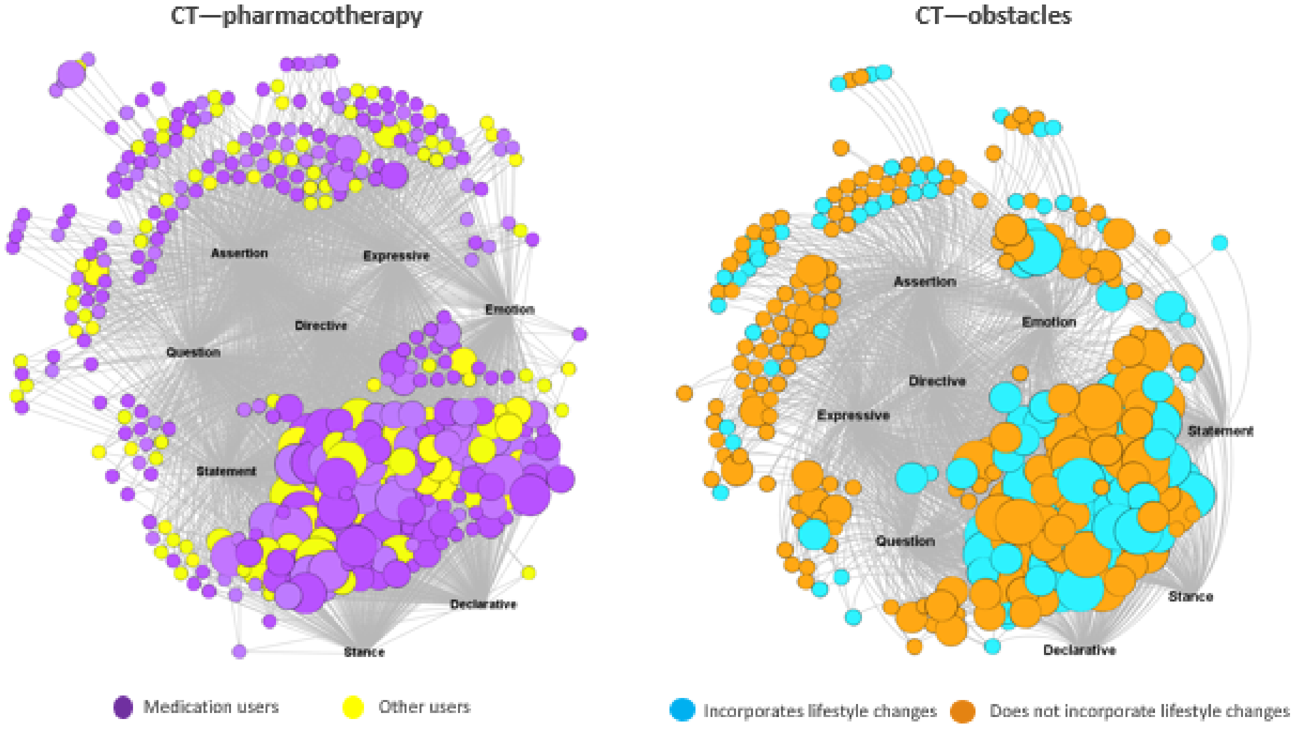
		Users (n=529), n (%)
Medication profile		
	Oral only	237 (44.8)
	Injectable only	63 (11.9)
	Both (oral+injectable)	77 (14.6)
	No medications	52 (9.8)
	No information	102 (19.3)
Diagnosis profile		
	Pre-existing diabetes	428 (80.9)
	Newly diagnosed	4 (0.8)
	No information	99 (18.7)
Lifestyle profile	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