

Developing eHealth Interventions to Improve Diabetes Management in Emerging Adulthood: A Qualitative Formative Study

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Table of Contents

Original Manuscript.....	5
---------------------------------	----------

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Abstract

Background: Emerging adulthood is a high-risk period during which many with type 1 diabetes (T1D) demonstrate suboptimal diabetes management and glycemic control. There is a need for effective and scalable interventions designed specifically for this population. Technology-based approaches are readily accessed by this age group. Further, interventions that are consistent with self-determination theory (SDT) – which posits the fulfillment of psychological needs for autonomy, self-efficacy, and relatedness promote intrinsic motivation for change – may resonate well with emerging adults' (EAs) developmental needs for establishing independence, autonomy, and growing their social network.

Objective: To gather patient feedback on three SDT-informed mHealth interventions for EAs with T1D: a Motivational Interviewing-based counseling intervention, one-way text message reminders to complete diabetes care, and a question prompt tool to empower EAs to actively participate during medical visits.

Methods: In this qualitative formative study, 20 EAs reviewed and provided feedback on the newly developed interventions via individual interviews. Interviews were analyzed using Framework Matrix Analysis, an efficient approach to inductive thematic analysis.

Results: EAs provided high ratings for intervention acceptability and helpfulness. EAs appreciated the technology-based approach and the tailoring to their demographic characteristics, illness experiences, and personal preferences. They also highlighted SDT-related intervention elements that aligned with SDT. Recommendations for intervention improvement included additional tailoring to personal preferences including the frequency and duration of intervention, intervention content, and personalizing reminders with the recipient's name.

Conclusions: EA feedback supports the acceptability and utility of this intervention and will be used to refine the interventions. The unique contribution of each intervention to improvements in glycemic control will be tested in a randomized controlled trial using the multiphase optimization strategy (MOST) to build the most efficacious multicomponent intervention. Clinical Trial: N/A

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Original Manuscript

Original Paper

Developing eHealth Interventions to Improve Diabetes Management in Emerging Adulthood: A Qualitative Formative Study

Abstract

Background: Emerging adulthood is a high-risk period during which many with type 1 diabetes (T1D) demonstrate suboptimal diabetes management and glycemic control. There is a need for effective and scalable interventions designed specifically for this population. Technology-based approaches are readily accessed by this age group. Further, interventions that are consistent with self-determination theory (SDT) – which posits the fulfillment of psychological needs for autonomy, self-efficacy, and relatedness promote intrinsic motivation for change – may resonate well with emerging adults' (EAs) developmental needs for establishing independence, autonomy, and growing their social network.

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Trial Registration: N/A

Keywords: emerging adults, young adults, type 1 diabetes, behavioral intervention, eHealth

Introduction

Type 1 diabetes (T1D) management is complex, demanding, and primarily under the control of the individual. [1] Diabetes management often deteriorates during adolescence, affecting every component of diabetes care. [2-5] Once thought to be temporary, evidence suggests suboptimal diabetes management and glycemic control can persist into emerging adulthood. [6, 7] Emerging adulthood spans adolescence and young adulthood (roughly age 18-25 years) and is characterized by growing independence, identity consolidation, and multiple life transitions. [8] Some have described emerging adulthood as the “most volatile years of life.” [8]

EAs self-report suboptimal diabetes management, [5] demonstrate infrequent blood glucose monitoring (<1 test per day [9]), and suboptimal continuous glucose monitor (CGM) wear rates. [10] EAs have the worst glycemic health indicators of any age group, [11] with HbA1c levels averaging

from 8.4-9.3% [5, 9] (levels <7% are recommended [12]); 83% fail to meet glycemic recommendations. [9] More concerning, by age 21, 32% of EAs have at least one diabetes-related complication or comorbidity. [13] Suboptimal diabetes management in EAs is related to decreased parental involvement in daily activities and increased reliance on peer and other support, [8] transitioning from pediatric to adult clinical care, and infrequent clinic attendance. [14]

While the challenges of managing T1D during emerging adulthood are well described, [15-18] few efficacious interventions specifically designed for EAs with T1D have been developed. To date, the majority of EA T1D intervention research has examined the use of advanced diabetes management technology (e.g., CGM [19-21] and closed loop insulin delivery [22, 23] or on optimizing the transition from the pediatric to the adult health care systems. [24-26] Other approaches are rare, with mixed results. In a pilot clinical trial of REAL-T (Resilient Empowered Active Living with T1D), an occupational therapy intervention targeting diabetes management and its social ecology, the intervention improved glycemic control (HbA1c), diabetes-related quality of life (DQOL), and blood glucose monitoring habits among EAs with T1D and T2D (type 2 diabetes). However, blood glucose monitoring and medication adherence behaviors were unchanged, as were mediators of behavior change (diabetes knowledge, problem-solving, and self-efficacy). [27] Subsequently, a fully powered clinical trial of REAL-T for EAs with T1D, delivered via telehealth, showed improved DQOL and diabetes distress, but no change in glycemic outcomes, diabetes self-management, self-efficacy, or autonomy. [28] The CoYoTi (Colorado Young Adults with T1D) intervention combined telehealth clinical diabetes care with virtual peer support groups to improve diabetes outcomes (HbA1c, diabetes-related distress, depression, and self-efficacy). [29] In a randomized controlled trial, per protocol analyses showed that participants in the active condition demonstrated significant improvement in glycemic control and CGM use, but depression symptoms increased and diabetes distress and self-efficacy were unchanged. Intent-to-treat analyses were not published and intervention participation rates were low, as 53% did not attend a single session. FAMS-T1D (Family/Friend Activation to Motivate Self-Care), a mHealth intervention to improve EAs' self- and social-regulation, was tested in a pilot clinical trial (single group, pre-test/post-test design) and shown to be well-received (79% of those approached agreed to participate and 93% were retained). Post-intervention, EAs demonstrated improved diabetes management, self-efficacy, and diabetes distress, but changes in glycemic control were not statistically or clinically significant. [30] Other interventions for EAs demonstrate a similar pattern of either low engagement or limited improvement in glycemic outcomes. [31-34]

Capitalizing on EAs' unique developmental stage, in which feelings of autonomy and self-efficacy are paramount, may be key to intervention efficacy. Self-Determination Theory (SDT [35]) is an empirically-derived theory of human motivation that posits three innate psychological needs: competence, relatedness, and autonomy. According to SDT, fulfilling these needs enhances intrinsic motivation and facilitates behavior change. To illustrate, autonomy-supportive communication by diabetes providers has been associated with better diabetes management in adolescents [36] and adults. [37] Because of their salient developmental need for independence, autonomy-focused interventions grounded in SDT may be particularly effective with EAs.

Unfortunately, there are few examples of autonomy supportive interventions to improve diabetes outcomes in EAs with T1D. Guided Self-Determination (GSD) is an autonomy-oriented approach to shared decision-making involving the completion of 8 reflection worksheets over 8-12 months which are discussed in 1-hour sessions with diabetes clinicians. While GSD increased adolescents' perceptions of autonomy and decreased amotivation for diabetes self-management, it did not improve glycemic control. [38] Further, 20% refused to participate and 30% of those allocated to GSD did not complete the intervention. GSD for adults was reduced to 7 worksheets/sessions and

clinical trial results indicated GSD improved diabetes distress, diabetes competence, amotivation, and perceptions of provider autonomy supportive communication, but only improved glycemic control for women in the trial. [39] Additionally, 25% of participants ($M_{\text{age}} = 25.7$ years) either discontinued or failed to initiate treatment and required additional sessions ($M_d = 8$, $R = 5-14$) to complete treatment. An online version of GSD for EAs, improved autonomous motivation and perceptions of provider support for autonomy, but did not impact glycemic control. [31] Online GSD was insufficient to improve engagement as 65% of EAs failed to initiate treatment, only 28% of initiators completed treatment and 66% were lost to follow-up at 6 months. Autonomy supportive T1D camp (a 6-day experience intentionally designed to leverage SDT during diabetes education, meal planning assistance, camper-led parent training, glucose management, as well as typical camp activities) increased adolescents' (13-18 years) sense of relatedness, but autonomy and competence remained unchanged; glycemic control was not examined. [40] Neither study examined the effect of autonomy supportive interventions on diabetes self-management behavior.

The present study was conducted in preparation for a larger clinical trial testing an autonomy supportive intervention to improve diabetes self-management among older adolescents and EAs (16-25 years old) with type 1 diabetes (T1D) and an elevated hemoglobin A1c ($HbA1c \geq 9.0\%$) [41] Here, we report on qualitative and quantitative feedback regarding three SDT-informed eHealth intervention components to promote diabetes management and glycemic control. First, the Motivation Enhancement System (MES), is a counseling intervention grounded in Motivational Interviewing [42-45] to enhance EAs' autonomy and self-efficacy for diabetes self-management. Second, TXT is one-way text message reminders to complete diabetes care, a strategy to increase self-efficacy for diabetes self-management [46-50] and generate feelings of social support, [51] which can occur even when patients know the text messages are automated. [48] Third, the question prompt list (QPL) is a tool to empower patients to assume a more active role during medical visits by asking questions and stating concerns. [52, 53] Active participation during medical visits increases patients' feelings of control and competency, which, in turn, empowers them to more consistently complete their medical care outside of medical visits.

Methods

Design

EAs with T1D participated in a single study visit during which they completed a brief demographic survey and reviewed either the MES intervention or the TXT and QPL interventions. They were then interviewed to obtain feedback on intervention content and delivery format.

Participants

EAs were recruited from a university-affiliated tertiary care diabetes clinic located in a large metropolitan city in the midwestern United States. Study inclusion criteria were 16-25 years of age (inclusive) with a diagnosis of T1D for at least 6 months and a hemoglobin A1c ($HbA1c$) greater than or equal to 9.0% currently and over the prior six months, English language fluency, and residence within 30 miles of the recruitment location. Exclusion criteria were determined via medical chart review and were limited to medical diagnoses requiring atypical diabetes care or mental health conditions and developmental learning disabilities that resulted in the inability to independently participate in the research study.

Table 1 summarizes the characteristics of the EAs participating in this study. On average, EAs were 18.8 years old ($SD = 1.7$), 50% (10) were female, and 80% (16) identified as Black, non-Hispanic. EAs had completed an average of 12.0 years of education ($SD = 1.8$), reported their socioeconomic status as 5.9 out of 10 ($SD = 1.6$) on the McArthur Scale of Subjective Socioeconomic Status, [54]

and most (65%, n=13) were not employed. EAs had been diagnosed with T1D for 11.1 years (SD = 4.8), 65% (n=13) used a glucometer to monitor their blood glucose levels, and 75% (n=15) administered their insulin via injection.

Table 1. Demographic and disease characteristics of study participants (n = 20).

	n or M	% or SD
Age, in years	18.8	1.7
Gender		
Female	10	50%
Male	10	50%
Race/ethnicity		
Black, non-Hispanic	16	80%
White, Hispanic	2	10%
Bi-racial, Hispanic	2	10%
Education, years	12.0	1.8
Subjective Socioeconomic Status*	5.9	1.6
Employment status		
Employed part-time	5	25%
Employed full-time	2	10%
Not employed	13	65%
Duration of diabetes, in years	11.1	4.8
Blood glucose monitoring method		
Meter	13	65%
Continuous glucose monitor	7	35%
Insulin delivery method		
Injected insulin	15	75%
Insulin infusion pump	5	25%

*The MacArthur Scale of Subjective Social Status uses a 10-point scale where 0 = lowest social status and 10 = highest social status

Procedures

Standardized procedures were used to minimize barriers to study participation and increase the integrity of the data collected. First, potentially eligible EAs were identified via medical chart review. The initial data pull identified 701 potentially eligible EAs. Of these, 511 (73%) did not meet one or more study inclusion criteria. Research staff mailed a study introduction letter to 190 study eligible EAs; letters were addressed to EAs ≥ 18 years old or the caregivers of EAs < 18 years old. After an opt out period of two weeks, research staff followed up these letters with telephone calls to explain the details of the study, confirm study eligibility, and enroll interested, eligible EAs. EAs were enrolled on a rolling basis until the target sample size of 10 EAs to review the MES intervention was achieved. This process was repeated for the review of the TXT and QPL interventions. A total of 20 EAs were enrolled and 4 declined to participate.

Study visits were completed using two strategies designed to overcome common barriers to participation (e.g., lack of transportation). Initially, research staff conducted all study visits in EAs' homes. Study visits began with informed consent, or parental consent and informed assent for EAs

<18 years. EAs then used a study tablet to complete a brief demographic questionnaire via Qualtrics XM [55] and to review one or more of the intervention components. Research staff then engaged EAs in a semi-structured qualitative interview to gather their impressions of the intervention components and recommendations to make the interventions more consistent with the language and experiences of EAs. In March 2020, all study visits were transitioned from the home setting to online video conference calls due to the onset of the COVID-19 pandemic. The same procedures were followed, with minor modification for the virtual context. Specifically, the consent/assent forms were emailed to study participants in advance of the study visit and study staff displayed them using the screen sharing feature. EAs completed the demographic questionnaire via a link sent via the video conference software chat feature or verbally responded to the questions displayed via the screen sharing feature. Similarly, research staff sent links to the online intervention components for EAs to review the intervention content or research staff walked EAs through the intervention component using the screen sharing feature.

Interventions

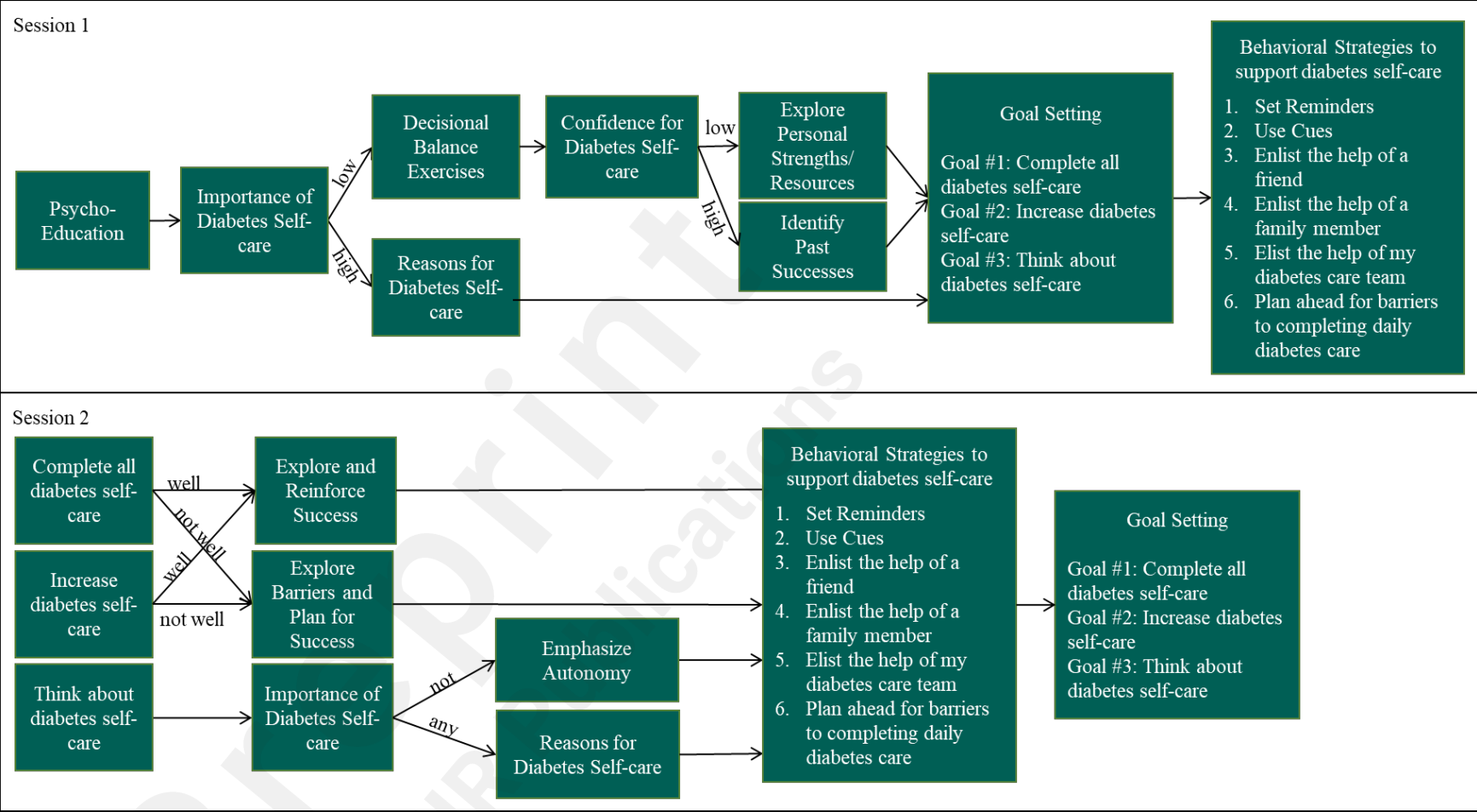
All three interventions were developed and delivered using the Computerized Intervention Authorizing Software, version 3.0 (CIAS 3.0 [56]), a no-code Software-as-a-Service platform allowing development of interactive mobile web apps and text messaging interventions without coding. The MES and QPL interventions were delivered via a link to a CIAS 3.0 intervention session, which will be texted to participants in the clinical trial. Both interventions leveraged CIAS 3.0's interactive and emotive narrator. Consistent with Human-Computer Interaction research, [57] this narrator functions as an engaging guide throughout the intervention by reading text displayed on the screen and displaying emotional responses, such as surprise, sadness, or thoughtfulness, as appropriate. TXT is deployed by CIAS 3.0 as text messages. All three interventions were reviewed by a pediatric endocrinologist for clinical relevance prior to feasibility testing.

The Motivation Enhancement System (MES) is a brief (<15 minute), two session, mHealth, counseling intervention grounded in Motivational Interviewing (MI [42-45]) and the Information-Motivation-Behavioral Skills (IMB) model of health behavior change. [58, 59] The IMB model posits that behavior change results from the joint function of three critical components: accurate information about risk behaviors (e.g., risks of suboptimal diabetes self-management) or their replacement behaviors (e.g., benefits of effective diabetes self-management), motivation to change behavior, and behavioral skills necessary to perform the behavior (e.g., self-efficacy). MI is an evidence-based strategy to optimize behavior change through use of client-centered and goal-oriented directive communication to enhance intrinsic motivation and self-efficacy. The MES intervention was originally developed to reduce drug use among urban, post-partum women. [60, 61] Our research group has successfully adapted MES to improve self-management for persons living with a variety of chronic illnesses including EAs with HIV who are newly prescribed antiretroviral medication, [62, 63] EAs with uncontrolled moderate to severe persistent asthma, [64, 65] and preadolescents with T1D. [66-68] In the present study, Session 1 began with psychoeducation about the target behavior (i.e., three key components of diabetes management referred to as 'The 3Ms': glucose monitoring, insulin administration (medicine), and dietary management (meals)) delivered via video clips from an endocrinologist and supported with a peer testimonial. Participants then advanced through motivation-enhancing exercises designed to increase feelings of motivation and self-efficacy for changing the targeted illness behavior (i.e., diabetes management). Session 1 ended with goal setting with three options: (1) completing the targeted illness behavior as recommended (i.e., doing all diabetes care every day), (2) increasing the targeted illness behavior (i.e., do more diabetes care every day), and (3) thinking more about changing one's behavior, an autonomy-supportive option for those not yet ready to change their behavior. Session 2 began by eliciting progress toward the diabetes care goal established in Session 1 and then continued to grow

motivation using motivation-enhancing exercises.

In this study, we adapted the T1D MES for EAs by refining the content to make it more consistent with the needs and experiences of EAs from our urban community. We edited the language used in the intervention to more strongly emphasize EAs' autonomy for diabetes self-management, updated the peer testimonial video to be delivered by EAs (there was a male and female version) from diverse backgrounds, and revised the content of interactive components to be developmentally consistent with EA experiences, including the reasons to engage in self-management activities, potential past successes, and personal strengths/weaknesses. We also added a new intervention content area, behavioral strategies (e.g., setting reminders, establishing cues, and enlisting social support) to support goal attainment. These strategies were introduced in Session 1 with an option to select one or more strategies to try. In Session 2, participants were asked which strategies they used and asked whether the strategies were helpful for completing diabetes care. Participants were then given the option to revisit the behavioral strategies information and re-select strategies to use. Figure 1 illustrates MES for EAs with T1D.

Figure 1: *Motivation Enhancing System (MES)*



The second intervention component was Text Message Reminders (TXT), one-way tailored text messages to remind EAs to complete their diabetes care. Text message reminders were grounded in social cognitive theory which states the individual, the behavior, and the environment reciprocally interact and influence one another. [69] Applied to diabetes self-management, text message reminders promote self-management by providing an external prompt (environment) to the individual to complete the task. This process increases the likelihood of task completion which leads to perceptions of control over the health behavior (autonomy), fosters feelings of competence (self-efficacy) and supports goal attainment. [70] The TXT intervention tested in this study was adapted from a similar intervention to increase medication adherence for EAs with uncontrolled moderate-to-severe persistent asthma. [65] The asthma intervention consisted of 30 days of once daily medication reminders via one-way text message. In the current study, we updated the content of the messages to reflect the key components of the T1D regimen (insulin administration, blood glucose testing, and carbohydrate counting). EAs could choose to receive reminders for one of these components or a general reminder to complete all their diabetes care. EAs were also able to tailor the timing of reminder delivery. Figure 2 illustrates TXT for EAs with T1D.

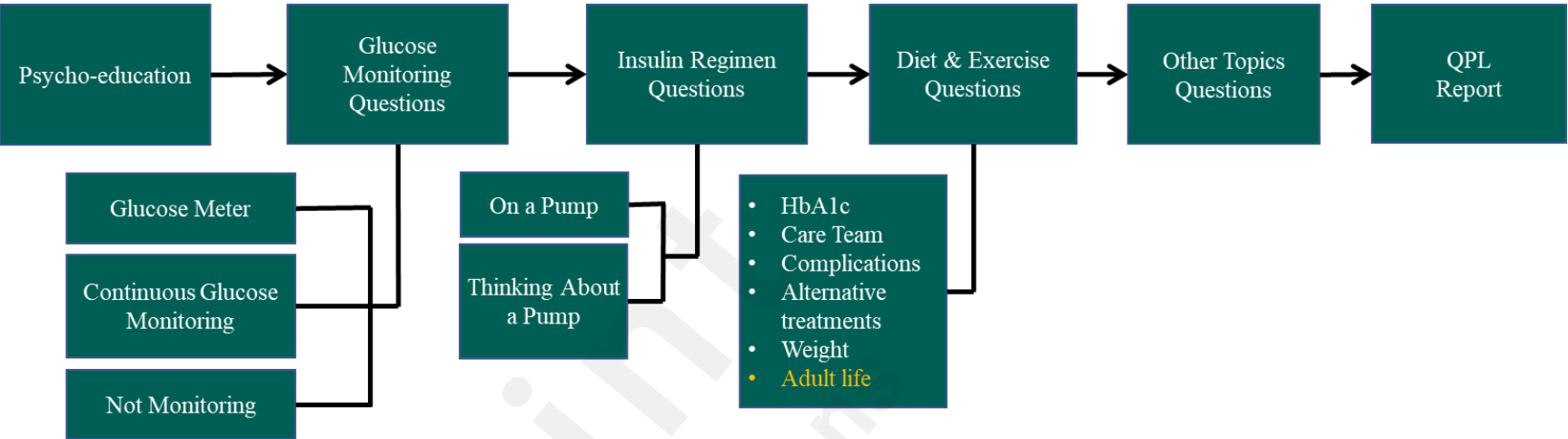
Figure 2: Text Message Reminders (TXT)



The third intervention was a Question Prompt List (QPL), a communication tool to empower patients to actively participate during medical visits by, for example, asking questions and stating

concerns and preferences. [52, 53] QPLs are comprised of lists of questions related to the physical and psychosocial aspects of illness and treatment that patients may want to ask their physicians or other clinicians during a clinic visit. The theoretical foundation for the QPL resides in social cognitive theory which posits that behavioral performance is largely a function of confidence in one's ability to perform the behavior (self-efficacy) and the expectation that the behavior will result in the desired outcome. [71] Patients prepared with a QPL are more likely to ask questions and state their concerns, enabling shared decision making and bolstering self-efficacy. The QPL developed for this study was based on a cancer QPL designed to increase patients' participation during oncology treatment interactions. [72, 73] The diabetes QPL was developed by first compiling diabetes-related questions gleaned from a literature search, web-based resources, and consultation with three diabetes medical care providers. Questions addressed common concerns in the three previously mentioned diabetes care domains and EA-specific topics (e.g., impact of tobacco or alcohol use on diabetes health). The intervention begins with a brief education component explaining the purpose of the QPL and the importance of communicating questions and concerns to their health care team. EAs are then presented lists of questions organized by content area from which they select the questions they would like to raise at the clinic visit. EAs are routed to question sets tailored to their diabetes treatment regimen, for example, those monitoring their blood glucose with a glucometer are presented a set of questions specific to that method of blood glucose monitoring and those using a continuous glucose monitor get a set of questions tailored to that approach. The questions selected by the EA are compiled into a personalized report and emailed to the EA upon completion and again the day prior to the clinic visit. Figure 3 illustrates the intervention flow of the QPL for EAs with T1D.

Figure 3: Diabetes Question Prompt List (QPL)



Data Collection

The *Family Information Form (FIF)* is an investigator-developed measure to gather participant characteristics. The FIF collects participant demographic information such as age, race/ethnicity, gender, income, and family structure. The FIF also asks EAs information about their illness, including the EAs' date of diagnosis and current diabetes self-care regimen. Research staff used a *semi-structured interview guide* developed for the study to guide the interviews. The interviews began with an explanation of the purpose of each intervention after which the research staff guided EAs through a demonstration of the interventions. After reviewing the intervention, the research staff elicited EAs' feedback using the interview guide, provided as Supplemental Document 1. After 10 interviews, the feedback offered had reached the point of saturation and was deemed sufficient. Interviews were recorded and professionally transcribed for analysis.

Data Analysis

A coding team composed of two coders (one undergraduate psychology and one graduate public health student) and a qualitative expert (the study PI) analyzed the transcribed interview data using Framework Matrix Analysis (FMA [74]), an efficient approach to inductive thematic analysis. After an initial training period in which coders became familiar with the study design and aims, data collection procedures, and analytic approach, the coding team developed the initial coding matrix based on the content of the interview guide. Coders used this matrix to independently review interview transcripts 'charting' summaries of EAs' responses to interview questions into their coding matrix. Coders then met to compare their independently coded matrices and develop a consensus coded matrix. Discrepancies were resolved through discussion and review of the interview transcripts. Once all interview transcripts were coded, the coders met to identify and summarize the themes that emerged across EAs' feedback. Coders developed descriptions of each theme with illustrative quotes extracted from the interview transcripts.

Results

EAs found all three interventions to be helpful and useful. They highlighted the integration of the interventions into the technology they use daily as a strength: "it has a high potential to be effective, especially with the amount of technology that's used nowadays" and "I'm always on my phone as a young adult."

Motivation Enhancement System (MES)

Overall, EAs found the MES intervention *helpful* and the delivery structure *acceptable* with 9 of 10 EAs reported the length and number of sessions "About Right". EAs found the 3Ms mnemonic (3Ms = Monitoring, Medicine, and Meals) a helpful prompt for remembering the essential diabetes care tasks: "it would be something very helpful to remember because when you're in the heat of the moment or you're just not focusing, that's something you should remember." When asked about the likelihood that EAs would recommend the MES program to other EAs, 8 of 10 EAs stated they would "certainly" recommend the program (M = 9.5 out of 10). When asked to elaborate, EAs highlighted the video elements of the intervention.

EAs found the physician depicted in the educational video a *credible* and *trustworthy* authority figure: "She got her message across, and it just makes sense. I understand why I need to do the things I need to do. The way she spoke about the things was very credible. I feel like I can trust

her word.” EAs found the physician video content acknowledging the stress and challenge of diabetes care consistent with their own experiences: “I had diabetes since I was four. So, when she [the physician] was like, ‘It begins to get hard,’ and stuff like that, I understood that because it’s hard for me, especially now that I’m driving and working and doing other things.”

EAs reported the peer testimonial videos were *relatable* in two ways. First, the experiences depicted in the testimonial resonated with their own challenges with diabetes care: “I can relate to [what] she’s saying too because I am tired too. It was way easier when I was a kid. Your parents may have to do all that, but now it’s my turn and it’s hard.” Demographic similarities in the EAs depicted in the peer testimonial video enhanced participants’ feelings of relatability: “She’s in college. She’s my age or around my age. Everything she was saying was the truth. Yeah, it was nice to see somebody who was my age similar to me. She’s same complexion. Yeah, it’s nice that there’s a black person talking to me.” EAs found other, non-video elements of the intervention credible and relatable including lists of common barriers to diabetes care: “I’ve done almost everything on here.”

EAs’ comments on the MES intervention highlighted its *autonomy supportive* nature. EAs reported less reliance on family support and input and a desire for greater independence and control when making diabetes care decisions: “I don’t know if people would do something like that [enlist the support of family] in college”. Asking for help with diabetes care was viewed as undermining their autonomy: “that is one of my goals because I know how to ask for help but I prefer not to.” EAs explained independently caring for their diabetes helped build their *self-efficacy* for diabetes care by giving them the sense that “I believe in myself” and that they were, therefore, in control of their health.

EAs viewed the behavioral strategies to support diabetes care as helpful tools to help them be autonomous. To illustrate, one EA found the suggestion to use reminders to prompt diabetes care useful: “That’s smart, with the sticky note on the fridge or wherever they get their food from, or try to get their food from. Just seeing that, it’s like, ‘all right, let me check my blood before I head out’, or ‘let me check my blood before I make this or eat this’. And for the putting an alarm on the phone, that’s very helpful, because when that time comes up and your alarm is screaming at you to do something, I feel like that’s very helpful as well.” Another EA found the suggestion to use cues to prompt diabetes care to be an effective strategy: “It would be very much useful, especially for those who are always running around and forget to do things. Having those cues to put a thought in their head like, ‘wait, I should do this. I should do that before I do this or that’.” A third EA reported using a similar strategy to prompt blood glucose monitoring: “I’ll put my [blood glucose monitoring] kit in the basket with my toothbrush and my soap and stuff. So, before I do any of that stuff, I got to pull this out and check my blood sugar. Or, if I have an early morning class, at night I’ll put this blood sugar kit in my jacket pocket. So, if I don’t check it when I wake up, by the time I get to the class or whatever, I’ll just pull it out and I’ll check it.”

Text Message Reminders (TXT)

Overall, EAs reported TXT would be a helpful reminder to stay “on track” with diabetes care tasks and increase the consistency of diabetes care: “I’m trying to get on a schedule, but sometimes other things interfere with that. So, having those reminders will help.” They thought receiving reminders at critical times would be particularly helpful, such as early morning (“when

I wake up that's the first notification I see on my phone"), afternoon ("the time where everybody would be up, so they will be alert when they get the message"), and late evening ("Sometimes you almost forget and it's about to get late [around] bedtime."). EAs noted texting reminders was preferred over email because "a lot [of] people look at their phone more than they look at emails", apps that "take up gigs [gigabytes/storage] on [my] phone", and other technology-based reminders which they tend to ignore: "I already set up reminders in my phone. I don't really pay attention to it though."

EAs appreciated the "straightforward" wording of the text messages and suggested making the language even more directive: "Take your insulin" versus "Don't forget to take your insulin". EAs also preferred a variety of messages, suggesting we "use different ones, not the same wording every single day", and a message personalized with their name. Using emojis in the messages was recommended to make them more engaging and consistent with other texts they receive: "Did you give insulin? with a smiley face." EAs emphasized the importance of being able to tailor the reminders to their own preferences. Specifically, the ability to select delivery times that aligned with their daily routines and mealtimes was a strength: "They're very good choices because these are around [the] time you eat". Most EAs thought a single reminder would be insufficient and suggested 2-4 texts per day was preferable and more than 7 texts would be viewed as "spamming".

Lastly, EAs recommended increasing the range of topics addressed by the messages. EAs suggested including reminders to exercise: "It'd probably motivate them or remind them that they maybe need to go out, take a jog, walk or lift some weights or just do some type of exercise to get their blood pumping." EAs recommended messages prompting blood glucose monitoring during exercise: "I want to make sure that I'm not running low doing them [exercises], so having a reminder to make sure you're on your sugar [checking glucose levels] while you're doing exercise to make sure that it doesn't run low or high." EAs also suggested reminders to check ketones: "Make sure you check your ketones, if their reading's above a certain level."

Question Prompt List (QPL)

Overall, EAs reported the QPL was a useful tool to prepare for diabetes clinic visits: "It was incredibly useful. I think it would help me out at my next [doctor's] appointment. It's definitely less time consuming than sitting there researching stuff and writing it out on your own." The variety of questions was viewed as a strength: "The questions were very diverse, very broad. There were some questions I had when I first got diabetes a long time ago versus some that I never thought to ask [my doctors] to this day." EAs remarked the QPL would be particularly useful for EAs newly diagnosed with diabetes: "If I was older and I had gotten diagnosed, these would have been the kinds of questions I would ask".

EAs found the different content areas of the QPL valuable. They described the glucose monitoring questions as "beneficial", "thoughtful", and "diverse". EAs emphasized the importance of the insulin questions noting the questions could help "prevent a 'situation'" by elevating important discussion topics: "These ones are really important and specifically address things I may have overlooked". EAs who were administering their insulin via injection (n = 8) thought the questions about transitioning to an insulin infusion pump helpful: "I always wanted to know what is it or what does it do". Those already using an insulin infusion pump (n = 2)

described these questions as very “relevant”: “All of these questions are questions that I had when I was transitioning to the pump.” One topic of particular interest to EAs was the section on transitioning to adult life with diabetes: “I really like the adult life part because I think that [is] something that's important that you consider before you get there rather than learn from experience”. EAs found these questions novel and thought-provoking remarking: “Some of the questions might change my mindset. Questions I didn't know I had.” They highlighted the importance of these questions for stimulating conversation on relevant but difficult to raise topics, including tattoos, pregnancy, and piercings: “I really think that these questions address some misconceptions that people may hear and feel nervous about.” EAs suggestions to expand the content of the QPL included adding questions about diabetes care challenges (“What are some of the struggles you are having with your diabetes?”) and to expand upon the diabetes care topics: “Why do I have a random high blood sugar if I haven't eaten anything?”, “What type of insulin works better for me?”, and questions about “free carbs”, “insulin resistance”, and “how to navigate CGM sensor errors.”

When it came to aesthetics and logistics, EAs preferred the ability to tailor the intervention to their preferences including the name of the QPL which ranged from integrating the patient's own name into the title (“[Name]’s Diabetes Questions List”) to a “less diabetes specific” name (“Keeping My Life on Track”). Most EAs thought sending their diabetes question list directly to their doctor's office would make it easier to communicate their concerns: “some people [are] not comfortable with their doctors yet or don't like speaking out”. While some preferred receiving their question list by email explaining they preferred email for a “bigger document” and “things that are important”, others thought email delivery allowed them to “read it off of my phone” noting “I usually always have my phone on me” and the accessibility of emails across devices: “You will always have it on file because it will be on email.” For EAs preferring text message delivery, it was due to a personal preference (“I check my text messages more than I check my email”) and ease of access (“I have thousands of emails inside there, so I think text would be way better because I can just search it up.”) One EA suggested an option to mail the QPL for those without email access. Other preferences included font size, optional narration, delivery timing, and sharing their questions list with others.

Discussion

Principal Results

The goal of this research was to obtain feedback on the content and delivery format of three eHealth interventions to improve diabetes self-management and glycemic control among EAs with T1D and elevated blood glucose levels. Overall, EAs found the interventions acceptable and thought they would be a helpful support for diabetes care. The integration of the interventions into technology EAs already frequently use was highlighted as a strength across interventions. Others have noted adolescents and young adults prefer interventions delivered to their mobile phone, [75] are more likely to use interventions when delivered to their personal device [76] and when delivered via text message. [30, 77] To reap the benefits of eHealth interventions, engagement is critical. [32, 76] Thus, finding ways to engage EAs in an intervention is a critical first step and text messaging based interventions using EAs' own devices may be an optimal strategy. The Unified Theory of Acceptance and Use of Technology (UTAUT) [78] lends further support to this conclusion, as it suggests interventions integrated into the technology people use

are more likely to be accepted and used because of the ease of use (effort expectancy). Among other influences, UTAUT also points to the perception that other people support use of the intervention (social influence) and the automaticity of using the intervention (habit) as factors that may be particularly relevant for EAs and SDT-based interventions.

A second cross-cutting finding was EAs' preference for tailored intervention content, specifically content tailored to their illness experience, demographic characteristics, and personal preferences. For example, EAs found resonance in the QPL questions that were aligned with those they had previously asked during their own health care encounters or felt they would ask in the future. In the MES videos, EAs found the representation of peers with demographic characteristics (e.g., age and race) similar to their own to be highly relatable. And in TXT, the ability to tailor the reminders to personal preferences (e.g., timing and subject of reminders) was viewed as a strength. We planned for a once daily reminder to be delivered based on EAs' time of day preference but increased the frequency to twice daily based on EAs' feedback reported here. The majority of EAs' recommendations for intervention improvement related to augmenting the capacity to tailor the interventions to personal preferences including increasing the frequency and duration of intervention, augmenting the intervention content, and personalizing reminders with the recipient's name. Tailoring to individual preferences is consistent with EAs' developmental need for autonomy and has been noted as an important element for engagement in technology-based interventions. [79, 80]

The interventions developed in this study were all grounded in self-determination theory (SDT [35]). SDT was selected as the guiding framework because of the resonance enhancing feelings of autonomy, self-efficacy, and relatedness has for EAs who are at a developmental stage in which forging independence, a unique identity, and social connections are paramount. [8] EAs participating in this study noted each intervention contained elements that resonated with this framework. Specifically, EAs found the credibility and trustworthiness of the videos embedded in the MES intervention promoted autonomous diabetes care. The videos' relatability, particularly the peer testimonial, helped foster feelings of relatedness. EAs found other MES elements, such as the behavioral strategies to support diabetes care goals, also fostered feelings of autonomy. EAs embraced text messaging as a strategy to promote consistent diabetes care, an approach previously linked to improvements in diabetes self-efficacy. [48] EAs noted multiple QPL questions were questions they had in the past or would consider asking in the future, fostering both feelings of confidence (self-efficacy) and relatedness. Questions addressing adult issues (e.g., alcohol use) resonated with EAs' goal of independence (autonomy). While theory-based interventions are more likely to improve glycemic control and psychological outcomes, [81] SDT-guided interventions, to date, have not demonstrated improvements in glycemic control. [38, 40] Guided Self-Determination, the most widely tested SDT intervention, relies upon the completion of worksheets that form the basis of conversations with diabetes educators. [31, 37, 39] Not only has this approach failed to demonstrate improvements in glycemic control, poor recruitment and retention rates suggest this approach is unacceptable to EAs. [31, 38, 39]

Limitations

This study's small sample size limits the generalizability of this study to other T1D and EAs populations. This limitation is offset by the fact that the EAs included were mostly non-Hispanic Black and were selected based on suboptimal glycemic control from an urban setting. Such

populations are underrepresented in the research literature and frequently absent from intervention development research. In addition, the findings reported here parallel those from a similar study conducted with a mainly White (89%) rural population of EAs who reviewed the same interventions and also highlighted the excellent fit of technology-delivered interventions for their age group, expressed a preference for individualized interventions, and stated the value of intervention elements that enhanced their feelings of autonomy. [82]

Conclusions

The eHealth interventions developed in this study were designed to leverage SDT to promote diabetes care and ultimately diabetes health. SDT emphasizes the psychological need for autonomy, self-efficacy and relatedness as levers for behavior change, needs that are developmentally aligned with EAs. The next step of this study is to conduct a randomized controlled trial using the multiphase optimization strategy (MOST [83]), where the goal is to test the preliminary efficacy of the MES, TXT, and QPL interventions to improve glycemic control and build the most efficacious multicomponent intervention. [41] EAs' feedback from this study will be used to refine the interventions prior to this study. Specifically, the MES will be refined based on EAs' language preferences. The planned frequency of TXT will be increased from one to two messages per day with the variety of messages increased to avoid too much repetition and redundancy. The tailoring of TXT will also be enhanced. In addition to tailoring the content of messages and timing of message delivery to EAs' preferences, messages will also be tailored to integrating the EA's name into the message. The wording of the QPL questions will be revised in accordance with EAs' preferences and new questions will be added to augment the scope of question content. EAs' feedback will also help other researchers develop interventions aligned with the needs and preferences of EAs which will increase their acceptability and future effectiveness.

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Conflicts of Interest

None declared

Abbreviations

3Ms: Monitoring, Medicine, and Meals

CGM: continuous glucose monitor

CIAS 3.0: Computerized Intervention Authorizing Software, version 3.0

DQOL: diabetes-related quality of life

EAs: emerging adults
FIF: Family Information Form
FMA: Framework Matrix Analysis
GSD: Guided Self-Determination
HbA1c: hemoglobin A1c
IMB: Information-Motivation-Behavioral Skills
MES: Motivation Enhancement System
MI: Motivational interviewing
MOST: multiphase optimization strategy
QPL: question prompt list
SDT: Self-determination theory
T1D: Type 1 diabetes
T2D: Type 2 diabetes
TXT: text message reminders

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