# **Barriers and Strategies for Type 1 Diabetes Management** Among Emerging Adults: A Qualitative Study

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### ABSTRACT

PURPOSE: Individuals in the emerging adult age group (18-30 years) with type 1 diabetes (T1DM) have unique medical and social needs. The purpose of this study was to observe barriers and strategies for diabetes management among emerging adults with T1DM.

METHODS: A qualitative grounded theory model was utilized. An open-ended approach with a telephone interview was designed to allow a deeper understanding of the T1DM experience. The participants were from a larger survey-volunteer participant group and were asked to complete 1 interview in spring 2020 (n = 21, diagnosed age: mean 15.00 ± 8.00, females, n = 19). The data were analyzed for cohesive themes using grounded theory.

RESULTS: Participants indicated three main barrier themes (physiology, environment, and insurance) and 3 barrier subthemes (mental health, lack of social support, and weather). Three main strategy themes to diabetes management were recognized (medical technology, access to social support, and physical activity). There were 2 strategy subthemes (social media and social accountability).

CONCLUSIONS: Regular use of social media can be a key tool for social accountability while lack of social support and physiological shifts can be barriers to management of T1DM. Physical activity should be considered as part of an individualized plan for management of diabetes.

KEYWORDS: Anxiety, environment, physical activity, stress, glycemic variability, COVID-19

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Type 1 diabetes (T1DM) is an autoimmune disease, clinically described as the destruction of insulin producing  $\beta$ -cells in the pancreas, which requires complete insulin therapy.<sup>1</sup> This disease requires daily blood glucose measurement and precisely dosed insulin injections.<sup>1</sup> Blood glucose can be measured through a continuous blood glucose monitor or finger pricks.<sup>2</sup> Long term glycemic stability can be measured through glycated hemoglobin (A1C), which gives an indication of average blood glucose levels over the previous 3 months. In addition, individuals must carefully count dietary carbohydrates in order to properly dose the insulin needed for blood glucose absorption.<sup>3</sup> If mismanaged, an individual can decrease glycemic stability and increase risk for medical complications.<sup>3</sup> Diabetes management can be hindered by work and school schedules and social events since management is very strenuous. The long-term complications of unsafe management may be comorbidities such as cardiovascular disease, stroke, and neuropathy.3 The short-term difficulties can be hyper- or hypoglycemia, diabetes seizure, or diabetes ketoacidosis.<sup>2</sup> These acute and chronic conditions may require medical intervention through hospitalization.

An emerging adult as defined by Arnett<sup>4</sup> is an individual between adolescence and adulthood (aged 18-29 years) striving to establish independence during this period of role exploration. During emerging adulthood, significant decisions arise conflicts of interest with respect to the research, authorship, and/or publication of this article CORRESPONDING AUTHOR: Bailee Sawyer, Department of Medical Laboratory Sciences, Public Health & Nutrition Science, Tarleton State University, 1333 W. Washington St., Stephenville, TX, 76402, USA. Email: sawyer.bailee@gmail.com

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which may include committing to a lifelong partner, working toward building a career, potentially through higher education, and/or moving to a permanent home away from the original family unit.4 "Emerging adult" is a well-defined term, based on stage of development, but usually refers to age 18 to the 20s when individuals may be both transitioning their health plan from parents to self-support while at the same time, choosing risk-taking behaviors such as sexual experimentation, drug use, binge drinking, and other health risks.<sup>4-6</sup> Of paramount importance, at the age of 26, individuals are no longer eligible to remain as a dependent on a parent's or guardian's medical insurance. Thus, they must procure this insurance through an employer, the government, or an individual plan.<sup>4,5</sup>

Creating a schedule and making decisions around responsible dietary habits and physical activity is typically a challenge for this age group.<sup>3,5</sup> Several risk behaviors peak during this age period leading emerging adults to an increased risk of making decisions that can affect their future, financial stability, and overall well-being.<sup>4</sup> These individuals are at a higher risk for mismanagement of diabetes.<sup>3</sup> The American Diabetes Association<sup>3</sup> has identified emerging adults to be at risk for not meeting target A1C goals. Emerging adults may struggle with disease management due to financial and/or social hardships and may be at higher risk for clinical depression and diabetes distress.<sup>3</sup> Diabetes supplies are expensive and may be difficult to afford even with a

() () NC Creative Commons Non Commercial CC BY-NC: This article is distributed under the terms of the Creative Commons Attribution-NonCommercial 4.0 License (https://creativecommons.org/licenses/by-nc/4.0/) which permits non-commercial use, reproduction and distribution of the work without further permission provided the original work is attributed as specified on the SAGE and Open Access pages (https://us.sagepub.com/en-us/nam/open-access-at-sage). full-time job.<sup>6</sup> Previous researchers have identified that social support can impact glycemic control among emerging adults. In addition, qualitative studies have suggested how social support can affect diabetes management.<sup>8-10</sup> Despite being at higher risk for lapses in control of diabetes compared to non-emerging adults with T1DM, emerging adults with T1DM who feel socially supported by family, medical professionals, and friends/significant others have improved self-care while living with T1D.<sup>8-10</sup>

Emerging adults with T1DM have extensive challenges related to diabetes management. Fifty percent of emerging adults with TIDM develop diabetes-related complications in their 20s including retinopathy, neuropathy, and hypertension, related to moving to a new location.<sup>11</sup> Emerging adults are in a dynamic flux of change, such as temporary disengagement from professional medical care while transitioning between homes, jobs, school, etc. and also, can be challenging to recruit and study for the purposes of research.<sup>11</sup> Emerging adults with T1DM may feel more pressure to securing a full-time job related to establishing medical insurance.<sup>11</sup> Current research provides evidence to support the need to assess obstacles and tactics for emerging adults with T1DM to promote disease management.<sup>11</sup> The goal of this study was to identify barriers and strategies to diabetes management as informed by the lived experiences of emerging adults with T1DM.

# Methods

A qualitative grounded theory model was utilized to assess barriers and strategies to management of T1DM among emerging adults (aged 18-30). An open-ended approach to qualitative data with a telephone interview was designed to allow a deeper understanding of the T1DM experience among emerging adults. During the time of the study, there were national COVID-19 restrictions for in-person interviews.<sup>12</sup> The study was approved by: (1) the Department of Health, Nutrition, and Exercise Sciences (2/2020), and (2) the Institutional Review Board (3/2020, #HE20244) of North Dakota State University, Fargo, ND before recruitment.

# Participants

During May 2020, English speaking emerging adults with T1DM (aged 18-30) were recruited to participate in an electronic questionnaire via email, through targeted messaging using both a convenience sample and word-of-mouth. The university electronic mailing list and social media portals (eg, Facebook and Instagram) were utilized for recruitment. After completing the questionnaire regarding T1DM (results reported elsewhere), interested participants received a follow-up email requesting a telephone interview. The sample participants had no relationship to the researcher prior to the beginning of the study and completed an informed consent procedure lto explain reasons for doing research before

interviews were conducted. Figure 1 shows a flowchart of participants from the larger survey and telephone interview.

## Data collection

The researcher wrote the telephone interview questions with approval of the research team, which included 3 registered dietitian/PhDs. The telephone interview questions were informed by a survey, completed by 115 emerging adults during April 2020, who self-reported living with diabetes. The survey was based on questions from an adapted version of the CDC Youth Behavior Risk Survey<sup>13</sup> (eg, risk behaviors and demographic questions), the Diabetes Attitude Questionnaire-DES14 a survey for self-management, the Diabetes Self-Management Questionnaire (DSMQ),<sup>15</sup> and the Diabetes Eating Problems Survey-Revised (DEPS-R).16 The research assistant (RA) was a female doctoral candidate at the time and dietitian with 5 years of both professional and research experience in academia and dietetics. The interview questions were pilot tested by the RA with 2 non-study participants chosen from those who also pilot tested the diabetes-related survey. For the pilot, an iPhone telephone application (Rev - Call Recorder, San Francisco, CA) was utilized to record the interview. The pilot testing interviews took ~45 minutes on average. Based on pilot testing feedback, the following changes were made: each question was read once with a long pause to wait for a response; and the terms "diabetes self-efficacy" and "compliance" were revised to "diabetes management" and "habits."

Participants were contacted via email to schedule a time for the single telephone interview. During the scheduled time, the RA contacted the participant using the Rev – Call Recorder. The interview lengths on average were similar to the pilot interviews (~45 minutes each). Telephone interviews were conducted using a semi-structured format with scripted questions. However, the RA conducting the interviews added needed prompts based on expertise in T1DM.

All identifiable information was kept strictly confidential between the members of the research team. After data were analyzed, any links to names/contact information were destroyed. Field notes were data processed by the RA during the telephone interview and saved by participant number to guide data analysis.

*Procedures.* Telephone interviews were audio recorded, transcribed, and analyzed for themes and patterns by the RA using grounded theory, an inductive approach described by others.<sup>17</sup> Recorded interviews were transcribed twice. The first transcription included a word-by-word approach to capture exactly what participants stated. The second transcription was completed to check for missed words and assure completeness. The next step was thematic analysis via open coding. This process included writing out notes and headings from the recordings. These notes and headings were grouped into

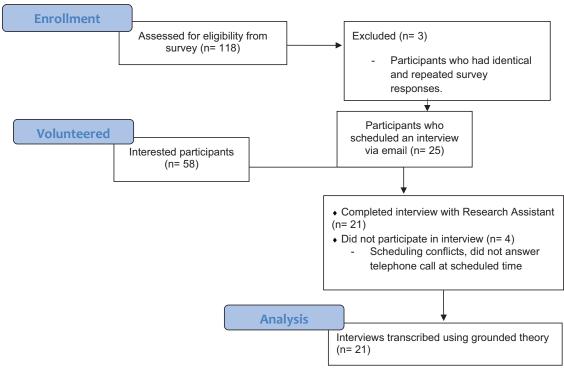
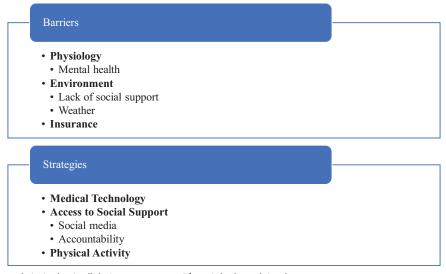
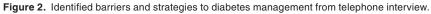


Figure 1. Consort flowchart of qualitative telephone interview.





various subcategories. Subcategories with similar content were grouped into 2 or more main categories using the qualitative content analysis process.<sup>18</sup>

# Results

Ninety percent of the total participants (n = 21) completing telephone interviews were female (n = 19). The participants were split utilizing an insulin pump (n = 12) and insulin injections (n = 9). Reportedly due to lack of insurance support, there were participants who did not have a continuous glucose monitor (CGM) (n = 2) and those who did (n = 19). The mean age of diagnosis was at  $15.0 \pm 8.0$  years of age for all participants. Figure 2 lists the main themes and subthemes identified as barriers and strategies in managing diabetes.

Three themes, 1 containing 2 subthemes, and 1 containing 1 subtheme were identified for barriers and 3 themes, 1 of which included 2 subthemes, were identified for strategies, and are detailed in the next section.

# Barrier themes

*Physiology.* Physiology, an aspect of biology that pertains to the normal function of the body, was a challenge for emerging adults with diabetes. All participants in the current study

indicated challenges with managing alterations in metabolism. Adjusting insulin dosage based on blood glucose values may be a challenge to manage because of frequent metabolic shifts. The time of day influenced metabolism, as evidenced by many participants habitually waking up with upward trending blood glucose. Hyperglycemia in the morning is common for some individuals with T1DM, which may influence work schedule, morning routine, and meal consumption<sup>19</sup> and may also affect responsibilities, such as parenting, work, and school class schedules. There is typically no medical reason for morning hyperglycemia, but a trend some individuals encounter.<sup>19</sup> Waking up with high blood glucose meant participants would choose to consume a later mid-morning breakfast until blood glucose normalized. Several participants described these experiences by stating the following:

"I could eat the same food, the same time, with the same insulin units, and my blood glucose readings could still be an extreme difference," 26-year-old female, diagnosed 16 months old.

"Taking medication and counting carbohydrates is an easy part, but the management of blood glucose is much more than that," 22-year-old female, diagnosed 20 years old.

"I wish my wife understood diabetes better. There are days where my blood glucose is really high for no reason and I can't get it to come down with insulin. She doesn't understand why I am so upset and moody," 24-year-old male, diagnosed 19 years old.

Participants suggested daily living seemed to be demanding because each minute could be different. Trying to predict how the body would respond was difficult and created a sense of anxiety. Many participants suggested the daily variation and lack of predictable blood glucose levels was the most challenging aspect of diabetes management.

*Mental health*. Mental health is a unique aspect of physiology. Mental health can affect stress hormone response in the body, which may induce difficulties for insulin dosing, blood glucose levels, and increase A1C.<sup>7,20</sup> This subtheme was observed as a barrier to diabetes management. The inability to self-motivate and mental burnout were hindrances to diabetes management. Several participants shared examples:

"I know what I am supposed to do, but this doesn't always mean I have the motivation to actually do it," 27-year-old female, diagnosed 6 years old.

"The worst part of the pandemic is I always used time and a busy schedule as an excuse to management, but now since I am home and have plenty of time, the problem is me and not time," 27-year-old female, diagnosed 2 years old.

"Burnout is a major issue in diabetes management and known in the community. It is the exhaustion of having to do everything perfect all the time to be healthy that you finally just say, 'I don't care anymore'," 30-year-old female, diagnosed 10 years old. There were participants that did seek regular sessions with a professional counselor whose expertise was chronic diseases. Over half of the participants (n = 12) explained they had struggled with various forms of depression in the past.

*Environment.* Environment was referenced for time, place, and outside temperature as an obstacle for diabetes self-directed goals. There were 2 subthemes included with this barrier: lack of social support and weather. Adapting to a new environment whilst diagnosed with T1DM appeared to be a challenge for many individuals.

Lack of social support. The participants' living arrangements and their social environment affected how they managed diabetes. They reported living alone (n=5), with family/guardian (n=8), or with a partner (n=8). Absence of social support removed accountability and created stress for participants which impacted management. Regardless, half of the participants felt the parent/guardian was supportive and offered a shoulder to lean on during difficult times, such as examples listed here:

"Dosing changes a lot throughout the year for me. I eat differently when I am at home versus when I am at college. I am also more active in the summer so that changes dosing. Even though I have had my pump for a year, when my schedule changes I have to readjust dosing and food intake," 21-year-old female, diagnosed 10 years old.

"When I lived with roommates I was able to voice my day with diabetes, now living alone I really don't have anyone to tell. Sometimes it's just nice to have someone to be around and talk about diabetes with," 25-year-old female, diagnosed 12 years old.

"I have a hard time sleeping at night alone since I live alone and I am worried about my blood sugars changing without me knowing," 22-year-old female, diagnosed 20 years old.

Living with people who supported diabetes management seemed to improve blood glucose management confidence. These supports provided empathy for daily varying changes in blood glucose and management with dietary intake and insulin regimen. The support also included communication in the form of verbal, text messaging, phone calls, etc. from roommates/ spouses/parents/partners for the management variables. While on the other hand, participants that experienced loneliness or isolation struggled with daily management when living alone.

*Weather.* An interesting barrier was weather, specifically temperature or season of the year. Participants explained that season of the year affected glycemic variability by increasing difficulty for physical activity or daily walks. Temperature was viewed as a concern by participants who have signs and symptoms of changing blood glucose levels. Participants identified seasonal changes that impacted daily living with T1DM in the examples listed here:

"Summer is a tough season. The heat really changes my sugars. They will shoot up really high for no reason in the heat but then when I come inside they will drop fast," 28-year-old female, diagnosed 18 years old.

"I think winter is a hard time of year. Not only are you around holiday events with lots of food, but since I live in the upper East coast, it's too cold to be physically active outside," 28-year-old female, diagnosed 18 months old.

The participants explained that hot outdoor temperatures increase blood glucose naturally but then once inside cool, airconditioned indoors climate, blood glucose would typically drop.

*Insurance.* Health care insurance was an identified barrier, specifically regarding coverage for supplies and medical appointments. Participants explained family/individual insurance may or may not cover medical supplies such as insulin, a continuous glucose monitor (CGM), or even primary care appointments with the medical team. Examples are included here:

"I feel like if I could get a Dexcom (CGM) a lot of my stress would decrease and I would be much more controlled," 21-year-old female, diagnosed 20 years old.

"If you don't know how to talk to insurance companies, it can be really tough to get approved for what you actually need," 27-yearold female, diagnosed 6 years old.

"A struggle for me is taking insulin and making sure I take my blood sugar. I don't have insurance right now, so I can't afford all the fun stuff like the pump and CGM, so we are going with what we got," 21-year-old female, diagnosed age 15 years old.

"At some point, even for those who have had diabetes for a long time, you are going to run into issues with insurance. It's just insane to me, it's not my fault I have an autoimmune disease that I need medication to survive everyday," 30-year-old female, diagnosed 15 years old.

One participant, a dual Canadian and American citizen, indicated that living in Canada with diabetes is much easier due to the availability of medical services. The participant explained health care in Canada is designed so individuals who have an autoimmune disease, such as T1DM, can meet with their medical team more frequently. For example, CGM's are more accessible for personal use, and insulin is more affordable.

#### Strategy themes

There were 3 main strategy themes, listed below, which influenced overall diabetes health.

*Medical technology.* Almost half of the participants (n=10) were approved through insurance to have both an insulin pump and a CGM. The advancement of technology for items such as the CGM allowed participants to have better "real time" glycemic targets for diabetes. These 2 devices, plus the use of

an insulin pen, can record blood glucose, and register insulin dosing throughout the day automatically. Participants who were diagnosed with diabetes at an earlier age explained that the progression in medical technology in recent years helped decrease anxiety and fear of the future.

"My diabetes did not like the pump. I could never get the insulin settings correct, especially for physical activity. Switching to the pen (insulin injections) created a lot more freedom and I can still connect to my Dexcom that tracks everything really well. The best part about the pen or pump is it will tell you how much insulin you still have in your blood stream so you don't over dose," 21-year-old female, diagnosed 12 years old.

"The Dexcom continues to improve. The more research is done the more accurate the readings are. I still use the finger prick morning and night, but I am confident in what my Dexcom says," 26-year-old female, diagnosed 13 years old.

Half of the participants (n = 11) suggested technology improved management by observing trends in blood glucose and automatic, responsive insulin dosing. In addition, 3 participants switched from an insulin pump to insulin injections explaining the change created a sense of freedom. Participants predicted that as technology increased in reliability, then management of their T1DM would be achieved or at least less stressful.

Type of supplies, such as the CGM, insulin pen, or insulin pump were strategies to diabetes management improvement. The participants who had access to these supplies explained that ability to manage the disease improved for both laboratory measures of management and feeling of personal achievement. Understanding how to use these items correctly was a strategy for improved management as well. Once approved through either a medical professional or insurance, participants would receive training on the tools from a diabetes care and education specialist or endocrinologist.

"The easiest part about diabetes for me is using all my supplies, I know how to insulin dose, count carbs, and read my blood glucose monitor well," 24-year-old female, diagnosed 18 years old.

Compliance or following directions in a recommended manner for the applicable types of technology, was indicated as a means for successful diabetes management. Participants described the best way to improve T1DM health was to take insulin, calculate dietary carbohydrate intake, and record and interpret blood glucose trends. Some of the participants who had diabetes for a longer duration were not expressively different in medical management responses.

"Even if you have not had diabetes very long, the teaching for diabetes (insulin, pump, monitor, etc.), is pretty simplistic," 24-yearold female, diagnosed 18 years old.

"I love my sweets, I love my candy so making sure I am checking my blood sugar and dosing correctly helps me still enjoy those foods," 21-year-old female, diagnosed 15 years old. "The training for carbohydrate counting and insulin dosing were and still are the easiest part of diabetes," 21-year-old female, diagnosed age 10 years old.

Access to social support. Access to social support was identified as a strategy for risk reduction living with diabetes. Participants who had support from family or healthcare providers reported overall better management.

"My pediatric diabetes care and education specialist became a family friend; I always felt welcome like she understood what I was going through. She was available for quick check-ups if my endocrinologist was busy," 27-year-old female, diagnosed 6 years old.

"Both my parents have always been really supportive of my diabetes. I still feel like even in adulthood they help. I had a lot of independence with my diabetes at around 8th grade, taking my own shots and dosing insulin myself. But my mom still went with me to appointments to make sure she knew what was going on," 26-yearold female, diagnosed 13 years old.

Many participants explained that their peers who also had T1DM understood the daily challenges of diabetes on a deeper level, creating a sense of comradery, instead of the science-based advice, which came from the medical professional.

Social media. Social media (ie, Twitter, Instagram, Facebook, and Snapchat) was selected as a strategy for improved management. All participants discussed "Instagram icons" or admired professional athletes who have T1DM, as role models for management support and motivation. Quick access to a community for T1DM seemed to improve motivation and outlook, and decrease anxiety for participants who felt alone:

"This is really silly but I look up to Nick Jonas. He is very outspoken about his diabetes. When I see him able to perform and tour, I say to myself '*If he can do all these things, so can I*," 24-year-old female, diagnosed 18 years old.

"I was going through a really tough time with burnout. I was able to find the Diabetic Therapist (Instagram account). She had an online therapy training that was 6 weeks. I've never met her in person but I was able to work through a lot of struggles online and be trained to handle obstacles," 27-year-old female, diagnosed 16 years old.

"I used to be part of an online chat group through diabetes camps that was connected through email. You could log in and respond to other people through the chat group. Once that closed I joined a bunch of Facebook groups to reconnect with others," 21-year-old female, diagnosed age 10 years old.

Many participants discussed Facebook groups for daily management skills or topics. Participants explained they would direct message Instagram accounts for support. Many participants developed personal relationships with others they had never met in person. The social media application, Snapchat, was seen as supportive for many individuals in the study. Participants sent videos or pictures about daily management to social media contacts. One participant, quoted above, stated Nick Jonas was a role model for diabetes. Nick Jonas is a 24-year-old singer, songwriter, producer, and actor with T1DM (diagnosed at 13 years old).<sup>21</sup> According to a medical magazine article, Nick shares similar T1DM experiences with the participants in this study. These experiences include "being independent, but wanting familial support" and "being frustrated with the unpredictable day-to-day changes."<sup>21</sup>

*Social accountability.* Accountability, or a sense of responsibility, was identified as a strategy for diabetes management. Study participants who could identify a person in their life, who asked about topics such as blood glucose levels, insulin injections, physical activity, weight management, medical appointments, etc., stated they had better overall health outcomes. Accountability partners included romantic partners, social media friends, family members, or medical professionals.

"My parents keep me accountable, especially my mom. She tracks my blood sugars from my Dexcom on her phone and checks in with me throughout the day," 26-year-old female, diagnosed 13 years old.

"My friends from diabetes camp are really supportive. We check in with each other on our group Snapchat and compare Dexcom graphs. It really helps when you are having a rough day and don't feel motivated," 21-year-old female, diagnosed 10 years old.

"My husband is my mentor. He will always encourage me to go on a walk with him when he knows I am high. Especially since we have been working together for 2 years for me to be super controlled and get pregnant, he knows how important it means to me," 25-year-old female, diagnosed 1 year old.

"One of my friends was diagnosed a year before I was in high school became my role model and we would ask each other during the day or between classes how insulin and blood sugars were going," 21-year-old female, diagnosed at 15 years old.

*Physical activity*. Physical activity was identified as a strategy to diabetes management. All participants discussed how leisure and moderate to vigorous physical activity improved blood glucose levels. There was not a guided question on type or level of physical activity during the telephone interview, however participants chose to describe the level and type of physical activity probed by other scripted questions. All participants (n=21) partook in a daily afternoon walk about 20 to 30 minutes, to counter increased blood glucose (> 120 mg/dL) that occurred between 2 and 5 pm. There were a few participants (n = 3) who reported weekly resistance training, with sessions lasting about 45 minutes to increase blood glucose values even though the session was high intensity weight lifting. The report of high intensity weight lifting increasing blood glucose without dietary intake is a phenomenon that needs additional research to understand this strange metabolic process. Lastly, 10 participants explained that weekly (3-5 times per week) 45 to 60 minutes runs would decrease

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blood glucose values very quickly and therefore participants had to monitor low blood glucose during and after the run. Participants (n = 21) were able to use less insulin, noticed benefits for A1C, and expressed feeling better overall if they chose to be routinely physically active once or twice during the day. All participants discussed that both a morning and evening walk improved normal fluctuations in blood glucose levels. However, physical activity also increased awareness or concern for blood glucose fluctuations.

"I tend to plan my school and work schedule around exercise. I really like running and know that will keep my blood sugar under control. When my hemoglobin A1C hit under 6 that was a big goal for me and I know exercise really helped," 23-year-old female, diagnosed 13 years old.

"Physical activity is the best way to control my sugars. It makes me feel better, even if it's just a 10-minute walk," 30-year-old female, diagnosed 10 years old.

"I really wanted to get fit, even with diabetes. Since I was diagnosed going into sophomore year (as a college basketball player) I just kinda let things go and ate what I want. Now I have physical goals (for weight lifting) and how I want to be in shape, knowing that it will help my diabetes control too," 28-year-old male, diagnosed 19 years old.

"From since I was diagnosed, I had the mindset that things would be different but I wasn't going to let diabetes stop me from doing the things I love, like being physically active and traveling," 30-year-old female, diagnosed 18 years old.

Physical activity was a part of the daily routine or added to bring a high blood glucose level down without taking insulin. Being active and exercising seemed to improve overall mental health and well-being for participants.

#### Discussion

Our attempt in digging deeper to understand living with T1DM among emerging adults revealed both successes and struggles reflected by examples and storytelling. The examples sequenced into detailed stances that help to inform identification of themes. The ever-changing biological response, "physiology," including insulin, dietary consumption, physical activity, stress, etc., was identified as a barrier to diabetes care for participants in this study. Environment, specifically the social support subtheme, was noted to both detract from and to improve diabetes management.

Having more males in the current study would have deepened understanding of gender differences. Mixed results have been reported in the literature. As part of a linear regression model, socioeconomic status, sex, and family structure only slightly affected diabetes management as measured by A1C among 18- to 21-year-olds diagnosed with TID (n=202).<sup>9</sup> The other subtheme of environment, weather, was identified as a barrier to diabetes management. Participants discussed how both the temperature and the season create an obstacle for diabetes care. A comparable qualitative study, using semistructured interviews and concerning attitudes and barriers to exercise for adults with T1DM discovered environment was a barrier for participants to exercise (n=26, mean age  $42.6 \pm 13.3$ ).<sup>10</sup> Specifically, the participants reported that high temperatures interfered with walking or cycling.<sup>10</sup> Additionally another study found A1C may change seasonally, tracking over a 3 year time-period with children and adolescents (n=677, age  $13.3 \pm 9.1$ ).<sup>22</sup> The highest A1C was in the winter months (December, January, February) while the lowest measured A1C was during the late summer months (August and September).<sup>22</sup> Season and environment may alter glycemic variability for individuals with T1DM.

Especially during a pandemic, mental health can be challenging for emerging adults without chronic disease, but the added layer of having to manage T1DM was identified as a topic of concern among the current study participants. Inadequate blood glucose control can result from underlying depressive symptoms, such as diabetes distress.9 Depression and anxiety are 2 of the most commonly reported mental health issues among those with T1DM and emerging adults.9 Emerging adults are more likely to be hospitalized with depression concerns.<sup>5</sup> Adults with T1DM are 4 times more likely to have prevalence of depressive symptoms than their healthy peers.7 Researchers have previously found T1DM may create increased mental health distress compared to healthy controls.9 This current study did not compare depression, anxiety, and mental health among participants with and without T1DM. In a recent study that aimed to investigate the association between symptoms of depression and leisure-time physical activity (LTPA), individuals who reported lower leisure-time activity frequency, and intensity, also reported greater depressive symptoms compared to those had more LTPA (P < .001).<sup>23</sup> In this current study, physical activity was identified as a strategy for diabetes management but can improve mental health status as well.

Similar to the telephone interview participants in the current study, a previous qualitative study identified the CGM as an effective type of technology in preventing hypoglycemia, but insurance was a barrier to obtaining the needed equipment.<sup>10</sup> In 1 U.S. state, the average cost to an individual for 1 day of insulin is \$15 or almost \$6000 per year.<sup>24</sup> This does not include the costs incurred for proper insulin storage (insulin must be refrigerated). Emerging adults lose parental or guardian healthcare insurance at the age of 26. There are government bills waiting approval in the U.S. legislature aimed at altering insulin cost for emergency coverage. Emergency coverage is intended for periods when an individual has lost employment or is transitioning between insurance companies.

In the United States, individuals over age 26 may apply for individual health insurance through HealthCare.gov during

"Open Enrollment." However, the coverage for an individual with T1DM may be costly and only cover emergency medical services, such as diabetic ketoacidosis. This coverage may or may not cover preventative items such as insulin or any glucose monitoring system (finger prick or CGM). The monthly premium may not cover deductibles for primary care appointments or specialty appointments, such as a certified diabetes care and education specialist or registered dietitian. If the individual misses the deadline to apply during "Open Enrollment," then specific criteria must be met for eligibility for this health insurance. The "Special Enrollment" period allows individuals to apply for health coverage if the following criteria are met lost health coverage within 60 days, birth, marriage, death in immediate family, gained a dependent, change in income, had a change in residence, denied Medicaid, gained citizenship, or released from incarceration. Lack of health coverage can hinder insulin usage since the cost of insulin continues to rise.<sup>5</sup> In addition, the transition period for emerging adults from pediatric to adult medical care can be stunted if lack of insurance coverage for appointments is a barrier.<sup>5</sup> Additionally, the longer the transition occurs the more likely A1C will climb to unhealthy levels.<sup>5</sup> Emergency coverage is intended for periods when an individual has lost employment or is transitioning between insurance companies. One example is the Minnesota assistance program.<sup>26</sup> Over half of the participants explained during the interview that at least once a month a full day is typically spent working through insurance difficulties. These difficulties include calling insurance companies, communicating with pharmacy for supplies, and navigating insurance deductibles. In contrast there are countries with free healthcare insurance, as noted by one of the dual citizen participants (30-year-old female, diagnosed at 15 years old). Canada has been an example since the start of 1964 to create a national commission for comprehensive health coverage, including health services, access to health personnel, and health-care financing.<sup>27</sup>

Social media can play a role in diabetes management for both the individual with T1DM and health care professionals. All participants in this study identified social media as a strategy diabetes care, specifically for social connections with peers who also have T1D. In a similar qualitative study (n=21) that enrolled participants with both T1DM (n=12) and T2DM (n=9) (aged 20-82 years, mean = 52) using semi-structured interviews with a thematic process,<sup>28</sup> participants described when they were interactive online on discussion boards such as Facebook groups for diabetes, they felt empowered to actively engage with health-care professionals.27 In previous work, researchers tracked A1C trends for 1 year and split children and emerging adults (aged 14-23) in 2 groups.<sup>28</sup> One group (n=29) was treated using standard medical protocols with inperson clinic visits for diabetes care.<sup>29</sup> The second group (n=27) was treated using both Skype (sound and video) and

Facebook (chats) for at home interventions and medical care.<sup>29</sup> Both groups improved A1C target levels at 12 months showing that internet medical care can be effective and that personalization, presentation, and participation can be improved by both use of web-based medical care and also, by using social media for support.<sup>28</sup> Social media can be utilized as an alternative method for diabetes care for health care professionals based on patient preference for communication similar to regular visits. Social media can also provide a sense of community connection and empowerment for personal medical goals for emerging adults with T1D.

In addition to social media improving interaction with their medial team and thus diabetes management, peer support has been shown improve diabetes management accessibility. One qualitative study explored adolescent experience and perspective to utilize social media as a tool to interact with their medical team and peers using semi-structured interviews.<sup>30</sup> Recruited from the Seattle, WA area, there were 45 adolescents involved in the study (mean age  $15.9 \pm 1.7$  years; 58% male). One of themes that was identified was the connection to peers with T1DM for additional day-to-day diabetes support. Social media can be a place where individuals can interact with peers and find relationships and can relate impact daily success and struggles without living in close proximity to individuals that offer support.

Physical activity helps lower blood glucose without the use of insulin.3 Physical activity and daily exercise are important for individuals with T1DM to maintain a healthy BMI and waist-to-hip ratio, which can decrease CVD risk.<sup>3</sup> The current American Diabetes Association physical activity recommendations for adults with diabetes are a minimum of 150 minutes of physical activity per week.<sup>3</sup> All participants in the current study identified physical activity as a benefit to overall diabetes management. Participants who discussed personal goals around strenuous physical activity, such as planned resistance training and aerobic training, chose to change from insulin pump to insulin pen. Insulin pumps may have a more reliable delivery system and quickness in method but can still allow a wide variation of blood glucose values during exercise and should be monitored closely.<sup>31</sup> One participant explained that during intense aerobic training evading low blood glucose was a challenge prior to changing to an insulin pen. Avoiding hypoglycemia during exercise can be difficult due to the various physical activity types, duration, and intensity among individuals diagnosed with T1DM.<sup>31</sup> Researchers have identified the need for a higher insulin dose as a barrier to an active lifestyle for individuals with T1DM.31 Blood glucose monitoring and tracking of blood glucose patterns must be utilized to exercise safely.<sup>31</sup> All participants discussed daily morning or evening walks (15-30 minutes) as a benefit to diabetes management. Any prolonged sedentary behavior should be interrupted every 30 minutes for blood glucose benefits.<sup>3</sup> If intense physical activity is a particular goal, a change in supplies can

allow for individual freedom. Individual goals should be considered by the medical team for diabetes supplies and physical activity.

A limitation for the study was the lack of transcript verification by study participants. To avoid respondent fatigue after having to complete a long survey, then an interview, this step was intentionally avoided. Respondent fatigue is associated with a loss in interest for the study and can increase false responses from the participants.<sup>32</sup> The telephone interview was completed during the coronavirus (COVID-19) pandemic, a time when individuals were overwhelmed with stressors such as increased screen time and lack of face-toface human contact.<sup>33</sup> Gender influences individual opportunities, choices, and health,<sup>34</sup> and unfortunately, our study included only 10% men. This high female response may have not addressed barriers and strategies specific to their male peers. The local, state, and national pandemic regulations could have increased level of participant anxiety and/or depression due to isolation and disruptions in normal routine.<sup>33</sup> In addition, the pandemic could have decreased the ability for participants to meet with their medical team due to COVID-19 restrictions.<sup>35</sup> A strength of the study was there were no restrictions to length of T1DM diagnosis. Having more participants may have brought results to data saturation. Future studies should include not only males, but more diverse participants overall.

### Conclusions

Emerging adults with T1DM have significant daily management challenges in avoiding intensive medical interventions. To circumvent dangerous disease management complications, this study identified 3 main strategies to improve self-care, including medical technology, social support, and physical activity. However, there were barriers also identified that hinder management. Future implications for diabetes educational programming for this age group with T1DM should include an emphasis on fostering social support. Social media was identified as a strategy for individuals to discover a support system, especially for individuals that are isolated or in transition. Daily planned physical activity around weather concerns can improve diabetes management. Education topics specific to physiology, season, and weather changes should be considered for medical professionals. In addition, diabetes education management training for family, and other supporters and an increase in resources for mental health would be beneficial to diabetes management. Future research designed to compare sex, for all age groups among, and other diverse populations emerging adults with T1DM is needed in order to inform individual self-care curriculum. Lastly, public policy targeting accessible, affordable insurance that significantly improves access to insulin and other diabetes management supplies and professionals will benefit diabetes management for this age group.

## **Ethics Declaration**

The host university's Institutional Review Board for the protection of human participants approved all procedures.

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## REFERENCES

- American Diabetes Association. Classification and diagnosis of diabetes: standards of medical care in diabetes—2019. *Diabetes Care*. 2019;42:S13-S28.
- American Diabetes Association. Diabetes technology: standards of medical care in diabetes—2019. *Diabetes Care*. 2019;42:S1-S2.
- American Diabetes Association. Lifestyle management: standards of medical care in diabetes—2019. *Diabetes Care*. 2019;42:S46-S60.
- Arnett JJ. Conceptual foundations of emerging adulthood. In: *Emerging Adulthood and Higher Education: A New Student Development Paradigm*. Routledge, Taylor & Francis Group, 2019;11-24.
- Bowen ME, Henske JA, Potter A. Health care transition in adolescents and young adults with diabetes. *Clin Diabetes*. 2010;28:99-106.
- Centers for Disease Control and Prevention. National Diabetes Statistics Report. Centers for Disease Control and Prevention, U.S. Dept. of Health and Human Services; 2017.
- Roy T, Lloyd CE. Epidemiology of depression and diabetes: a systematic review. J Affect Disord. 2012;142:S8-S21.
- Serlachius A, Northam E, Frydenberg E, Cameron F. Adapting a generic coping skills programme for adolescents with type 1 diabetes: a qualitative study. *J Health Psychol.* 2012;17:313-323.
- Bächle C, Lange K, Stahl-Pehe A, et al. Associations between HbA1c and depressive symptoms in young adults with early-onset type 1 diabetes. *Psychoneuroendocrinology*. 2015;55:48-58.
- Trief PM, Sandberg JG, Dimmock JA, Forken PJ, Weinstock RS. Personal and relationship challenges of adults with type 1 diabetes: a qualitative focus group study. *Diabetes Care*. 2013;36:2483-2488.
- 11. Findley MK, Cha E, Wong E, Faulkner MS. A systematic review of transitional care for emerging adults with diabetes. *J Pediatr Nurs*. 2015;30:e47-e62.
- Nivette AE, Zahnow R, Aguilar R, et al. A global analysis of the impact of COVID-19 stay-at-home restrictions on crime. *Nat Hum Behav.* 2021;5:868-877.
- Brener ND, Kann L, Shanklin S, et al. Methodology of the youth risk behavior surveillance system—2013. MMWR Recomm Rep. 2013;62:1-20.
- Anderson RM, Funnell MM, Fitzgerald JT, Marrero DG. The diabetes empowerment scale: a measure of psychosocial self-efficacy. *Diabetes Care*. 2000;23:739-743.
- Schmitt A, Gahr A, Hermanns N, Kulzer B, Huber J, Haak T. The diabetes selfmanagement questionnaire (DSMQ): development and evaluation of an instrument to assess diabetes self-care activities associated with glycemic control. *Health Qual Life Outcomes.* 2013;11:138.
- Markowitz JT, Butler DA, Volkening LK, Antisdel JE, Anderson BJ, Laffel LMB. Brief screening tool for disordered eating in diabetes: internal consistency and external validity in a contemporary sample of pediatric patients with type 1 diabetes. *Diabetes Care*. 2010;33:495-500.
- Brown JW. Health as expanding consciousness: a nursing perspective for grounded theory research. Nurs Sci Q. 2011;24:197-201.
- Elo S, Kyngäs H. The qualitative content analysis process. J Adv Nurs. 2008;62: 107-115.
- Desjardins K, Brazeau AS, Strychar I, Leroux C, Gingras V, Rabasa-Lhoret R. Association between post-dinner dietary intakes and nocturnal hypoglycemic risk in adult patients with type 1 diabetes. *Diabetes Res Clin Pract.* 2014;106: 420-427.
- Stahl-Pehe A, Lange K, Bächle C, Castillo K, Holl RW, Rosenbauer J. Mental health problems among adolescents with early-onset and long-duration type 1 diabetes and their association with quality of life: a population-based survey. *PLoS One.* 2014;9:e92473.
- Medline Plus. Nick Jonas talks about life with type 1 diabetes. 2017. Accessed April, 2021. https://magazine.medlineplus.gov/article/nick-jonas-talks-life -with-type-1-diabetes
- Mianowska B, Fendler W, Szadkowska A, et al. HbA(1c) levels in schoolchildren with type 1 diabetes are seasonally variable and dependent on weather conditions. *Diabetologia*. 2011;54:749-756.
- Ahola AJ, Tikkanen-Dolenc H, Forsblom C, Harjutsalo V, Groop PH; FinnDiane Study Group. Symptoms of depression are associated with reduced leisure-time physical activity in adult individuals with type 1 diabetes. *Acta Diabetol.* 2021;58:1373-1380.

- Litchman ML, Allen NA. Real-time continuous glucose monitoring facilitates feelings of safety in older adults with type 1 diabetes: a qualitative study. J Diabetes Sci Technol. 2017;11:988-995.
- North Dakota Department of Human Services. North Dakota diabetes report. 2014. Accessed April, 2021. https://www.ndhealth.gov/NutrPhyAct/North\_ Dakota\_HB1443\_Final\_Draft.pdf
- 26. Baumgarten A. MSUM student diabetes pushes for affordable insulin prices nationwide. *The Forum: Fargo-Moorhead*. 2019.
- Martin D, Miller AP, Quesnel-Vallée A, Caron NR, Vissandjée B, Marchildon GP. Canada's universal health-care system: achieving its potential. *Lancet*. 2018;391:1718-1735.
- Brady E, Segar J, Sanders C. Accessing support and empowerment online: the experiences of individuals with diabetes. *Health Expect.* 2017;20:1088-1095.
- Petrovski G, Zivkovic M, Stratrova SS. Social media and diabetes: can Facebook and Skype improve glucose control in patients with type 1 diabetes on pump therapy? One-year experience. *Diabetes Care*. 2015;38:e51-e52.

- Malik FS, Panlasigui N, Gritton J, Gill H, Yi-Frazier JP, Moreno MA. Adolescent Perspectives on the use of social media to support type 1 diabetes management: focus group study. *J Med Internet Res.* 2019;21:e12149.
- Leroux C, Gingras V, Desjardins K, et al. In adult patients with type 1 diabetes healthy lifestyle associates with a better cardiometabolic profile. *Nutr Metab Cardiovasc Dis*. 2015;25:444-451.
- Lavrakas PJ. Encyclopedia of Survey Research Methods. SAGE Publications, Inc; 2008.
- Matias T, Dominski FH, Marks DF. Human needs in COVID-19 isolation. J Health Psychol. 2020;25:871-882.
- Weber AM, Gupta R, Abdalla S, Cislaghi B, Meausoone V, Darmstadt GL Gender-related data missingness, imbalance and bias in global health surveys. *BMJ Glob Health*. 2021;6:e007405.
- Provenzano DA, Sitzman BT, Florentino SA, Buterbaugh GA. Clinical and economic strategies in outpatient medical care during the COVID-19 pandemic. *Reg Anesth Pain Med.* 2020;45:579-585.