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RESEARCH ARTICLE

## Taking a Walk in Their Shoes: The Lived Experiences of Emerging Adults with Type 1 Diabetes

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**ABSTRACT**

The period of emerging adulthood, which has been defined as the time from 18-30 years old, is one of the most challenging developmental periods to navigate through because of all of the significant life changes that occur during this time. Add type 1 diabetes to the mix and the period of emerging adulthood becomes even more challenging. This paper is a secondary analysis of a qualitative descriptive study on challenges of diabetes self-management in emerging adults with type 1 diabetes. It presents three vignettes of emerging adults with type 1 diabetes to help clinicians better understand how these individuals view diabetes management and related challenges during this especially critical developmental stage that is rife with transitions. The vignettes exemplify the multitudes of thoughts, feelings, and emotions experienced by emerging adults with type 1 diabetes when dealing with various aspects of their everyday lives. Important takeaway messages include that apparent diabetes mismanagement is usually not due to negligence, females have extreme fear of hypoglycemia, trying to exercise can be frustrating, mature considerations are made when deciding whether or not to drink alcohol, and diabetes technology can be very helpful but is not helpful for everybody. Additionally, regarding diabetes follow-up visits, the emerging adults in this study desired the personal touch of in-person visits. It is hoped that if clinicians are better able to understand what emerging adults with diabetes are going through during this period of time, in their own words, interventions and care plans can be devised to best meet their needs.

## Introduction

The period of emerging adulthood, which has been defined as the time from 18-30 years old, is filled with big life changes and their accompanying challenges.<sup>1,2</sup> It is a time of identity exploration, self-focus, and a time filled with optimism where anything seems possible. It is also a time of feeling in-between, because the emerging adult is no longer a child but does not yet feel like a full-fledged adult. Additionally, it is a time of instability because of the many transitions that occur during this time. These can include living away from and/or leaving the family home for the first time, being in charge of one's own schedule for the first time, and joining the work force. Developmentally, the transition tasks that occur during this time are establishing independence, defining who they are, and making important educational and/or vocational/career choices.<sup>1-4</sup>

Add type 1 diabetes to the mix and the period of emerging adulthood becomes even more challenging. They are living apart from their parents often for the first time in their lives, and experiencing changes in their support systems. They have irregular schedules and different eating behaviors, and also have fear of hypoglycemia.<sup>5-11</sup> Additionally, emerging adults with type 1 diabetes have a desire to appear "normal" in front of their peers and others.<sup>3</sup> As a result, there is often decreased adherence to diabetes self-management tasks, such that these individuals are often not able to keep up with their complex diabetes regimen sufficiently enough to maintain blood sugars in the target range 70-80% of the time and/or a HbA1c  $\leq 7\%$  (53 mmol/mol).<sup>12-16</sup> All of these developmental and diabetes-specific challenges can also adversely affect academics and job performance in addition to diabetes self-management practices.<sup>6, 8-10, 17-23</sup> Given the above, emerging adults with type 1 diabetes are at especially high risk of suboptimal glycemic control. Structural challenges of the current healthcare system can also potentiate the problem.<sup>12-16</sup>

Emerging adults with type 1 diabetes are no longer considered pediatric patients, but many of them are not yet established with adult diabetes services. There is a paucity of transition programs for youth with diabetes in the United States and presumably elsewhere around the world as well, and there is great variation in the programs that do exist. Additionally, emerging adults with type 1 diabetes have unstable living conditions, changing residences when they go to college and/or start their first job. It is not uncommon for them to be changing residences every few years during early emerging

adulthood. This may contribute to them being lost to follow-up in regards to their diabetes care.

If diabetes clinicians have a better understanding of what emerging adults with type 1 diabetes face, and all of the thoughts and considerations behind their actions, they will be able to create diabetes education and follow-up programs that better meet these youngsters' needs. This article presents three vignettes of emerging adults with type 1 diabetes to help clinicians better understand how they view diabetes management and related challenges during this especially critical developmental stage that is rife with transitions. The vignettes are compilations of the words spoken by study participants who took part in a qualitative study on challenges faced by emerging adults with type 1 diabetes.<sup>11</sup> They exemplify the multitudes of thoughts, feelings, and emotions experienced by emerging adults with type 1 diabetes when dealing with various aspects of their everyday lives.

## Methods

The vignettes portrayed below are a compilation of quotations from a qualitative descriptive study on challenges in diabetes self-management in emerging adults 18-29 years old with type 1 diabetes.<sup>11</sup> Study participants were recruited from a university medical center in a major metropolitan area in the northeastern United States using purposive sampling as well as snowball/referral sampling. Inclusion criteria were English-speaking individuals who were 18-29 years old with type 1 diabetes, able to function independently, and had internet access. Exclusion criteria were pregnant or breastfeeding, unstable renal or thyroid disease, corticosteroid therapy, or cancer that was actively being treated, as the presence of any of these could potentially skew the data being collected.

Data were collected through semi-structured focus groups with supplemental semi-structured interviews. Question topics included diabetes self-management practices, facilitators and barriers to performing diabetes self-management tasks, and unmet needs in the participants' current healthcare services. The focus groups were stratified by gender, and an attempt was made to stratify by age in case younger and older emerging adults faced different challenges. There were a total of 4 focus groups (3 female and 1 male) and 3 interviews (all males) across a total of 21 study participants (15F/6M). All focus groups were audio-recorded and transcribed verbatim by the primary investigator.

DATA ANALYSIS. Scientific adequacy of findings for the primary study were ensured with peer

debriefing, employing reflexivity, member checking, having an audit trail, using rich, descriptive data, and triangulation of data sources. Informational redundancy was reached except for in males and issues specific to Black females. Descriptive statistics were analyzed using Microsoft Excel (Microsoft, Redmond, WA). Focus group and interview qualitative data were analyzed using the Krueger note-based method,<sup>24</sup> with audio tape corroboration. The vignettes in this paper are a secondary analysis, and were put together by grouping together quotations from individuals of similar age and gender to portray a comprehensive picture of three different emerging adults at different stages of emerging adulthood. The names used below are not the names of any of the study participants.

A more comprehensive description of the methods of this IRB-approved study have been published elsewhere.<sup>11</sup> The focus groups were conducted in 2017, when FDA-approved hybrid closed loop systems were in their infancy and prior to the widespread use of video visits. The individuals portrayed here may have different feelings about telehealth than portrayed below if the study were to be repeated in today's post-pandemic world.

## Results - Vignettes of Emerging Adults With Type 1 Diabetes

### SALLY, A 20 YEAR-OLD COLLEGE STUDENT

Sally is a 20 year-old young woman who has completed the first two years of study towards her Bachelor's degree. She has had type 1 diabetes since childhood. During the focus group, she expressed the challenges and frustrations she experiences related to having diabetes. When asked what it was like having diabetes, she said, "Diabetes is like having a full-time job. That's why I get stressed out." "You can't 100% turn off. It always has to be a part of your thought process." "You can't even, like, I can't just run out to the grocery store, I have to bring all my sh\*t with me. Like, *everything* you do, like, when I go to work, I'm like, all right, I'm going to be gone for 14 hours, do I have enough insulin, do I have extra, what if this fails, what if that ..." "I have to take a bag everywhere now. Like I have to take a bag if I go grocery shopping down the street." "Yeah, and that's frustrating."

**Life With Diabetes.** When asked about life with diabetes, Sally was very candid. "It's so tough, when, like, being our age and like, having crazy schedules, and like, people are like partying, and like, eating, like, a ton of food, and, it's just really it's difficult, it's so difficult. So like, a 7.7 (% HbA1c,

or 61 mmol/mol), like, pat yourself on the back. It's so good for like, the age that we are right now." "I want to live a full life, and like, if I want to, like, I have to take care of myself, even though like, some days you just wake up and you don't want to take care of it." What do you tell someone if they ask how things are going with your diabetes? "It's like you're not dying, and you're fine, but like also, like, there are times where you're really low and you're like oh! Am I ok? So, it's kind of hard to...for people to actually like understand and grasp like how serious it can be. Because like, people always see me like 'oh, I forget you have diabetes' and I'm like 'I don't because it's on my mind 24/7' so that can be challenging too."

**College Life.** When specifically asked about college, Sally liked that, "In college I have my own schedule, I can do what I want when I want." This was something positive for her. She went on, "Being away from home forced me to pay attention." She faced challenges transitioning between college and summer break. "I feel like it always changes when I'm going through like transitional phases like summer to school, it's like 'ok, what's gonna happen now?'" She has not yet mastered these transitions, as this phenomenon is still relatively new.

**Food.** Despite paying more attention to her diabetes management in college, "I went to college and carbohydrate counting went out the window." "I don't know what to eat or I'm running here and there or whatever so I'll either eat nothing" because she does not want to deal with the hypoglycemia that may ensue from unpredictable or sporadic activity "or then I'll eat everything on the weekends especially um..." One of the other study participants added, "Carb counting and eating whatever you want are not friends." Sally continued, "I've been noticing even 16 years later how much food really impacts my blood sugars." She then commented on following best practices for giving boluses: "The whole bolus 15 minutes before you eat thing is like such a barrier. Like I'm not really compliant with that, because I'm like...." "Especially with nursing school," said one of the other study participants. Sally continued, "If you're...like I don't necessarily know when I'm going to eat. So...especially at work. Like I don't know when my lunch break is until 5 seconds before I'm going. So it's like, difficult...I've tried to get better at bolusing like 10-15 minutes beforehand, but, um – I think that's definitely like, a barrier."

**Exercise.** Exercise was also challenging. Sally hated having to eat before she exercised to treat or prevent a low blood sugar. "What's the point [of exercising]?" she queried. She also felt her freedom

to exercise whenever she wanted was limited by the constraints of her diabetes management: "It's like, I can't just throw on my shoes and go for a run when you wake up, you know, it's like, you have to [check your blood glucose (BG)] first."

**Diabetes Management.** Despite her best efforts, Sally's blood glucose values are not always in the target range. Her diabetes clinician sometimes confronts her about this. "Sometimes you can't really put words into why your A1c is high," she responded regarding this situation. Additionally, her parents and her diabetes clinicians sometimes bother Sally about her HbA1c and how it is not on point for them. "But it's on point for me so why are you bothering me?"

**Hypoglycemia.** It was astounding to learn how big of a fear Sally and her peers had about hypoglycemia. "Going low is my biggest fear, right up there with drowning." "As soon as I go to sleep it's just like all bets are off. I don't wake up, apparently." "The way that I think about it is one single high isn't going to do very much damage. One single low could." "If you're high during class or at work or commuting or whatever you can deal with it." "When I'm low I literally have to stop what I'm doing because my vision gets really blurry, I shake, like, all those symptoms you have...so that's why for a while I was scared of going low. That was a huge issue."

**Drinking.** Sally's insights regarding drinking alcohol with her peers were unexpected and quite eye-opening. Regarding trying to manage diabetes when drinking alcohol: "It's just so scary...it's just such a mess." "It's just kind of counterintuitive. Yeah, there's definitely no winning." "I don't want to do that (get high), but like I also want to have a good time like when my friends are having a good time, like, and I don't know, it's really tough." The most unexpected comment Sally made was "If they [my friends] are drinking too I can't be their responsibility." The maturity of this response was beyond that expected of a college student. Finally, Sally admitted the decision to imbibe or not was a toss-up between "sacrificing your perfect A1c to like, have a good time with your friends because like, at the end of the day you just want to be like a normal college student too."

**Diabetes Technology.** Diabetes technology (insulin pumps and continuous glucose monitors; also do-it-yourself artificial pancreas) helped keep sugars in range but it also came with its own challenges. "You are now sort of forever you know, you plus whatever machine you're using. And you are reliant on something else to keep living. You literally have

your life in your hands every moment of every day and that can be pretty heavy." Sally uses an insulin pump and a continuous glucose monitor (CGM) to manage her diabetes. She does not yet have a hybrid closed loop system. Regarding using the pump and CGM to keep her sugars in the target range, she says, "It's not that hard, it just takes that much more effort." "When I see that I'm on a good streak I'll like be even more encouraged to keep it up, like 'oh my God, 3 hours of like straight of 110' I like, and then I'll get like scared to eat, I'm like, I can't eat carbs now, I'm just gonna like be really careful, and then like one thing can set it off and then I'm like 'screw everything.' I think I'm more encouraged when I see it's been good anyway." But everything is not always so easy. "I have a lot of good moments but then one thing can easily set it off and it can be hours to days until it [BG's] gets back in range."

**Continuous Glucose Monitoring (CGM):** Despite a few challenges with sensor insertion, Sally is extremely reliant on her CGM. "I get anxiety when I don't have my Dexcom. I'm to the point where it makes me nervous how much I rely on it." She shares her CGM values with a few good friends on campus, but not with her parents or significant other. One of her peers in the focus group asked, "You don't let your parents follow you[r Dexcom]?" Sally quickly responded, "Oh, absolutely not!" She then explained why: "My mom will be like, 'how's your blood sugar today?' and I'm like, 'what kind of a question is that?' Like, 'I'm low in the morning, I'm high now, like – you know what I mean? Like you can't answer that in one question. I just – it would like make me so frustrated.'" Furthermore, if her mother was following her Dexcom she was afraid her mother would be texting her at school checking to see if she was ok. "I'm an individual. I can handle this on my own. If I need help I'll let you know." Sally did not share her CGM readings with her significant other because "It's like moving in."

**Parental Relationships.** Besides not sharing her CGM readings with her parents, Sally sometimes lies to her parents about her BG's. She does this for self-preservation, and not because of any malicious intent: "I lie to them now, I just say that everything is fine" because they "still have the psyche that if my sugar is high I did something bad, and that just adds extra anxiety. It's better just to tell them that my A1c is great, and not explain."

**Work.** In addition to studying full-time, Sally works part-time. "It's tough. Because like you want to be, like managing yourself and like managing, like, taking care of your own diabetes and like, what



you need to do but also be on top of what you need to do for your job.”

#### KRISTEN, A 25 YEAR-OLD WORKING PROFESSIONAL

Kristen is a 25 year-old young woman with long-standing type 1 diabetes who has a white-collar job in a vibrant city in the northeastern United States. When asked about what it was like living with diabetes, she responded, “Diabetes makes us so vulnerable.” “My most recent realization was it’s like a 24/7 job. It’s literally everything you do.” “You’re just constantly thinking...You can’t like enjoy what you’re doing because you’re thinking about your diabetes. Something that’s supposed to be relaxing (yoga) I’m 300 (mg/dl (16.7 mmol/L)), and it’s not fun anymore. And then I have to walk a mile home and the fear of going low is consuming. It sucks.”

**Diabetes Management.** Regarding diabetes management, Kristen said “It would be great if I had nothing else to do.” When asked what else gets in the way, she candidly responded, “Life.” She continued, “I think, those times when you really have to zero in to like, how well you really have to manage and like, predict what your diabetes is going to do, *affects* my management....and when I get home after that workout, I’m like, this is so much work to make sure I was back in range. It’s too much!” Additionally, “Your A1c doesn’t quantify the mental and emotional burden of diabetes. There’s so much behind that number.”

**Identity.** Kristen wanted it to be known that despite the time and attention that diabetes takes, “it’s a huge part of my life, and I’m not denying that, but it’s very much not who I am. I’m not like Kristen the diabetic, I’m like, Kristen, I happen to have diabetes, it’s something I’ve dealt with just about my whole life. But that doesn’t have to be who I am.”

**Work.** Like Sally, Kristen found it challenging trying to balance diabetes management and work. “It’s trying to find that balance between having a job that I love but also having the best diabetes control that I can. ...You kind of have to have a life at the same time and do something fulfilling,... and kind of work diabetes into it as best as possible.” Her peers agreed. One, who is a teacher, agreed. “Sometimes I forget to bolus because I am running around like a chicken with my head cut off chasing the elementary school kids. Or sometimes I deliberately don’t bolus because I am running around school and I don’t want to be low. But I still think ‘I hope that’s not too high...’” Kristen responded, “When I forget to bolus I think, ‘What do I do now? Should I correct the high (BG) or bolus

after the fact for the food that I ate?’” Kristen went on, “I don’t actively do things for people to see [at work].” “I haven’t really asked for anything [at work]. I think, like, I don’t know, I’ve always kind of struggled at work in finding the like, line between like, talking too much between myself and like, I don’t want my coworkers to think I’m less capable, or whatever.” Sometimes Kristen is late to work because of a diabetes-related issue. “I don’t share that as much (i.e., issues like having a failed pump site) because I find that people have trouble differentiating between like, being really really sick and like, an issue of I just need a little time. I don’t want people to say ‘you don’t need to come in’ or to ask if I need to take time off.” She wants to be seen as a valuable contributor to her job, not someone with an affliction who needs special accommodations.

**Hypoglycemia.** Kristen is also deathly afraid of hypoglycemia, and especially nocturnal hypoglycemia. “Going low is my biggest fear in terms of living with diabetes. The fear of low blood sugar is so strong it messes up your whole day.” “The fear of lows is so real, I got on the wrong subway yesterday.” “It’s crippling.” “When someone says ‘you’re going to eat 15 grams of carbohydrate for a low – yeah, right. Nobody’s actually doing that. It’s like survival mode, so...’” “Literally survival mode. It’s like, I need everything and I need it in my body and I need it now.”

**Diabetes Technology.** Kristen found diabetes technology, especially CGM and her hybrid closed loop pump, to be extremely helpful. CGM “gave a little more confidence.” It was “definitely easier. More work though, because you are more conscious of what your body is doing and what’s happening, so it’s more mental burden, definitely. And pressure – pressure to keep your BG between those two lines. If you’re outside of them, you fail.” It was interesting to hear that Kristen felt judged by the target range lines on her CGM. Kristen had to give up her Dexcom CGM because it was not compatible with the insulin pump that was part of her hybrid closed loop system. This made her feel a bit insecure, because she could no longer share her CGM readings with anyone. “The hardest thing about giving up my Dexcom was giving up the Share ... it’s like an emergency, a safety thing.” “It’s nice insurance, someone knows that you’re alive.” However, she really appreciated her hybrid closed loop system. “I never wake up low anymore.” “I never thought that would be achievable.” She reported that even her roommate said, “I never hear you wake up anymore, I never hear you rummaging through the fridge.” To which Kristen responded, “I know, I’m sleeping so well!”

Some of Kristen's peers did not want to use CGM, despite the potential benefits. One said, "We hate each other (she and CGM)." She told doctor she would wear both CGM and a pump but "I can't do both because I'll go crazy, because I get obsessed." Another one distrusted the CGM readings.

**Exercise.** "I love exercising," said Kristen. "I don't know if exercise gets in the way of my diabetes or diabetes gets in the way of my exercise but it never works." The yo-yo BG's and/or wide BG swings associated with exercising and overreacting to prevent a low, then taking insulin to correct the high BG "drove me insane. It drove me absolutely insane."

**Food.** Kristen realizes she is not doing as well as she could be with carbohydrate counting. "I try, so hard...but I think my estimations are off." She is not ready to ask for help yet though, because "It's the mental getting over that hump of admitting that 'ok, you need to relearn how to carb count.'"

**Drinking.** Kristen does not drink much alcohol. "Getting drunk is always a hassle." "I can't have too much fun because I have to make sure I wake up in the morning."

**Parental Support.** At this point of emerging adulthood, Kristen is independent and does not rely on her parents much for help with diabetes-related issues. "I don't turn to them (my parents) for support. ...I mean, I want their support but I don't know how to, you know, reengage them and how to make them understand and how to... I feel there are too many pent-up feelings from like adolescence and teenage years and like, a lot of tension that I don't know how to get them to be involved without me just like, getting angry and going through all that." She also acknowledged that "Parents show they care in small, quiet ways."

**Support From Friends.** Kristen has also been reserved about relying on her friends for support with her diabetes. "It's hard to open up to people," she admitted. "If you don't understand, I don't talk about it [my diabetes]." "[My friends] want to know more but they're afraid to ask because they don't want to be intrusive." "I want people to ask me questions about diabetes because I don't know how to start the conversation."

One day Kirsten overheard her roommate and some other friends talking about another young woman with type 1 diabetes, who always talked about how much she had to do to manage her diabetes. Kristen does not talk a lot about

everything she needs to take into consideration for optimal diabetes management. When she heard her friends talking about how bad this other person's diabetes was, Kristen felt like she had been punched in the gut. "Oh my gosh, you have no idea, we've lived together for 2 years, this was a good friend...I was so offended and angry...but at the same time, you don't know what I do because I don't talk about it. That's also on me because I'm not opening up to you."

**Support From Significant Others.** Kristen is still learning how to navigate getting support for her diabetes management from her significant other. "You want the help but then when you get it you're like ugh, you're doing too much." "I wanted the support so I have to take it in whatever form he gives it to me. He's not going to give it to me when I want it."

#### JACK, A 22 YEAR-OLD COLLEGE STUDENT

Jack is a 22 year-old college student who was diagnosed with type 1 diabetes in early adolescence. Like so many other young men with type 1 diabetes, Jack gives the impression of taking everything in stride: "I'm pretty chill about everything. Kind of just roll with the punches and move on with my life." Which mostly, he does, but there is a lot going on behind the scenes for him too.

**Life With Diabetes.** "Every, you know, kind of waking moment of being, since I've been independent, diabetes has been a factor...I feel like that makes it very tough for me to get to a point where I'm like 'I'm not checking my blood sugar any more.' It's just too ingrained." "It's a lot of extra preparedness and being prepared for whatever you're doing." "It's just sort of like every day is a big math problem playing with the rates you give yourself." "It's not that diabetes gets in the way, I guess that mismanaging your diabetes gets in the way. Too low or too high going into something." "You have infinite number of frustrations, between being high, seemingly without reason in the morning, or, you know, not being able to eat something because my blood sugar is off or I know it will make my blood sugar off, being able to eat it with a sacrifice or sacrificing and not eating it type of thing...little things that are frustrating. But that's kind of part of it I guess."

**Diabetes Management.** For Jack, diabetes management is very different in college than it was in high school. "You just figure out what your thing is, how to react with it,...but it obviously takes time. It's not something that happens overnight. There's certain situations you have to go through to figure out what your thing is. It's kind of like trial by fire a

little bit.” Sometimes he does not check his sugar or bolus when he should, which is a conscious decision based on his surroundings rather than negligence. “A lot of the time I see health as like a secondary concern to whatever is going on with like school, or work. And that’s a big mistake obviously. Other times it’s so much as having social anxiety, to just take it out and measure in like a college classroom. I know nobody cares, I know nobody’s looking, but, it’s just that little beep from the monitor, and like I’m obviously, I’m drawing blood from my finger, so someone would be like, ‘What’s that guy doing?’ So, I don’t know, it’s just that little aspect of social anxiety, that sometimes keeps me from measuring it in class.” “I didn’t want to make it seem like I needed like special attention or anything like that with diabetes. And obviously if your blood sugar is super low all the time or super high all the time you need special attention. So it was more of like, a, I kind of wanna, you know, just kind of blend in and not have this be a huge thing. So that was kind of my motivation behind, you know, keeping everything [in range].” Nevertheless, he still realizes that “It’s when you’re alone, whether it’s in college or the first time you’re being away from your parents, and you realize that you know, you’re kind of all you have to take care of yourself. That’s the first time when you’re like, ‘my parents aren’t around, I can’t do these things I used to do when I was younger’.”

**Hypoglycemia.** Contrary to the young women, Jack and the other young men in the study were generally not afraid of hypoglycemia. “Now that I’m used to diabetes, I’m getting used to everything. I’m not really scared of either, going high or low. It’s just a matter of either correcting it and fixing it for the long term or just trying to eat something or suspend it, depending on the situation.” Additionally, “I didn’t love asking people for help, especially in college and high school....I like to do things on my own, when it comes to diabetes, and I think when you’re put in a situation where you generally need help and you don’t want to ask for help, that’s kind of one of the things where it’s like you don’t want to put yourself in that situation to begin with.” This was also very much a guy thing.

**College.** The transition to college was a learning experience. Jack’s first year in college, “when I was starting to figure everything out, it was a lot of peaks and valleys, since I was on such an intensive course list. So I wouldn’t really think too much about diabetes, it would be more of ‘I need to study, I need to get ready for this exam, I need to get all my homework done, I don’t wanna be that guy to not do anything in college.’”

**CGM.** “The CGM has been like the best thing I’ve gotten, that I’ve done with this. And I’m kicking myself that it took me so long to finally cave in.” “I think having it for college is huge.” “It’s just so cool looking at it.” “It’s completely changed my life.”

**Drinking.** Jack is not a big drinker. “It’s not my thing.” When he does imbibe an alcoholic beverage, “you just have to be smart with it.”

**Work.** Similar to college, Jack does not like to make a big deal about his diabetes at work. “It feels like it’s sort of a, more of a personal private thing, that, outside of just surface level knowledge I don’t feel like uh, much more than that needs to be shared at work.”

**Support From Parents.** “I don’t know if it’s a daily thing, but when I need it it’s kind of always there.” “It’s always there, and I know it’s always there, it’s just not one of those things that we have a daily conversation (about diabetes).”

**Support From Peers & Significant Others.** As mentioned above, Jack does not like to share much with others about his diabetes, nor does he like to ask for help with his diabetes management. But he appreciates the assistance he receives from the few close friends who know more about his diabetes. “I was surprised at how helpful my friends were.” “It’s just the little things,” for example, one friend runs a juice box across campus for him when his blood sugar is low. His roommates “are pretty good about...if they see my meter lying around they ask if I need it, but aside from that they are not terribly involved.” And if they see his pump, they ask, “Oh, what are you doing with that, do you do that every time?” “Maybe I should bring it up more, if that’s ok, I’m not sure,” surmised Jack.

How about Jack’s girlfriend? “She’s there if I ever need it for sure.”

#### DIABETES PROVIDERS AND FOLLOW-UP

All of the emerging adults whose stories were shared above had bonded with their pediatric diabetes providers and were hesitant to leave, even though some of them realized it was time to move on. “Yes, I was still with Peds until earlier this year. That was so embarrassing!” said Sally (20 years old), who was embarrassed sitting in a waiting room with the younger children when she was so much older. “But she was my heart and soul.” “She felt like another mom. She knew me, she knew my diabetes, when I had burnout, she would walk me through those and talk me through those.” Kristen (25 years old) concurred. “I had a really hard time separating myself. It took a lot of convincing....I got

so attached to this one (Pediatric) Endocrinologist that I felt like I couldn't find anyone else. But I was wrong." "You really get an attachment to that particular person (one's pediatric diabetes provider). Even to this day I still keep in contact with her. This was the best doctor ever and no one can ever measure up to her!" "That [relationship is] what I want to build now." Jack (22 years old) also agreed. "My Endocrinologist is like a family member. Going to see him is like visiting an uncle."

Jack (22 years old) did not voice any issues regarding diabetes follow-up visits. "It's just carving out time for it, really." However, both scheduling follow-up visits and the visit itself were viewed as problematic for the females in this study. "Getting appointments is stressful," said Kristen (25 years old). "I find it hard sometimes to get the motivation to do the huge amount of effort it takes to set up an appointment and stick to a schedule and come in from [a significant distance away]," added Sally (20 years old). Sally did not like having to find a local diabetes provider when she was away at college. "It's irritating getting coverage for 1 year while away at school because the new doctor doesn't know me and doesn't get a chance to know me because then I am gone. But commuting 2 hours each way to see my regular diabetes provider is too much." "There's sometimes like these little things, where, like, and even because it's just a little thing it can still make a big difference, where it's like, 'Oh well this person doesn't know completely what they're talking about, so I'm not going to divulge everything because they don't know.' [pause] You know it's like a subconscious thing but I feel like that's, it definitely makes a difference." About her new diabetes provider, she continued, "You have no idea what's going on. Don't give me a judgement because my A1c isn't 6[%] (42 mmol/mol)." "I think sometimes the issue with providers is like they just see the diabetes part of you, and like, you have a whole life, and the idea is like that your care is supposed to fit into that and not become your whole life because no one's going to pay you to be a good diabetic and like sit at home," said Kristen (25 years old). She also commented on mental health services: "If the psychologist or social worker does not know much about diabetes, you waste your time trying to explain your care. Mentally, this is really draining."

For the emerging adults in this study, their ideal diabetes follow-up program included in-person visits that were similar to what they experienced when they were followed by their pediatric diabetes providers. Further details of their ideals appear elsewhere.<sup>11</sup>

## Discussion

As the vignettes above exemplify, it is challenging managing type 1 diabetes during emerging adulthood.<sup>5-23</sup> This fact is not new, but the poignancy of putting the challenges faced by emerging adults with type 1 diabetes in their own words in the peer-reviewed literature is. At the American Diabetes Association's 83rd Scientific Sessions this year (San Diego, CA, USA, June 2023), a prominent pediatric diabetes researcher highlighted the period of emerging adulthood as being the most difficult time to manage diabetes (presentation by Dr. Lori Laffel from Joslin Diabetes Center, June 23, 2023). Several researchers are studying interventions that might help these individuals do better with their diabetes during this time, but this area of study is still in its infancy.

There are some important takeaway messages from the vignettes portrayed above. First, what may appear as diabetes mismanagement to the diabetes clinician often has a multitude of considerations behind the various actions and/or inactions that occur. To our knowledge, this is the first study in the literature that has discovered this. Second, whether or not they say anything during an office visit, emerging adults with type 1 diabetes, especially the females, have great fear of hypoglycemia. While this is consistent with the existing literature,<sup>5-11</sup> the extent of the fear expressed by the emerging adults in this study was astounding. Third, trying to exercise can be frustrating because the carbohydrates needed to offset the hypoglycemia induced by exercise may negate the effects of exercise, in their minds, which may lead to less physical activity than desired. It is already known that some individuals with type 1 diabetes are hesitant to engage in physical activity because of fear of hypoglycemia, and that food intake before or during exercise is used to prevent or treat it.<sup>25,26</sup> However, this is one of the first studies in the literature describing the frustration with needing to eat before exercise in order to prevent or minimize a low blood sugar. Fourth, the comments the emerging adults in this study made about drinking alcohol were very mature and totally unexpected by the research team, and also something that has only previously been published by this research team.<sup>11</sup> Fifth, insulin pumps and continuous glucose monitoring were viewed as extremely helpful diabetes management tools for most, but not all, of the emerging adults in this study. This last point is discussed in more detail below.

It is important to note that this study was done when hybrid closed loop (HCL) pumps had just hit the



market, and the only automated systems available were the Medtronic MiniMed 670G (Medtronic, Northridge, CA, USA) and the do-it-yourself pancreas (DIYP). Technology has advanced exponentially in the six years since the focus groups were held and many more HCL insulin delivery systems are available today. HCL systems help minimize hypoglycemia (and therefore hopefully decrease the fear of hypoglycemia) and also help keep more blood sugars in the target range of 70-180 mg/dl (3.9-10.0 mmol/L) than stand-alone insulin pumps or multiple daily injections, provided the user boluses for the food they eat and does not try to micromanage the HCL system's decisions. The more recently FDA-approved automated insulin delivery (AID) systems, such as Beta Bionics iLet (Beta Bionics, Irvine, CA, USA) and Tidepool Loop (Tidepool, Palo Alto, CA, USA), may help with additional challenges faced by the emerging adults in this study because they do not require the user to count carbohydrates. Some of these newer systems ask that the user identify the size of the meal rather than the actual amount of carbohydrates being ingested, or have technology to account for inaccurate carbohydrate counting and/or the occasional missed food bolus, and at least one (Beta Bionic's iLet) does not require notification of food intake at all.<sup>27-29</sup> Managing blood sugars during exercise continues to be a challenge,<sup>30</sup> but working with these AID systems may also help decrease the exercise-related frustrations felt by emerging adults with type 1 diabetes. Studies need to be done to see how the newer AID systems affect diabetes management in emerging adults with type 1 diabetes, including if there is less or added mental burden and/or psychological distress, especially in specific populations, with increased use of AID systems. Studies also need to explore why some individuals choose not to use AID systems, so that alternate diabetes self-management strategies can be developed for these individuals as well.

If clinicians understand the challenges that emerging adults with type 1 diabetes face, they can offer appropriate anticipatory guidance, educational tools, and/or strategies to help these individuals. The emerging adults in this study expressed difficulties balancing diabetes management with everything else going on in their lives.<sup>11</sup> It would be helpful if diabetes clinicians can meet these individuals where they are instead of passing judgement on them for not having a "perfect" HbA1c or enough time in the target range, and then work with them to help get them where they need to be with regards to both their diabetes management and psychosocial well-being. Tangible, achievable goals are key. Praise the emerging adults for their successes, and

acknowledge their challenges. Take the time to find out why insulin doses or other medications are being missed and/or why glucose values are not available. The best interventions can only be designed when clinicians and researchers have a complete understanding of what is going on, and there is often more to the story than appears on the surface.

There is great need for mental health professionals who understand both diabetes and the developmental period of emerging adulthood to help these individuals successfully navigate through this time in their lives. The emerging adults in this study admitted they would not open up to a mental health professional who did not understand what living with diabetes was like. It is also important to take differing perspectives based on gender, race/ethnicity, and culture into account so that each individual has strategies and a care plan that meets their needs. Additionally, it would also be helpful to offer conversation starters around diabetes to assist with the communication between the individual with diabetes and their friends, peers, and co-workers for those emerging adults who want to say something about their diabetes to those around them but do not know where to start.

Regarding diabetes follow-up visits, it was anticipated that the emerging adults in this study would like the idea of video visits, since individuals in this age group are the highest users of the internet.<sup>31</sup> However, the emerging adults in this study unanimously preferred in-person visits to video visits, because they felt that many meaningful aspects of the visit would be missed or otherwise adversely affected if the visit was done via telehealth.<sup>11</sup> Of note, this study was done before the coronavirus pandemic of 2020, so virtual visits were not the norm. Emerging adults' preferences may or may not have changed in regards to the preference of in-person vs. video visits after their experiences during the past few years. Further research is needed to see if that indeed is the case.

It is important that this population remain engaged in diabetes-specific healthcare services for their overall well-being during this especially critical transitional time period. Various transition programs are currently being studied to determine what model(s) work best to assist emerging adults with type 1 diabetes transfer from pediatric to adult diabetes care.<sup>32,33</sup> Building a good relationship between provider and patient is key for success. Cultural variations or nuances in both diabetes self-management and the journey through emerging adulthood also need to be explored to try to better meet the needs of a diverse group of emerging

adults with type 1 diabetes when an intervention is designed, as variations have been noted in different subgroups.<sup>11</sup>

## Conclusion

The period of emerging adulthood is one of the most challenging times for managing type 1 diabetes. The multitudes of thoughts, feelings, and emotions experienced by emerging adults with type 1 diabetes when dealing with various aspects of their everyday lives, exemplified in the vignettes above, often do not surface during a diabetes office visit. It is only by understanding what emerging adults with diabetes are going through during this period of time, in their own words, that interventions and care plans can be devised to best meet their needs.

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