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The interplay of type 1 diabetes and weight management: A qualitative study exploring thematic progression from adolescence to young adulthood

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Abstract

Background: The impact of weight management in persons with type 1 diabetes (T1D) from childhood into adulthood has not been well described. The purpose of the study was to explore qualitative themes presented by young adults with T1D with respect to the dual management of weight and T1D.

Methods: We analyzed focus group data from 17 young adults with T1D (65% female, age 21.7 ± 2.1 years, HbA1c $8.1\% \pm 1.5$) via inductive qualitative analysis methods. Major themes were compared to themes presented by youth with T1D ages 13–16 years in previously published study in order to categorize thematic progression from early adolescence through adulthood.

Results: Themes from young adults with T1D, when compared to those from youth were categorized as: (a) persistent and unchanged themes, (b) evolving themes, and (c) newly reported themes. Hypoglycemia and a sense of futility around exercise was an unchanged theme. Importance of insulin usage and a healthy relationship with T1D evolved to gather greater conviction. Newly reported themes are unique to integration of adulthood into T1D, such as family planning and managing T1D with work obligations. Young adults also reported negative experiences with providers in their younger years and desire for more supportive provider relationships.

Conclusions: Issues identified by youth regarding the dual management of T1D and weight rarely resolve, but rather, persist or evolve to integrate other aspects of young adulthood. Individualized and age-appropriate clinical support and practice guidelines are warranted to facilitate the dual management of weight and T1D in persons with T1D.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

CONFLICT OF INTEREST

The authors declare no potential conflict of interest.

Keywords

pediatric obesity; pediatric type 1 diabetes; qualitative research; weight management

1 | INTRODUCTION

There has been a marked rise in obesity worldwide.¹ Changes in clinical management of type 1 diabetes (T1D) coupled with an obesogenic environment have been associated with an increase in the prevalence of overweight and obesity among adolescents and young adults with T1D.² The prevalence of obesity is now 13.1% while the prevalence of overweight is approximately 22.9% among adolescents and young adults with T1D ages 13–18.³ T1D and an elevated body mass index (BMI) are independent and compounding risk factors for cardiovascular and microvascular disease.^{4,5} Moreover, individuals with T1D face unique barriers to weight management due to requirements of maintaining euglycemia.^{6–8} Despite these considerations, no T1D-specific guidelines for improving outcomes of both glycemic control and weight management have been established.

The period extending from adolescence and into young adulthood is a particularly challenging time for glycemic control.^{9–11} Data consistently demonstrate an increase in hemoglobin A1c (HbA1c) in the young adult population, which remains elevated until a mean age of 30 years.¹¹ Additionally, this age range is a formative period for weight management,^{11–14} in individuals with T1D¹⁵ and in the general population,¹⁶ as well as establishment of self-care practices.^{17–19} This age also represents a high-risk period for becoming lost to follow up due to the transition from pediatric to adult care.^{20,21}

In a prior study, we used qualitative methods to study perceptions of the co-management of glycemic and weight outcomes among 34 youth and adolescents with T1D aged 12–17 (age 14.1 ± 3 years, HbA1c $8.9 \pm 1.8\%$, and BMI 26.1 ± 4.7 kg/m²). Participants were interviewed in groups of 3–6 using structured interview guides lasting approximately 2 hours. Youth described both a distinct and compounded burden of the dual management of weight and blood glucose and recognized that the management of one condition often facilitated optimization of the other.⁸ In the current study, we used an interview structure identical to the prior study to evaluate the relationship of weight and glycemic management. We hypothesized that there may be age-specific facilitators and barriers to the co-management of euglycemia and weight among young adults with T1D aged 18–25 years. Thus, our objective was to understand and characterize perceived experiences among this older group as compared to the youth group, thereby identifying potential areas where focused care and support from medical providers may facilitate a patient's achievement of weight and glycemic targets.

2 | METHODS**2.1 | Study overview**

We analyzed data from six focus groups, each comprising of two to three young adults with T1D, between August and October of 2017 at the AdventHealth Translational Research

Institute for Metabolism and Diabetes (TRI) in Orlando, Florida. Focus groups were stratified by sex and addressed questions related to eating behaviors, appetite, and the co-management of blood glucose and weight. The study was approved by the Institutional Review Boards at AdventHealth (study site) as well as the University of North Carolina at Chapel Hill and Stanford University (data analysis).

2.2 | Participants

Eligibility criteria were persons with T1D diagnosed for more than 1 year, HbA1c less than 13%, and age 18–25 years who are seen at TRI. Participants were recruited from an adult endocrinology clinic, local support groups, and through a local research database. IRB-approved recruitment materials such as flyers, social media advertisements, and postcards were also used to recruit potential participants. In total, 72 participants were sent materials without a prior contact from the recruitment team and nine participants were recruited in this fashion. The remaining eight were recruited at a local diabetes support group with 25 attendees. Participants identified through one of these methods were contacted using a standardized welcome letter. Potential participants were contacted again via phone and baseline eligibility criteria were assessed using a standardized phone script. Upon enrollment in the study, participants were assigned a participant number and were referred to by their number during focus groups to maintain anonymity.

2.3 | Screening visit

At their first visit, participants provided informed consent, were reevaluated to ensure they met the inclusion criteria, provided a medical history, and demographic information. To capture psychological states and eating behaviors, participants were also administered the Barrett Impulsiveness Survey (BIS-15),²² the Dutch Eating Behavior Questionnaire (DEBQ),²³ and the Diabetes Eating Problem Survey (DEPS-R)²⁴ at this screening visit. During this initial screening, the participants also answered the question, “How would you describe your weight?” with five response options (Very underweight, Slightly underweight, About the right weight, Slightly overweight, and Very overweight) to assess self-perception of weight.

2.4 | Focus group visit

During the second visit, participants attended focus group sessions guided by a member of the research team and a registered diabetes-focused mental health counselor. Focus group sessions were stratified by sex and lasted up to two and half hours with two to three participants per session. Scripted questions asked during each session were focused around eight categories: Appetite, Cravings, Overall Knowledge of Weight Loss, T1D Health vs Overall Health, Main Barriers Faced, Past Weight Loss Attempts, Ways Weight Loss Could Be Made Easier, and Willingness to Participate in Studies (Table S1). Focus group sessions were transcribed by members of the research team (DI and FM) and were subsequently rechecked and reviewed to ensure accuracy prior to analysis.

2.5 | Measures

2.5.1 | Clinical data—BMI (kg/m²), HbA1c, and diabetes duration were collected from electronic health records.

2.5.2 | Demographic information—Self-reported race and ethnicity were collected from all participants using the categories of African American, American Indian, Hispanic, White, and Other; participants were allowed to select more than one category.

Each participant completed three previously validated^{22–26} measures intended to elucidate behaviors around eating as well as disordered eating.

2.5.3 | Impulsivity—The abbreviated 15-item version of the Barratt Impulsivity Scale (BIS15)²² measures impulsivity on three subscales: non-planning, motor, and attentional. Subscales are summed to obtain a composite score. Higher scores indicate a greater degree of impulsivity.

2.5.4 | Eating behaviors—The DEBQ²³ consists of 33 items that measure eating behaviors on three subscales: emotional eating, external eating, and restrained eating. Higher subscale scores indicate a greater degree of the specific eating behavior assessed.

2.5.5 | Disordered eating—Both general and diabetes specific disordered eating behaviors were assessed using the 16-item Diabetes Eating Problem Survey (DEPSR).²⁴ Higher scores are indicative of greater disordered eating behavior.

2.6 | Data analysis

Descriptive analyses of measures were performed using SAS version 9.4 (Cary, NC).

All transcripts were read by the five investigators (AA, DI, AK, FM, and KS) who formed the analysis team. Each member developed an individual code list using an inductive approach to identify potential themes across transcripts. The analysis team then met to discuss themes and generate a consensus list of codes. This cycle of individual inductive coding followed by group consensus occurred three times. After the third cycle, the five members of the research team generated a final list of themes by identifying those codes that reached thematic saturation—this formed the codebook. The transcripts were then coded in accordance with the codebook by AA who developed a list of representative quotes for themes and sub-themes. The most representative quotes for each theme and subtheme were selected for inclusion in the results tables. The analysis team then completed a final verification of data integrity with an evaluation of the finalized themes and quotes. Code co-occurrence was visualized using co-occurrence tables. Qualitative analysis was performed on focus groups transcripts using the finalized codebook in Atlas.ti software version 8.2.4 for Mac (GmbH, Berlin, Germany).

When the data from the present study were fully coded, the themes were best organized when considered in relation to data from the prior study of adolescent youth,⁸ thereby highlighting the evolution of themes from adolescence to young adulthood. We developed a categorization framework based on the progression of themes:

Persistent and Unchanged—themes that were stable over time and expressed similarly in both age groups;

Evolving—themes that were consistent in content but expressed changing elements;

Newly Reported—themes expressed in the present study that were not expressed by participants in the adolescent youth study.

The most consistently expressed themes were incorporated to form a theoretical framework represented by a thematic map (Figure 1).

3 | RESULTS

Seventeen young adults (6 male, 11 female) consented to participate in the study, and 16 completed the focus groups. The characteristics of the study sample are summarized in Table 1. Participants had a mean age of 21.7 ± 2.1 years and an average T1D diagnosis duration of 8.6 ± 5.1 years; 52.9% of participants self-identified as non-Hispanic White, 23.5% as Hispanic, 11.8% as African American, and 11.8% as Other. Seventy percent of the participants used insulin pumps for their insulin delivery.

The mean BMI among participants was 27.9 ± 5.9 kg/m², with 41% of the participants classified as normal weight. When asked to assess their own weight by choosing from one of five categories ranging from “Very underweight” to “Very overweight,” participants appropriately assessed their weight status that demonstrates that the participants of this study are able to accurately provide their perspectives on weight.

The mean HbA1c was $8.1\% \pm 1.5\%$, with 24% of participant’s meeting American Diabetes Association HbA1c recommended goal of $<7.0\%$.²⁷ The mean scores for our sample population’s survey results for impulsivity, disordered eating, and eating behaviors was within one SD of published normative data and followed previously reported sex-related trends (Table S2).^{22–24}

3.1 | Thematic progression

Themes from young adults in the present study were interpreted in relation to themes from the adolescent youth cohort,⁸ here after referred to as “themes from youth.” There was a distinct thematic progression in young adults with T1D with respect to weight management (Figure 1). Namely, themes identified in youth rarely resolve, but rather persist unchanged or evolve to gather new characteristics. Additionally, young adults in the study demonstrate the emergence of novel themes unique to incorporating T1D and weight management into adulthood. The themes discussed were expressed uniformly by participants of both sexes as well as across the range of BMI and glycemic control.

3.2 | Themes persistently unchanged from youth to the young adult population

3.2.1 | Dual burden of T1D and weight management (Table 2)—The strong interplay between T1D and weight management remained essentially unchanged from the youth cohort. Young adults reported that this dual management was frustrating and “turns

your life into numbers.” Young adults reported that both high and low glucose values resulted in dysregulated eating patterns that increased the difficulty of managing both weight and glycemic control. Young adults perceived a need to optimize glucose control before the onset of and during an attempt at weight loss in order to be successful at either weight or T1D management.

3.2.2 | Hypoglycemia as a barrier to weight control (Table 2)—As in the youth cohort, the young adult cohort consistently described the treatment of hypoglycemia as a frequent barrier to optimal weight management, because of the required carbohydrate administration. Young adults expressed that exercise-induced hypoglycemia created a sense of futility around exercise for weight loss, as it resulted in a need for additional calorie consumption. They also voiced an interest in more detailed and personalized insulin regimen with regard to preventing hypoglycemia during exercise.

3.2.3 | Stigma surrounding T1D and weight (Table 2)—Young adults cited experiencing and perceiving stigma related to T1D and weight status in various ways, including misinformation by peers and family about the co-management of T1D and weight, perception that hypoglycemia treatment is a modifiable cause of weight gain in persons with T1D, and pressure to achieve target weight to counter stereotyped associations of obesity and diabetes. Women in the group also expressed feeling pressured to optimize their weight due to perceived societal expectations of weight goals for females. However, young adults discussed both the feeling that their T1D management is a large part of their day-to-day lives and the realization that accepting their T1D management is critical to achieving a healthy life.

3.2.4 | Desire for greater technology integration (Table 2)—Young adults reported that they would like more input from their health care providers regarding diabetes-specific technology. They expressed a lack of information on insulin pumps and perceived a sense of ambivalence from their providers on the use of diabetes technology. Participants discussed an interest in learning more about T1D technology including insulin pumps as well as accessibility to general education for improving glucose control. Additionally, young adults continued to endorse a desire for specific and individualized provider guidance surrounding T1D and weight management with input from technology. Participants also discussed the use of non-diabetes technology, such as phone-based apps and pedometers, to improve accuracy of physical activity monitoring and carbohydrate counting thereby facilitating their goals for optimal T1D and weight management.

3.2.5 | Needs in research studies (Table 2)—As with the youth cohort, young adults echoed a desire for multidisciplinary individualized interventional approach with physicians, nurses, diabetes educators, and dietitians composing the research team. They also expressed a desire for support group of peers and positive reinforcement from study team members throughout an intervention for weight management. This theme extended to potential participation in research studies, where participants reported that communication with the research staff would be helpful during weight management interventions in the following order of preference: text messages, emails, and phone calls.

3.3 | Evolving themes from youth to the young adult population

3.3.1 | The role of insulin in weight management (Table 3)—As in the youth sample, this young adult population reported opposition to insulin purging, defined as intentionally omitting insulin for weight loss. Participants additionally reported advising with parents and teens on the ill effects of insulin omission that represents a new mentorship role in diabetes care. Participants perceived a causal relationship between weight gain and increased insulin intake but also unequivocally stated that maintaining safety via insulin delivery supersedes any potential impact on weight gain.

3.3.2 | Prioritization of glycemic control over weight loss (Table 3)—While many young adults expressed a desire to lose weight, they also reported prioritizing glycemic control over weight loss for their health in a more consistent manner than the prior youth focus groups. Participants discussed that although they may not feel that they have their ideal body shape, improved glycemic control results in both an improved perception of their own health and a sense of accomplishment. As in the youth cohort, they emphasize the use of exercise as an effective means of optimal glycemic and weight control despite the potential for exercise-induced hypoglycemia.

3.3.3 | Unhealthy eating patterns (Table 3)—Participants describe an eating pattern characterized by fasting and subsequent bingeing that is heavily determined by work demands. Young adult participants reported previously described triggers such as boredom, availability of food, and dysregulated eating around of exercise. This type of dysregulated eating pattern expands from the night-time binge eating or hypoglycemia-specific binge eating that youth reported⁸ to episodes reflecting scheduling constraints and likely to occur at any time in the day.

3.3.4 | Personal relationship with T1D (Table 3)—Young adults described their personal relationship with dual management of T1D and weight as well as how they internalized comments from others. These themes evolved to add introspection and self-advocacy. They discussed the importance of advocating for their T1D management as a means of advocating for their health in discussions with peers and family. Participants reported educating family and peers on the need for insulin in a person with T1D, the role of fast-acting carbohydrates in treating hypoglycemia, and avoidance of low-carbohydrate weight loss diets.

3.4 | Newly emerged themes unique to young adult population

3.4.1 | Incorporating responsibilities of adulthood (Table 4)—Young adults described themes related to incorporating T1D and weight management into adulthood. They cite the impact of romantic partnership, financial considerations, and family planning as important and largely positive influence in the dual management of T1D and weight.

Participants who expressed a desire to have children (Table 4) shared a consistent concern related to fears of infertility, inability to maintain adequate health to support and sustain a pregnancy, and concern that their offspring could also have T1D.

Young adults who discussed romantic partnership (Table 4) generally reported them as a means of emotional support and accountability for dietary, exercise, and glycemic goals. When discussed, partnership was generally noted to have a significant role in safety, particularly around hypoglycemia management. Some participants noted that hypoglycemia was difficult to manage alone and found a benefit in partners knowing and anticipating their personal trends of glycemic variability.

Young adults discussed financial considerations (Table 4) both in general and specific to weight and T1D management. They described the financial burden associated with healthy eating, nutritional programs, physical training, sub-specialty care, and diabetes technology. They also reported that their daily life expenses such as rent, bills, and tuition were compounded by T1D costs, thereby further increasing their financial stress.

The young adult cohort discussed management of T1D around the commitments and requirements of work (Table 4). In addition to the generalized unhealthy eating patterns noted earlier, they described dysregulated eating specific to and triggered by their work environment. They report fasting for long periods of time due to the schedule and demands of work, inconsistent access to food, erratic timing of meals, and difficulty managing hypoglycemia. They described difficulty in predicting when they are able to eat and how easily they will be able to address a high or a low blood sugar because of work obligations. They reported that the activity level of their workplace offers an unmodifiable and complicating factor to glycemic control. Those who reported having sedentary jobs described feeling like they had poor health habits. Conversely, those who had active jobs reported hypoglycemia due to activity level and unreliable access to carbohydrate with frequent episodes of excessive eating after the work day.

3.4.2 | Role of medical providers (Table 4)—While there is a continued discussion of the supportive and important role that medical providers can play in diabetes and weight management, there is an emergence of a previously unreported adversarial relationship with providers. Participants reported non-supportive approaches to T1D management, weight management, and dual management from initial diagnosis onward, with reports ranging from information that is too vague to be helpful, to active criticism of glycemic control and weight management. They discussed that medical providers' approach to weight and T1D management can be more detrimental than helpful citing self-blame and a sense of hostility as a result of provider approaches. They also reported fear of being antagonized when they attended their medical visits. Finally, they noted that providers have a more forgiving attitude toward hypoglycemia and a critical approach to hyperglycemia. They frequently reported a desire for a more supportive relationship with their medical providers.

4 | DISCUSSION

While young adults with T1D reported experiences and barriers surrounding T1D and weight management that were similar to those reported by youth with T1D, they also describe specific concerns that evolved or presented unique to their stage in life. The present study highlights the complexity of dual management of weight and euglycemia specific to the life experiences and developmental milestones of young adults with T1D. The findings

from this study highlight T1D as a consideration and platform on which adulthood is processed and incorporated in young adults with T1D.

Persons with T1D face the unique task of balancing self-management practices to maintain both euglycemia and optimal weight management that are often at odds with one another.^{7,28} Foundational to weight management are managing caloric intake and increasing activity level. Yet for persons with T1D, hypoglycemia often occurs following exercise²⁹ and is compounded by the relative insulin sensitive state after exercise, require both carbohydrate intake to achieve euglycemia,⁷ and cessation of exercise. It is well established that these actions may lead to excess caloric intake and decreased activity level thereby leading to weight gain. The young adults echoed the well-established observation that insulin misdosing and overcorrection of hypoglycemia to achieve glycemic control results in weight gain with hypoglycemia as the mediating factor.^{7,30,31} This underscores the need for comprehensive dietary and insulin regimen education directed at self-management behaviors that promote both physical activity and euglycemia while preventing unnecessary hypoglycemia and weight gain.^{28,30}

Themes from the participants in this study demonstrate that many of the perceived barriers to optimal management of both weight and T1D persist into young adulthood unchanged from youth, including hypoglycemia and the dual burden of glucose and weight management. Additionally, these participants highlight adaptive behaviors and attitudes to normalize and ease the burden of dual management of T1D and weight control. By addressing persistent and unchanging barriers to the dual management of weight and T1D, providers can become better equipped to tailor discussion of hypoglycemia, feelings of futility, and importance of specific weight management recommendations in the individual with T1D.

While young adults discussed many facets of T1D and weight management that were expressed in the younger population, several novel themes emerged in this age group that are notable for health-care providers who are involved with patient transitions to adult care such as family planning and financial management. A significant finding from the present study is that incorporating adult responsibilities has direct implications for the management of T1D and weight. Participants discuss the added complexity of accounting for finances, work schedules, and family planning as well as incorporating of adult responsibilities into the management of both T1D and weight. Given that these themes were expressed uniformly across both sexes, and a range of BMI and HbA1c, a discussion of the integration of T1D management with responsibilities of adulthood by the medical provider is warranted. Moreover, the unchanged themes discussed by young adults in this small study suggest additional potential areas to target during this time of transition, including the prevention of exercise and non-exercise induced hypoglycemia. The novel themes discussed by young adults in this small study suggest potential areas to target during this time of transition. Pediatric and adult providers should focus on support on preventing exercise and non-exercise induced hypoglycemia, transitioning to adulthood, and the impact of relationships with partners on T1D and weight management.

In addition, attention should be given to a patient's early experiences with diabetes providers to identify and improve a possible adversarial relationship. The participants in this study describe the effects and repercussions of negative or adversarial discussions around glycemic control and weight. This sense of an adversarial relationship was not noted in the youth cohort but is consistently reported among young adults. However, many of the examples that the young adults cited occurred during the childhood period. Childhood events can surface in adulthood as a means of latent processing of stressful or situations.^{32–34} It is well established that a positive relationship with one's provider is associated with improved glycemic control.³⁵ These data are supportive of a need for a thoughtful approach to both glycemic control and weight management in the person with T1D, further supporting emerging data of the benefit of thoughtful language and incorporating patient-first language on the part of providers.³⁶

Limitations of this study include a small sample size associated with the exploratory pilot study design. The small sample size may have contributed to underemphasized codes or themes. A larger sample size may have allowed for an exploration of thematic variability across weight status or gender. Additionally, participants were recruited from a single center, were predominantly non-Hispanic white, and expressed interest in a focus group study, thereby limiting generalizability to other young adults with T1D. Although the focus groups were stratified by sex, the smaller percentage of male participants may limit the ability to achieve thematic saturation around differences in sex. In addition, it may limit the generalizability of the findings specifically for males with T1D. Participants' survey measures are within the normative data suggesting that their views on eating and impulse are consistent with the larger population. By conducting the focus groups with scripted questions, all participants were exposed to the same questions, mitigating the effect of response bias. Strengths of the study include rigorous qualitative analysis of themes to ensure both thematic saturation and agreement on the interpretation of themes by the analysis team.

To our knowledge, this is the first study to (a) explore themes of T1D care and weight management in the young adult population and (b) compare and contrast the identified themes to those reported in youth. Insights on the thematic progression of the relationship between T1D and weight management are critical for the development of sensible and meaningful guidelines to support persons with T1D. Such guidelines may be particularly important in adolescence and extending through young adulthood, which is a particularly challenging time for glycemic control.^{9–11} These themes can also be used to inform future research questions.

In conclusion, the young adults in this pilot study presented themes that can be characterized as newly emerged, evolved, and persisted and unchanged from themes expressed in a parallel study that recruited youth with T1D. These data offer insight for clinicians seeking to improve counseling and support across age groups with T1D, particularly the transition from pediatric to adult endocrinology care. There is a need for education, access to resources, and evidence-based medical guidelines to help young adults with T1D develop self-management skills for the dynamic progression of the interplay between glucose and weight management to ultimately optimize both outcomes in the long term.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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FIGURE 1.
Theoretical framework of the thematic progression of the dual management of weight and T1D from youth to young adulthood

TABLE 1

Patient demographics and characteristics

Characteristic	<u>All young adults</u> (n = 17)	<u>Normal weight^a</u> (n = 7)	<u>Overweight^a</u> (n = 10)
Demographic characteristics			
Age, years; mean (SD)	21.7 (2.1)	21.3 (2.2)	22 (2.2)
Female sex; n (%)	11 (64.7)	5 (29.5)	6 (35.3)
Race/Ethnicity; n (%)			
Non-Hispanic White	9 (52.9)	3 (42.9)	6 (60)
Non-Hispanic African American	2 (11.8)	2 (28.6)	0 (0)
Hispanic	4 (23.5)	1 (14.3)	3 (30)
Other	2 (11.8)	1 (14.3)	1 (10)
Clinical characteristics			
HbA1c, % (mmol/mol); mean (SD)	8.06 (1.5)	7.3 (0.8)	8.6 (1.6)
Body mass index (BMI); mean (SD)	27.9 (5.9)	23 (1.9)	31.3 (5.3)

^aNormal weight defined as a body mass index <25. Overweight was defined as a body mass index ≥ 25.

TABLE 2

Persistent and unchanged themes from youth to young adulthood

Theme	Representative quotation	Speaker codes ^a
Dual burden of T1D and weight management (2A)	Being diabetic and then having the whole weight loss thing it turns your life into numbers which can be really frustrating because now you are watching your carbs and your calories	349 F NW AT
	It was like, from the beginning, every appointment, it was like, what are your numbers, not just your blood sugar, but what's your weight at this time	358 F OW IT
	You know you're working so hard, you're working out, you're eating much less than all your skinny friends are eating, and you're not losing the weight, and you don't understand why, and you start thinking, "it's my diabetes, and it's all my other health conditions," and it's so discouraging, and it's so depressing	360 F OW IT
Hypoglycemia as a barrier to weight control (2B)	"I'm going to eat a salad for lunch," and then your blood sugar is 50 after that, and you're like, "Well, I tried, I guess." Now I have to eat like 20, 30 carbs, so it kind of defeats the purpose, and you're like, "Okay, why did I even try this,"	358 F OW IT
	And I'll have people tell me, "You know, if you didn't drink juice or eat fruit snacks when you go low, you probably could get abs, and I'm like, "What do you want me to do?"	358 F OW IT
	Tunnel vision, all I get in my mind is, I need to get in the kitchen to grab something... feel like I don't have the power to scream, so weak from being low	176 M OB AT
Stigma surrounding T1D and weight (2C)	Aside from just being a woman, which is pressure enough just to maintain our weight or be thinner	360 F OW IT
	It kind of goes into the whole, for me at least, phase of why bother, you know. You have so many dreams, just like a regular person, but you always have that, what if, or you always have that, maybe it's not for you, you know	361 F NW IT
	You think diabetes and you think the type two and you think being overweight, so I want people to not associate that stigma, so I think it adds an additional pressure... I don't want to be the type two diabetic image that people usually think of	360 F OW IT
Desire for greater technology integration (2D)	I feel like once I got the pump, after I stopped injections, having the pump makes it so much easier that you don't think as much about what you are eating.	351 F OWIT

Theme	Representative quotation	Speaker codes ^a
Needs in research studies (2E)	I will say my A1c and my blood sugar levels, ever since I had my pump the past like three months, have been like close to immaculate. It's way easier to control	178 M NW IT
	I've got an apple watch recently and that has made me more motivated because I like checking like how many steps and how far I have walked and ran. So I would say technology is a big thing that has made it easier to lose weight	351 F OW IT F OB IT M OB AT F OB IT
	It would be nice maybe just to have that if you needed it for sure because like we said about having a support group when you are doing that	351 F OW IT
	Especially if you could say, "Hey! Remember that four pounds you lost? Keep it up!" Like, yeah.	353 F OB AT
	I would say the best way for me usually texts or email.	351 F OB AT

^a Speaker codes: Numerical identifiers of individual participants are listed along with demographic identifiers: AT, above target HbA1c > 7%; M, male; NW, normal weight (BMI < 25 kg/m²); OB, obese (BMI ≥ 30 kg/m²); OW, overweight (25 ≤ BMI < 30 kg/m²).

TABLE 3

Evolving themes from youth to young adulthood

Theme	Representative quotation	Speaker codes ^a
Insulin's role in weight (3A)	They think in their mind that insulin makes them fat... It's a lifesaving medication... You don't want a lcs of 13 or 14. That's gonna do more damage than just being a couple pounds overweight	180 M OW AT
	I have a friend of mine who she is also diabetic and she actually stopped taking insulin ... she did lose weight, but because it was horrible because she had ketones and all that stuff ... that was scary enough for me to be like I will never do that	356 F NW AT
	I was talking to the parents of some tweens and teens, and they were saying how their girls are like dumping insulin... because they think in their mind that insulin makes them fat. Well technically it does, but that's not the mindset that you want	180 M OW AT
Prioritization of glycemic control over weight loss (3B)	I want to be healthy, not only with like weight, but with blood sugars	353 F OB IT
	I'll try to like eat better for an amount of time just to lose some, but overall I would say it's more about being healthy and just keeping my blood sugars in control	351 F OW IT
Unhealthy eating patterns (3C)	To try to lose weight, you definitely become more aware of your diabetes	206 F OWIT
	Instead of just getting one plate of something and going off that, now it's three or four plates piled as high as you can trying every single thing at that buffet. And that's bad	183 M OB AT
	Interviewer: So, in preparation for times like that, do you actually skip a meal? 183: Absolutely would. 180: Skip lunch, breakfast...	180 M NW IT
Personal relationship with T1D (3D)	I don't eat until I'm full, I eat until I hate myself. That kind of thinking.	183 M OB AT
	Don't put your weight loss plan before your health and your diabetes management. Don't think, 'Oh, it doesn't matter what my numbers are. I'm just trying to lose weight.'	180 M OW AT

Theme	Representative quotation	Speaker codes ^a
	You will have to eat something when you don't want to so just not to be discouraged by that. Just keep on.	351 F OW IT
	I have to do a lot of soul-searching to kind of just, that sounds weird but, to accept, like okay, this is the way my body is	358 F OW IT

^aSpeaker codes: Numerical identifiers of individual participants are listed along with demographic identifiers: AT, above target HbA1c >7%; F, female; IT, in-target HbA1c 7%; M, male; NW, normal weight (BMI < 25 kg/m²); OB, obese (BMI ≥ 30 kg/m²); OW, overweight (25 ≤ BMI < 30 kg/m²). [Correction statement added on 30 August 2019 after first online publication: The Speaker codes corresponding to the Representative quotation in Table 3 have been corrected in this version].

TABLE 4

Newly reported themes in young adulthood

Theme	Representative quotation	Speaker codes ^a
Family planning (4A)	And if your kids are going to be diabetic. It's terrifying thinking about a pregnancy.	360 F OW IT
	I always think about, oh, you know, will I be able to be pregnant one day? You have to take care of yourself so good. Even if you eat long before you try to be pregnant.	361 F NW IT
	My main concern right now is for when we start to try to have a child I want to be healthy, not only with like weight, but with blood sugars	353 F OB IT
Impact of partnership (4B)	And that's when my fiancé knows I have been low because I leave a spoon in the sink. So he is like, "Oh you had peanut butter last night?"	353 F OB IT
	Absolutely nothing to do with diabetes management, just about emotional support... It's absolutely amazing, and I think every single doctor's office should be pushing it.	103 M OW AT
	To me, my girlfriend's definitely gone on the track of, okay, you need to take better care of your sugars... Let's eat a good meal	176 M OB AT
Financial management (4C)	The amount of bills I have to pay for and on top of that I am like alright and now I also have to eat healthy, go to a gym and like all of that. It can be expensive.	349 F NW AT
	I have to pay out of pocket... The way my insurance works is I have to pay everything upfront	349 F NWAT
	So, it can be expensive to have the resources... Also, like good food isn't cheap either. No matter how hard you try to coupon and stuff	354 F OB AT
Impact of work (4D)	I work in a hospital... So sometimes I've been there for 8 hours before I can even stop to eat anything... I do try to stuff things into my pockets, so I can at least shove something into my mouth if I need to.	358 F OWIT
	I have a desk job, so I don't really do much, kind of just laze	103 M NW IT

Theme	Representative quotation	Speaker codes ^a
	There will be times at work they let me miss work if I have a doctor's appointment ... no matter what my sugar is I will still go to work	349 F NWAT
Adversarial role of physicians (4E)	My endocrinologist when I was younger, would put so much blame on me ... That traumatizes you for the rest of your life, you know, so it's definitely a self-blaming thing for all of us	360 F OWIT
	You're going to get lectured more for the highs, it's just the truth, because the lows kind of seems like, "Oh, that wasn't really their fault."	358 F OW AT
	I know you guys can't hold our hands throughout the way, but hold our hands throughout the way	361 F NWIT

^aSpeaker codes: Numerical identifiers of individual participants are listed along with demographic identifiers: AT, above target HbA1c >7%; F, female; IT, in-target HbA1c 7%; M, male; NW, normal weight (BMI < 25 kg/m²); OB, obese (BMI ≥ 30 kg/m²); OW, overweight (25 BMI < 30 kg/m²).