



# Disordered Eating Behaviors in Youth and Young Adults With Type 1 or Type 2 Diabetes Receiving Insulin Therapy: The SEARCH for Diabetes in Youth Study

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## OBJECTIVE

This study examines the prevalence of disordered eating behaviors (DEB) and its associations with glycemic control, insulin sensitivity (IS), and psychosocial functioning in a large, diverse cohort of youth and young adults with type 1 or type 2 diabetes.

## RESEARCH DESIGN AND METHODS

In the SEARCH for Diabetes in Youth study, 2,156 youth and young adults with type 1 diabetes (mean  $\pm$  SD age 17.7  $\pm$  4.3 years; 50.0% female) and 149 youth and young adults with type 2 diabetes (age 21.8 years  $\pm$  3.5; 64.4% female) who were receiving insulin therapy completed the Diabetes Eating Problem Survey–Revised (DEPS-R), a self-reported measure for identifying disordered eating. DEB were defined as a DEPS-R score  $\geq$ 20. Demographic characteristics, clinical measures, and health behaviors of participants with DEB and those without DEB were compared by using *t* tests.

## RESULTS

DEB were observed in 21.2% of participants with type 1 diabetes and 50.3% of participants with type 2 diabetes. Participants encountered challenges in maintaining a healthy weight while controlling their diabetes. For both types of diabetes, individuals with DEB had a significantly higher BMI *z* score, lower insulin sensitivity, more depressive symptoms, and poorer quality of life than those without DEB. Diabetic ketoacidosis episodes occurred more frequently in youth with type 1 diabetes with DEB compared to those without DEB.

## CONCLUSIONS

These findings highlight that DEB are prevalent among youth and young adults with type 1 and type 2 diabetes and who are receiving insulin therapy, and DEB are associated with poorer clinical outcomes and psychosocial well-being. Heightened awareness and early interventions are needed to address DEB for this at-risk population, as are longitudinal studies evaluating the course of DEB and diabetes outcomes.

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reports by medical providers. In our study, we used the recommended threshold, defining DEB as a DEPS-R score  $\geq 20$ . In addition, on the basis of the response to each question, we analyzed individual behaviors including self-induced vomiting, binge eating, and skipping meals. Responses could range from 0 to 5; scores  $\geq 2$  (i.e., responses of “sometimes,” “often,” “usually,” or “always”) were considered clinically significant.

Health outcomes were assessed by considering glycemic control, the presence of depressive symptoms, and overall quality of life. Glycemic control was measured by using HbA<sub>1c</sub>. Depressive symptoms were measured by using the CES-D, which is a 20-item scale that measures depressive symptoms and has good sensitivity and high internal consistency (Cronbach  $\alpha$  coefficient = 0.9) (18,25). A cut point of 16 was suggested for adolescents in order to stratify depression severity as minimal (scores 0–15), mild (scores 16–23), or moderate/severe (score 24–60).

Perceived quality of life was measured by using the PedsQL scale, which is a measure based on a model defining quality of life through the evaluation of major categories of fundamental life needs (Cronbach  $\alpha$  coefficient = 0.8). The items are categorized into four scales including physical, emotional, social, and school functioning. As an example, one question asks how much of a problem paying attention in class has been for the individual during the past 1 month. Items on the PedsQL scale are reverse-scored and transformed to a scale of 0–100. Higher scores indicate better perceived health-related quality of life (19).

### Statistical Analysis

Demographic characteristics of individuals in the study sample were summarized by using descriptive statistics. Sociodemographic characteristics and health outcomes were compared across DEB statuses by using the  $\chi^2$  test for categorical variables and the *t* test for continuous variables for each diabetes type. We used three age categories: 10–14 years, 15–19 years, and  $\geq 20$  years. Individual DEB were assessed by counting the frequency of responses for each question. Differences in BMI<sub>z</sub> and IS scores between those who did and those who did not exhibit DEB were

examined by using the *t* test. All analyses were performed separately for type 1 and type 2 diabetes, with a significance level of  $\alpha < 0.05$ . All analyses were performed in SAS version 9.4 (SAS Institute, Cary, NC).

## RESULTS

### Participant Characteristics

We analyzed a total of 2,156 youth and young adults with type 1 diabetes and 149 participants with type 2 diabetes who use insulin and were 10–25 years old. The mean  $\pm$  SD age was  $17.7 \pm 4.3$  years for participants with type 1 diabetes and  $21.8 \pm 3.5$  years for participants with type 2 diabetes. Females accounted for 50% of participants with type 1 diabetes and 64% of those with type 2 diabetes. The predominant racial/ethnic group was non-Hispanic white (75.6%) for individuals with type 1 diabetes and African American (51.0%) for those with type 2 diabetes (Table 1). Participants with type 1 diabetes had higher socioeconomic status and higher household income, and their parent(s) had more education, than participants with type 2 diabetes. The mean  $\pm$  SD HbA<sub>1c</sub> was  $9.2 \pm 1.8\%$  for individuals with type 1 diabetes and  $10.4 \pm 2.5\%$  for those with type 2 diabetes. Approximately 55% of participants with type 1 diabetes receive insulin through a pump and 18.5% use a continuous glucose monitoring (CGM) system, compared with 18.5% and 34.5% with type 2 diabetes, respectively. Overall, participants with type 1 diabetes had higher IS scores (mean  $\pm$  SD  $6.7 \pm 2.5$ ) than participants with type 2 diabetes ( $3.2 \pm 1.8$ ) (Table 1).

### Characteristics of Individuals With DEB

DEB (i.e., DEPS-R score  $\geq 20$ , with all questions analyzed) were observed in 21.2% of participants with type 1 diabetes and 50.3% of those with type 2 diabetes. Mean  $\pm$  SD DEPS-R score was  $12.7 \pm 10.3$  for youth with type 1 diabetes and  $21.9 \pm 12.6$  for youth with type 2 diabetes. The prevalence of DEB among both those with type 1 and those with type 2 diabetes was highest in the 15- to 19-year-old age group: 24.9% of adolescents aged 15–19 years and 16% of those aged 10–14 years with type 1 diabetes reported DEB. Among those with type 2 diabetes, ~67.8% of adolescents aged 15–19 years reported DEB. Among those who had DEB, approximately two-

thirds were female (71.2% of those with type 1 diabetes and 68.0% of those with type 2 diabetes). For youth and young adults with type 1 diabetes, individuals with DEB comprised a higher proportion of nonwhite youth and are characterized by having parents with less education, lower household income, and a lack of private health insurance. For youth with type 2 diabetes, we found no significant associations between DEB status and sociodemographic characteristics.

DEB were significantly associated with higher BMI<sub>z</sub> in participants with type 1 and participants with type 2 diabetes (Table 2). Participants with DEB had lower IS scores (type 1 diabetes: 5.2 vs. 7.1 in those without DEB; type 2 diabetes: 2.5 vs. 3.8 in those without DEB;  $P < 0.01$ ). We found no significant association of total daily insulin dose with DEB for either type of diabetes. Participants with type 1 diabetes who had DEB were less likely to use an insulin pump, but we observed no difference in CGM use between those with and those without DEB. Blood glucose was self-monitored less frequently in participants with DEB; half of the participants (those with type 1 and those with type 2 diabetes) reported checking blood glucose values three times or fewer per day.

### Health Outcomes

Youth with DEB had higher HbA<sub>1c</sub> than individuals without DEB (type 1 diabetes: mean  $\pm$  SD  $10.2 \pm 2\%$  vs.  $8.9 \pm 1.7\%$ ; type 2 diabetes:  $11.0 \pm 2.2\%$  vs.  $9.8 \pm 2.5\%$ ;  $P < 0.001$ ). Participants with type 1 diabetes who had DEB reported more frequent hospitalizations for diabetic ketoacidosis (DKA) in the 6 months before the study visit than did their counterparts without DEB. The frequency of hypoglycemia episodes was not significantly different between the two groups. For both types of diabetes, participants with DEB had significantly higher CES-D scores than those who did not have DEB (16.7 vs. 8.3 in type 1 diabetes; 20.9 vs. 11.9 in type 2 diabetes;  $P < 0.01$ ), indicating more depressive symptoms among those with DEB. They also had lower PedsQL scores than their counterparts, reflecting the overall poorer quality of life (Table 1).

### Specific Behaviors Related to DEB

Regarding specific behaviors queried by individual items on the DEPS-R survey,

**Table 1—Characteristics of cohort study participants stratified by diabetes type and DEB status\***

Characteristics	Type 1 diabetes (n = 2,156)			Type 2 diabetes (n = 149)		
	DEB (n = 458)	No DEB (n = 1,698)	P value	DEB (n = 75)	No DEB (n = 74)	P value
Age, years	18.2 ± 3.8	17.6 ± 4.4	<0.01	21.1 ± 3.3	22.6 ± 3.6	<0.01
Male sex (%)	28.8	55.2	<0.01	32.0	39.2	0.36
Race/ethnicity (%)						
Non-Hispanic black	18.1	8.6	<0.01	56.0	45.9	0.58
Hispanic	13.5	11.0		18.7	25.6	
White	66.4	78.0		21.3	21.7	
Other	2.0	2.4		4.0	6.8	
BMI, kg/m <sup>2</sup>	26.1 ± 5.3	23.2 ± 4.8	<0.01	37.8 ± 9.4	31.8 ± 8.7	<0.01
BMIz	1.0 ± 0.9	0.5 ± 0.9	<0.01	2.0 ± 0.6	1.3 ± 1.1	<0.01
Glycemic control						
HbA <sub>1c</sub> , %	10.2 ± 2.0	8.9 ± 1.7	<0.01	11.0 ± 2.3	9.8 ± 2.5	<0.01
Total daily insulin, units/kg/day	0.9 ± 0.4	0.8 ± 0.4	0.55	0.7 ± 0.4	0.8 ± 0.5	0.22
CGM use (%)	4.1	14.9	0.38	14.8	16.1	0.76
Self-monitoring of blood glucose (%)						
Less than once a week	15.2	0.0	<0.01	37.9	25.4	0.15
Less than once a day	0.0	10.0		0.0	0.0	
1–2 times/day	17.2	14.9		34.9	26.9	
3 times/day	17.9	54.2		15.2	26.9	
4–6 times/day	43.7	9.9		10.6	19.4	
≥7 times/day	6.0			1.4	1.4	
IS score	5.2 ± 2.0	7.1 ± 2.5	<0.01	2.5 ± 1.3	3.8 ± 1.9	<0.01
DKA (≥1 episode) in preceding 6 months (%)	12.0	4.7	<0.01	5.3	4.1	NS
CES-D score	16.7 ± 10.3	8.3 ± 7.5	<0.01	20.9 ± 11.0	11.9 ± 10.5	<0.01
PedsQL score	72.4 ± 14.6	84.8 ± 11.8	<0.01	68.7 ± 17.4	80.8 ± 16.7	<0.01

Data are mean ± SD unless otherwise indicated. \*DEB status is based on DEPS-R category.

31.5% of participants with type 1 diabetes and 60.3% of participants with type 2 diabetes reported challenges in maintaining a healthy weight while controlling their diabetes in the preceding month (Fig. 1). Among the participants, 20% of those with type 1 diabetes and 34.2% of those with

type 2 diabetes reported concern that their eating is out of control. Approximately 12% of youth with type 1 diabetes and ~33% with type 2 diabetes reported a desire to be thin even at the expense of good diabetes control. Approximately 18.2% of participants with type 1 diabetes

and 23.1% with type 2 diabetes reported taking less insulin than they should. Among the obese subjects with type 1 diabetes, 60.9% reported binge eating, whereas 47.2% of participants with a normal or low weight reported this behavior (Table 3). Skipping meals was more common among obese participants with type 1 diabetes.

Participants with type 1 diabetes who skipped meals had a higher frequency of reported severe hypoglycemic episodes (data not shown;  $P = 0.03$ ). We also analyzed individual behaviors with respect to BMI and IS scores for participants in both diabetes groups. Significantly higher BMI and lower IS scores were observed in participants with type 1 diabetes who restricted insulin, skipped meals, or binged, but this finding did not reach statistical significance in individuals with type 2 diabetes (Table 2).

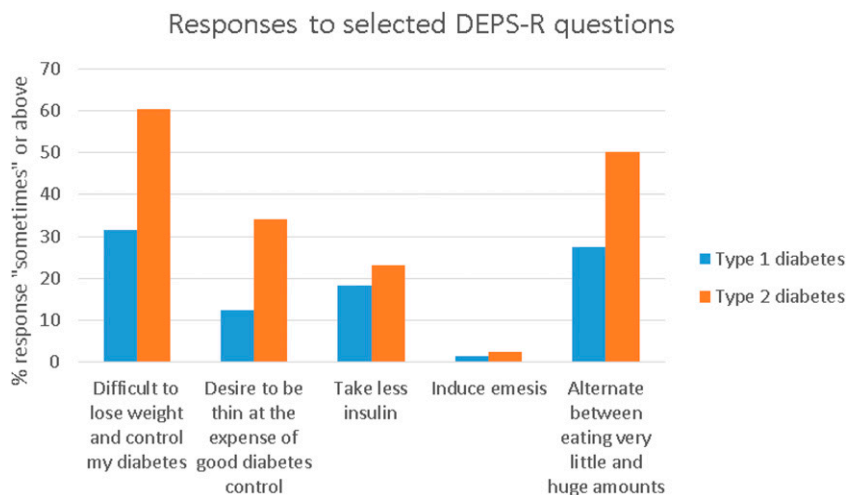
## CONCLUSIONS

In our study, which is to our knowledge one of the largest to include adolescents and young adults with type 1 or type 2 diabetes, DEB were observed in more than one in five of all participants with

**Table 2—BMI, HbA<sub>1c</sub>, and IS scores associated with the presence of individual DEB in participants with type 1 diabetes\***

DEB	BMI (kg/m <sup>2</sup> )	P value	HbA <sub>1c</sub> (%)	P value	IS score	P value
Insulin restriction#						
Yes	24.3 ± 4.9	0.03	10.5	<0.01	5.4 ± 2.0	<0.01
No	23.7 ± 5.0		8.9		7.0 ± 2.5	
Skipping meals##						
Yes	25.5 ± 5.4	<0.01	9.5	<0.01	5.9 ± 2.3	<0.01
No	22.9 ± 4.5		9.1		7.2 ± 2.5	
Binge eating###						
Yes	24.5 ± 5.1	<0.01	9.6	<0.01	6.1 ± 2.3	<0.01
No	23.1 ± 4.8		8.8		7.3 ± 2.5	
Self-induced vomiting####						
Yes	25.7 ± 5.4	0.04	10.2	<0.01	5.0 ± 2.0	<0.01
No	23.8 ± 5.0		9.2		6.8 ± 2.5	

\*Significant differences were not found in reported behaviors of participants with type 2 diabetes. #Behavior derived from the survey question regarding insulin restriction: "I take less insulin than I should." ##Behavior derived from the survey question regarding skipping meals: "I skip meals and/or snacks." ###Behavior derived from the survey question regarding binge eating: "I alternate between eating very little and eating huge amounts." ####Behavior derived from the survey question regarding self-induced vomiting: "I make myself vomit."



**Figure 1**—Responses to DEPS-R questions scored  $\geq 2$  (“sometimes,” “often,” “usually,” or “always”) by study participants with type 1 diabetes and participants with type 2 diabetes.

type 1 diabetes and in approximately half of participants with type 2 diabetes. The frequency of DEB in females with type 1 diabetes was 30% in our study, similar to previous reports that ~35–40% of females aged 10–19 years old who have type 1 diabetes have DEB (26). DEB were more prevalent in our cohort of youth and young adults with type 2 diabetes than is indicated by findings in adults with type 2 diabetes (6.5–20.0%) (11). Insulin omission was reported in 18% of participants with type 1 diabetes and in 23% of individuals with type 2 diabetes. The frequency of insulin restriction in our study was less than that reported among adults with type 1 diabetes (30–35%) (27); this perhaps is attributable, at least in part, to parents’ involvement in youths’ diabetes management.

Given the focus on planning meals, portioning food, and monitoring carbohydrate intake that is recommended for those managing diabetes, it is not surprising that individuals with diabetes are susceptible to unhealthy behaviors around food. The prevalence of subclinical eating disorders is estimated at 3.6% among the adult population, increasing

up to 15–20% among the obese population (10). Similarly, our study demonstrated that DEB are associated with higher BMIz in both types of diabetes. Youth and young adults who are overweight or obese may desire to lose weight, which may result in a negative body image, dieting, and DEB (11,26,28). Overweight and obese youth and young adults with diabetes are commonly counseled to reduce their weight, at which time health care professionals should query for, identify, and address DEB. Specific eating habits, such as binge-eating behaviors, are common among obese individuals. We corroborated this in our study using responses about alternating eating very small and very large food portions. It was surprising that, in our cohort, those who restricted insulin had a higher BMI than those who did not restrict insulin, given the catabolic effects of insulin deficiency (29). This association may reflect concomitant maladaptive behaviors such as binge eating that co-occur with insulin restriction. In the subset of participants with type 1 diabetes who have low BMI (z score 1 SD below the mean), ~10% had features of DEB, suggesting that components of

dieting or restricting meals in order to lose weight can occur along the weight spectrum. We observed no significant associations related to insulin restriction in our population with type 2 diabetes, likely because of the small sample size.

Recent evidence suggests that the age at onset of DEB decreases over time, with a current median age at onset estimated at 14–19 years (30). In our study, among those with type 1 diabetes, 16% of children aged 10–14 years and 24.9% of adolescents aged 15–19 years had some form of maladaptive behavior, such as binge eating and omitting insulin. Adolescence is a developmental stage in which risky behaviors such as alcohol use, unsafe sexual behaviors, and unhealthy dietary behaviors are increased. Furthermore, social media and peers influence many adolescents’ body image, and genetic risk for DEB is moderated by the onset of puberty (31,32). Thus, adolescence is a critical period of risk for the onset of DEB.

In our study, we found that youth with type 1 diabetes who reported DEB were more likely to be female. The development of type 1 diabetes during pre-adolescence seems to place already susceptible girls at an even greater risk for the subsequent development of eating disorders (33). We found no significant difference in DEB between females and males with type 2 diabetes in our study; both are susceptible to DEB. Thus, health care providers should be aware of the increased risk in both sexes (34).

In addition, we observed that DEB occur more often in those with lower household income and whose parents have less education. This may reflect less parental attention to their child’s diabetes, food insecurity (including challenges in purchasing healthy food and a paucity of structured meals), or both (35,36).

To our knowledge, this study is the first to look at the association between insulin sensitivity and DEB in individuals with diabetes by using IS scores

**Table 3**—Prevalence of each behavior per weight categories in type 1 diabetes

	Insulin restriction	Skipping meals	Binge eating	Self-induced vomiting
Normal weight or underweight ( <i>n</i> = 1,309)	18.3%	30.3%	47.2%	1.1%
Overweight ( <i>n</i> = 408)	16.2%	39.9%	57.5%	1.0%
Obese ( <i>n</i> = 258)	18.2%	55.2%	60.9%	3.1%
<i>P</i> value	0.6213	<0.001	<0.001	0.0632

Sample sizes by weight do not include all participants because of missing data for participants in each weight category.

estimated from clinical measures including waist circumference, HbA<sub>1c</sub>, and triglyceride levels (23). In both participants with type 1 and those with type 2 diabetes, DEB were associated with lower IS scores and hence more insulin resistance. It may be that those with DEB had a higher BMI<sub>z</sub> and thus are more likely to have an unhealthy weight, leading to increased insulin resistance. This is in contrast to a previous study of individuals with anorexia nervosa but without diabetes, in which IS had a strong, positive genetic correlation with anorexia nervosa, related to the effect of leptin on regulating food intake and energy expenditure (37).

In our study, DEB were associated with worse glycemic control in participants with either type of diabetes. In particular, participants who reported skipping meals or binge eating had higher HbA<sub>1c</sub> values. Although not examined in this report, hyperglycemia and elevated HbA<sub>1c</sub> can lead to long-term diabetes-related complications including retinopathy, nephropathy, and neuropathy, which may be accelerated by DEB (38). DEB were also associated with a twofold increase in the number of DKA episodes in the past 6 months among participants with type 1 diabetes. Insulin omission is a unique but maladaptive strategy to promote weight loss in individuals with diabetes, and this places those individuals at increased risk for developing DKA (38). DKA is less often observed in people with type 2 diabetes despite poor glycemic control, largely because of relatively sufficient insulin to block lipolysis and ketoacid formation.

Participants with DEB were more likely than those without DEB to have more depressive symptoms and lower perceived quality of life, which may further compromise their diabetes management. Our study focused only on DEB; however, factors including adherence to the medical regimen, resilience against stress, and family/peer support also play important roles in diabetes management that can affect health outcomes. Declining diabetes control is common as children progress toward adolescence and is due to behavioral and health-related challenges in diabetes (39).

One limitation of our study is that the DEPS-R has not been validated in

individuals with type 2 diabetes. Most questions are relevant to individuals with type 2 diabetes who take insulin, including those regarding binge-eating behaviors, insulin omission, and efforts to control weight. However, one question asks whether weight loss is an important goal. We conducted additional analyses to explore the validity of the DEPS-R for youth with type 2 diabetes in our sample by excluding the item, "Losing weight is an important goal to me." We considered that this might be too general a question for youth and young adults with type 2 diabetes, as weight loss is recommended often. We maintained the same scoring system for individuals with type 2 diabetes. The majority of youth with type 2 diabetes scored high for this question, which might overestimate the overall scores. When this question was excluded, ~39% of participants screened positive for DEB; this did not change our results for youth with type 2 diabetes (Supplementary Table 1). The Youth Eating Disorder Examination Questionnaire was used in the TODAY study in order to measure eating disorder symptoms in young people with type 2 diabetes (12). Existing instruments/tools that are used to assess diabetes-specific eating and treatment behaviors and concerns in type 2 diabetes need to be refined. In addition, dietary intake and amount of exercise are not part of the DEPS-R screening tool.

Another limitation is the relatively small sample size of individuals with type 2 diabetes. Because of the questions related to insulin in the DEPS-R screening tool, we included only participants receiving insulin therapy, which limits the generalizability of our results. Because this was a cross-sectional study, we are unable to delineate the causal relationship between DEB and diabetes outcomes.

Strengths of the study include the diverse population in the cohort included in the SEARCH for Diabetes in Youth study, one of the largest studies of youth-onset type 1 and type 2 diabetes in the U.S. Both females and males with diverse ethnic, racial, and socioeconomic backgrounds were assessed in this study. Furthermore, we used a diabetes-specific tool to evaluate the prevalence of DEB among people with diabetes.

Various treatments exist for eating disorders, including family-based therapy and cognitive-behavioral therapy. Early intervention has been reported to improve long-term outcomes. However, few treatments for DEB have been tested specifically in patients with diabetes, and therapy tends to be less successful in patients with type 1 diabetes than in those without diabetes (40).

In conclusion, our study showed that DEB are common in youth with type 1 diabetes and youth with type 2 diabetes, and they are associated with poorer clinical and psychosocial functioning. Assessment for DEB is an important element of psychosocial care of youth and young adults with diabetes and is recommended to begin during early adolescence. Further studies of effective preventive interventions and treatments are needed.

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**Author Contributions.** A.S.Y.N. and C.P. wrote the manuscript, researched data, contributed to the discussion, and reviewed the manuscript. B.A.R. researched the data and reviewed the manuscript. D.D., A.B., E.J.M.-D., A.R.K., J.M.L., C.M.P., and L.D. contributed to the discussion and reviewed and edited the manuscript. A.S.Y.N. is the guarantor of this work and, as such, had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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