

Eating Disorders in Adolescent Girls and Young Adult Women With Type 1 Diabetes

Preface

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Teens with type 1 diabetes face two clashing realities. On the one hand, the results of studies such as the Diabetes Control and Complications Trial (DCCT) provide irrefutable evidence of the link between diabetes control and the onset and progression of diabetes-related microvascular complications.¹ The DCCT message was loud and clear: Control counts! On the other hand, there are numerous studies, including the DCCT, demonstrating that, during adolescence, metabolic control tends to be poorest and that the goals of intensive diabetes management are more difficult to achieve.^{2,3}

What are the reasons for poor glycemic control in adolescents with type 1 diabetes? I believe that it results from the complex interplay between biological (e.g., insulin resistance of puberty) and psychosocial (e.g., non-compliance, family environment) factors. Our group has focused on one specific contributing factor, namely, eating disorders in teenage girls with type 1 diabetes. This From Research to Practice section offers a review of this topic by our research group at the University of Toronto.

This is a departure from the usual format of *Diabetes Spectrum* research sections in that the entire section com-

prises contributions from a single research group. A number of groups around the world have made substantial contributions to this field, and we have been as diligent as possible in citing their enormous contributions. However, we do hope that our group has been able to provide a unifying view of the pathophysiology and impact of eating disturbances in girls and young women with type 1 diabetes. Our aim is to sensitize readers to the manifestations of this common co-morbidity and to highlight areas where further research is warranted.

Because this monograph-style presentation represents the combined efforts of all of the authors, we have listed only the primary contributors to the writing of each section. We have provided a single reference list at the end of the discussion to avoid unnecessary repetition of citations.

In addition to myself, contributors to this research section include Gary Rodin, MD, FRCPC; Jennifer Jones, PhD; Patricia Colton, MD; Anne Rydall, MSc; Sherry Maharaj, PhD; and Marion Olmsted, PhD of the Eating Disorders and Diabetes Research Group at the University of Toronto; the University Health Network; and the Hospital for Sick Children, in Toronto.

Eating Disorders in Adolescent Girls and Young Adult Women With Type 1 Diabetes

1. Introduction

Since the early 1980s, there has been increasing attention paid to the possible relationship between type 1 diabetes and eating disorders in young women. Initial interest was sparked by individual case reports of adolescent girls or young adult women with diabetes who also suffered from anorexia nervosa.⁴⁻⁶ The outcome of this combination is often catastrophic, with poor metabolic control, growth delay, recurrent diabetic ketoacidosis (DKA), earlier-than-expected onset of diabetes-related complications, and premature mortality. These clinical observations sparked a more systematic attempt to define the relationship between diabetes and eating disorders. Subsequent research by our group and others has allowed us to reach the following evidence-based conclusions:

- i. Eating disorders and their subthreshold variants are approximately twice as common in adolescent females with type 1 diabetes as in their peers without diabetes.⁷ These eating disorders fall largely into the categories of full-syndrome bulimia nervosa and its subthreshold variants, and eating disorder not otherwise specified (ED-NOS; binge-purge variety).
- ii. Eating disorders are associated with poor metabolic control (higher hemoglobin A_{1c} [A1C] levels) and earlier-than-expected onset of diabetes-related complications, particularly retinopathy.⁸⁻¹⁰
- iii. Adolescent girls and young adult women with diabetes frequently use deliberate insulin omission to achieve weight control or weight loss.^{7,10-12}
- iv. The quality of the family environment, maternal weight and shape concerns, and eating disturbances in young women with type 1 diabetes are closely interrelated.¹³⁻¹⁵

- v. The value of interventions to treat or prevent eating disorders in young women with diabetes is largely unknown.¹⁶

This From Research to Practice section presents a review of the data regarding eating disorders in young women with type 1 diabetes in order to alert health care professionals to the prevalence, presentation, and associated problems of this co-morbidity. The contributors to this monograph are all members of the Eating Disorders and Diabetes Research Group at the University of Toronto that comprises a multidisciplinary team of health care professionals including a pediatric endocrinologist (DD), psychiatrist (GR), clinical psychologists (MO, SM), research coordinator (AR), population health scientist (JJ), and graduate students and postdoctoral fellows (AR, JJ, SM, PC).

We include here a description of our model for the interaction between type 1 diabetes and eating disorders, a review of the evidence to support this linkage, and consideration of its relevance for health care professionals involved in the care of adolescent girls and young adult women with type 1 diabetes.

1. Model for the Interaction Between Type 1 Diabetes and Eating Disorders

We have postulated that there is an increased risk of eating disorders and their subthreshold variants in young women with type 1 diabetes, likely due to multiple interacting factors associated with diabetes and its treatment (Figure 1).¹⁷⁻¹⁹ We believe that specific aspects of diabetes and its management amplify the core features of eating and weight psychopathology, namely body dissatisfaction, dietary restraint, and the drive for

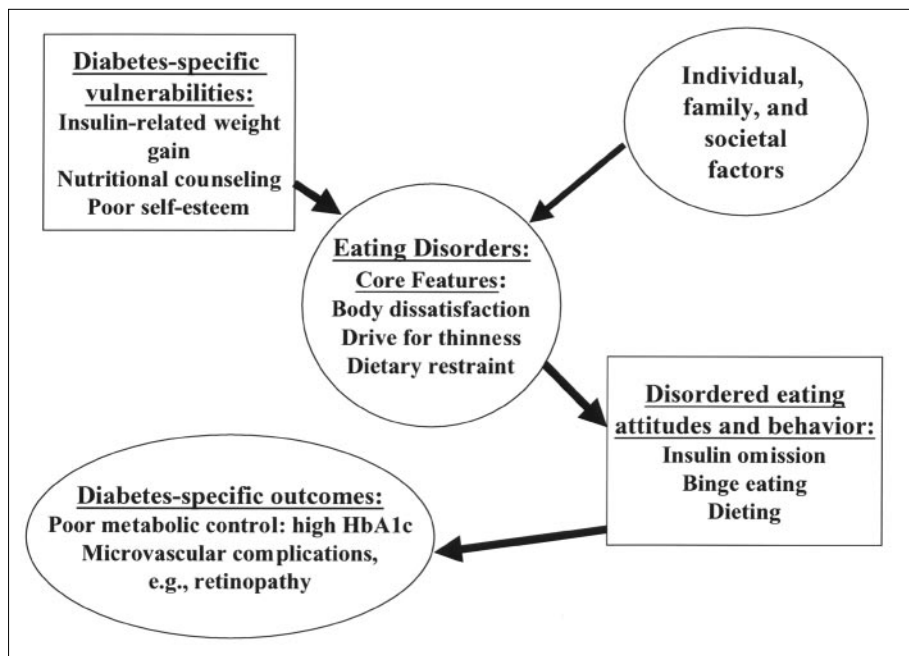


Figure 1. Model of the interaction between type 1 diabetes and eating disorders.

thinness. The following diabetes-specific factors interact with other individual, family, and societal vulnerabilities to lower the threshold for expression of an eating disorder in adolescent or young adult women with type 1 diabetes:

i. The weight gain and consequent body dissatisfaction that may be

associated with effective insulin therapy.^{3,20,21} By the time of diabetes diagnosis or during periods of poor metabolic control, there may be loss of weight. For some young women in the immediate preteen or early teen years, this weight loss may be perceived to be highly desirable. However, the

introduction of insulin treatment or improved metabolic control inevitably leads to weight gain, which may negatively affect the vulnerable teen.

ii. The perceived dietary restraint related to nutritional management of diabetes.¹⁷ All diabetes treatment regimens include education about food and its impact on diabetes control. More traditional diabetes diets (e.g., exchange type diets, weighed-and-measured approaches) provide a more rigid approach to nutritional planning and the potential for perceived dietary restraint. However, even more flexible approaches to meal planning (e.g., carbohydrate counting) may be perceived by many young women to impose dietary restraint.

iii. Deliberate insulin omission as a unique and readily available means of controlling weight, by inducing hyperglycemia and glycosuria.²² Many groups have shown that deliberate insulin omission or dose manipulation is the most common method of purging among girls with diabetes^{7,10,23} and that this behavior becomes progressively more common as weight and shape concerns increase in young women.¹⁰

In Brief

This section reviews the prevalence of eating disorders in young women with type 1 diabetes, highlighting changing diagnostic criteria, methodological, and sample-size issues. We present strong evidence that eating disorders are twice as common in young women with type 1 diabetes compared to their peers without diabetes. These data suggest the need for a high index of suspicion in this population and for the development of appropriate prevention and treatment interventions.

2. Prevalence of Eating Disorders in Girls With Type 1 Diabetes

Primary contributors: Jennifer Jones, PhD, and Patricia Colton, MD

A substantial number of studies have investigated the prevalence of eating disorders in adolescent girls and young adult women with type 1 diabetes. Systematic studies have determined that eating disturbances, including subthreshold and clinical (full-syndrome) eating disorders as well as milder behavioral disturbances, are common in young women with diabetes and are associated with poor metabolic control and increased long-term diabetes-related morbidity and mortality. However, the results of studies that have compared the prevalence of eating disorders in adolescent girls and adult women with type 1 diabetes to that of their peers without diabetes have varied considerably.^{7,23-29} The outcomes of these studies appear to depend heavily on the sample studied, the methodology employed, and the diagnostic criteria for eating disorders applied.

A few studies have assessed the occurrence of diabetes in clinical samples of patients with eating disorders. Not surprisingly, virtually all have failed to show a high prevalence of type 1 diabetes.^{5,30-33} However, in the majority of studies that have assessed eating psychopathology in samples with diabetes, the results have been more varied. While some of these studies have shown similar rates of eating disturbances as those reported in populations without diabetes,³⁴⁻³⁷

others have reported significantly higher rates.^{10,22,31,38-43}

Most of the early studies relied on self-report measures rather than standardized interviews to diagnose eating disorders and did not include control groups. Further, all of these studies have had relatively small samples of female subjects with diabetes within the age range at highest risk for eating disorders, namely, older adolescence and young adulthood. This has limited their generalizability and power to detect meaningful differences.

i. Methodological Considerations

It is likely that the varying diagnostic criteria used to identify clinical eating disorders in the above studies account, at least in part, for their conflicting findings. Indeed, prevalence rates have been greatly affected by changes in the diagnostic criteria for eating disorders specified in the revised editions of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) by the American Psychiatric Association. Earlier studies using DSM-III⁴⁴ and DSM-III-R⁴⁵ criteria most likely excluded many cases of eating disorders in young women with diabetes because insulin omission to produce weight loss was not yet considered an “inappropriate compensatory behavior” included in the criteria for the diagnosis of bulimia nervosa. On the other hand, the diagnostic criteria used

in the DSM-III were broader and in other ways more inclusive than those in the DSM-III-R and DSM-IV.⁴⁶ Insulin omission was included under “misuse of medications for weight loss” in the DSM-IV criteria for bulimia nervosa and ED-NOS. Table 1 lists the DSM-IV diagnostic criteria for eating disorders.

In studies using the broad DSM-III criteria, a diagnosis of an eating disorder was made in 17–35% of females with type 1 diabetes.^{38,39,42,43} The rate fell to 5–16% in studies using the far stricter DSM-III-R criteria.^{8,22–24,47,48}

Finally, studies using DSM-IV criteria have reported the prevalence of eating disorders to range from 7–11% of adolescent and young adult females with type 1 diabetes.^{7,29,49}

In all of the studies employing DSM-IV criteria, bulimia nervosa and ED-NOS are much more common than anorexia nervosa. This finding is not surprising, given that bulimia nervosa and its variants are more common than anorexia nervosa in the general population.^{46,50} In addition, the dietary dysregulation related to diabetes and the availability of insulin

omission for purging may specifically increase the risk of bulimia-spectrum disorders rather than that of restricting-type disorders, such as anorexia nervosa.

ii. Controlled Prevalence Studies Using Diagnostic Interviews

Since 1990, eight controlled, interview-based studies of the prevalence of eating disorders in type 1 diabetes have been reported (Table 2).^{7,23–29} In all but one of these,²⁵ the frequency of eating disorders in females with diabetes was at least 50% greater than among control subjects, although in only two was this difference statistically significant.^{7,29} All but the study by Jones and colleagues⁷ had small sample sizes and consequently insufficient power to demonstrate that a difference of this magnitude was statistically significant.

Peveler and colleagues²⁴ conducted a cross-sectional survey to determine the prevalence of eating disorders in 33 female and 43 male adolescents aged 11–18 years with type 1 diabetes, compared to 76 matched control subjects without diabetes. Features of eating disorders were not found in any of the male subjects. In the females, no subjects met criteria for anorexia nervosa or bulimia nervosa, but 9% of the adolescent girls with diabetes and 6% of the female control subjects met criteria for ED-NOS. This 50% difference between groups was not statistically significant, leading the authors to conclude that the prevalence of eating disorders is not increased in young women with type 1 diabetes. However, this study had only a 7.5% chance of detecting a significant difference of this magnitude, based on the sample size and the prevalence rates found. Further, although 12% of the sample with diabetes admitted to current manipulation of insulin dose for weight and shape reasons, the DSM-III-R criteria used in this study did not include the manipulation of medication (including insulin) as an inappropriate compensatory behavior. These methodological factors may account for a lower prevalence rate in the diabetes sample and for the lack of a statistically significant difference between the diabetes and control groups.

The same research group reported a similar study of an older group of 54 females with type 1 diabetes and 67 control subjects aged 18–25 years,²³ in which DSM-III-R eating

Table 1. Diagnostic Criteria for Eating Disorders*

Anorexia nervosa**

- Refusal to maintain body weight at or above a minimally normal weight for age and height
- Intense fear of gaining weight or becoming fat, even though underweight
- Disturbance in the way in which body weight or shape is experienced; undue influence of body weight and shape on self evaluation or denial of the seriousness of current low body weight
- In postmenarchal females, amenorrhea (absence of at least three consecutive menstrual cycles). A woman is considered to have amenorrhea if her periods occur only after hormone administration.

Bulimia nervosa**

- Recurrent episodes of binge eating
- Recurrent inappropriate compensatory behavior to prevent weight gain, such as self-induced vomiting; misuse of laxatives, diuretics, or other drugs (including insulin); fasting; or excessive exercise
- Binge eating and inappropriate compensatory behaviors both occur, on average, at least twice a week for 3 months
- Self-evaluation is unduly influenced by body shape and weight
- Disturbance does not occur exclusively during episodes of anorexia nervosa

Eating disorder not otherwise specified (ED-NOS)

- All the criteria for anorexia nervosa except amenorrhea; or
- All the criteria for anorexia nervosa, except that the subject does not report a fear of weight gain or a disturbance in the way in which her body weight or shape is experienced; or
- All the criteria for bulimia nervosa, except that the subject does not report self-evaluation being unduly influenced by shape or weight; or
- All the criteria for bulimia nervosa, except that binge eating and purging behavior occurred at least once a week over the past 3 months or twice weekly over the previous 4 weeks; or
- Regular inappropriate compensatory behavior in the absence of binge eating, for example, recurrent self-induced vomiting or insulin omission for shape and weight control at least once a week over the past 3 months or twice weekly over the previous 4 weeks; or
- Recurrent episodes of objective binge eating (at least once a week over the past 3 months or twice weekly over the previous 4 weeks)

Subthreshold disorders

- Occasional (a minimum of three episodes) binge eating or purging over the past 3 months; or
- Repeated chewing and spitting out of food to prevent weight gain (at least once a week over the preceding 3 months or twice weekly over the previous 4 weeks); or
- Regular extreme dietary restraint (<500 kcal/day) or excessive exercising (>120 minutes, 5 times a week) for the purpose of weight loss over the past 4 weeks, in the absence of binge eating.

*Based on DSM-IV diagnostic criteria for anorexia nervosa, bulimia nervosa, and ED-NOS⁴⁶ and the operational definition of subthreshold disorders.⁷

**Minimum of four symptoms needed for diagnosis

disorders were diagnosed in 11% of the subjects with diabetes and in 7.5% of the control subjects. Again, this difference was not statistically significant, although the study had very low power (<20%) to detect the observed difference.

Striegel-Moore et al.²⁵ studied 46 girls with diabetes aged 8–18 years and 46 control subjects using the Eating Disorder Examination interview.⁵¹ No cases of eating disorders were detected in either group. However, 6.5% of the subjects with diabetes reported insulin misuse within the previous month. Only two of the control subjects and none of the subjects with diabetes reported feeling a loss of control over eating, and 33% of the girls with diabetes compared to 24% of the control subjects reported excessive weight control within the past month. While the authors suggested that there does not appear to be an increased prevalence of eating disorders in the diabetes population, they did concede that the relatively small sample size raises questions regarding the generalizability of their findings.

Similar findings were reported by Vila and colleagues, who published two studies on the prevalence of eating disorders in young women with type 1 diabetes.^{26,28} In both, all subjects were within the age of highest risk for eating disorders and were interviewed

using a semi-structured interview based on DSM-III-R diagnostic criteria. Eating disorders were diagnosed in 8% of the subjects with diabetes in both studies. No eating disorder cases were detected in the control group studied in 1993, and only 2% of control subjects met eating disorder criteria in the 1995 study. Although these findings were not statistically significant, the authors concluded that girls with diabetes are likely at increased risk for eating disorders.

Mannucci and colleagues²⁷ conducted a study of 62 men and women with diabetes and 148 control subjects without diabetes, aged 15–60 years. The authors found that 1.6% of the subjects with diabetes and 0.9% of the control subjects met DSM-III-R criteria for anorexia nervosa; bulimia nervosa was diagnosed in 1.6% of the subjects with diabetes and 2.7% of controls; and ED-NOS was diagnosed in 4.9 and 2.7%, respectively. In addition, 33% of the subjects with diabetes met criteria for subthreshold disorders, compared to 22.5% of the control subjects. The average age of the subjects with diabetes was 34 years, which is beyond the peak age of highest risk for eating disorders, and the control sample was not randomly selected. Further, the inclusion of both men and women likely diluted the findings given the low risk of eating disorders in men.

In a recently published population-based study by Engstrom and colleagues,²⁹ 89 adolescent females with type 1 diabetes and 89 matched control subjects completed an eating disorder screening package. Subjects who scored above a predetermined cut-off were then asked to complete a semi-structured diagnostic interview. None of the control subjects met criteria for a DSM-IV eating disorder, whereas 7% of the subjects with diabetes met criteria for ED-NOS. There were no cases of anorexia nervosa or bulimia nervosa in either group. However, due to the small sample of subjects who were actually interviewed (including only two control subjects), the validity and reliability of this study are questionable, and these findings must be interpreted with caution.

The results of the above studies are difficult to interpret given their relatively small sample sizes. However, when we combined the results of these first seven prevalence studies,^{23–29} we found that 28 of 388 subjects with diabetes (7.2%) and 17 of 453 control subjects (3.7%) met criteria for an eating disorder, giving an odds ratio (OR) of 1.99 (CI 1.1–3.7). Furthermore, when subthreshold eating disorders were documented, these were found in 56 of 212 (26.4%) and 40 of 212 (16.5%) of the diabetes and control groups, respectively, giving an OR of 1.78 (CI 1.1–2.8).

Table 2. Controlled, Interview-Based Studies of the Prevalence of Eating Disorders in Adolescent Girls and Young Adult Women With Type 1 Diabetes

| Authors (age range studied) | Number with Diabetes (Controls) | DSM Disorders | | Subthreshold Disorders | |
|--|------------------------------------|------------------|---------|---------------------------|---------|
| | | Diabetes | Control | Diabetes | Control |
| Fairburn et al. ^{23*} (18–25 years) | 54 (67) | 11% | 7.5% | n/a | |
| Peveler et al. ^{24*} (11–18 years) | 33 (33) | 9% | 6% | n/a | |
| Striegel-Moore et al. ^{25*} (8–18 years) | 46 (46) | 0% | 0% | 33% | 24% |
| Vila et al. ^{26*} (12–19 years) | 52 (24) | 8% | 0% | 35% | 4% |
| Mannucci et al. ^{27*} (15–60 years) | 62 (148) | 8% | 6% | 33% | 22% |
| Vila et al. ^{28*} (13–19 years) | 52 (46) | 8% | 2% | 6.5% | 1.7% |
| Engstrom et al. ^{29**} (12–18 years) | 89 (89) | 7% | 0% | n/a | |
| Jones et al. ^{7**} (12–18 years) | 356 (1,098) | 10% | 4.5% | 13.8 | 7.7% |

*DSM-III-R criteria⁴⁵

**DSM-IV criteria⁴⁶

The inconclusive findings reported above and the elevated ORs of the combined studies provided the impetus for us to perform a study with sufficient power to definitively answer the question of whether eating disorders are more common among adolescent females with type 1 diabetes than among their peers without diabetes. This allowed us to test the hypotheses for disease causation or interaction as illustrated in the model in Figure 1 (p. 85).

In a large, multi-site, case-controlled study, we assessed the prevalence of disturbed eating attitudes, behavior, and clinical and subthreshold eating disorders in 356 adolescent girls with type 1 diabetes and 1,098 age-matched control subjects.⁷ The girls with diabetes were recruited from three large diabetes clinics in major cities in Canada (Toronto, Hamilton, and Ottawa), and the control subjects were recruited from eighteen schools distributed in these cities.

The most striking finding was that DSM-IV eating disorders (see Table 1 for diagnostic criteria) were more than twice as common in the diabetes sample as in the control group. Ten percent of the subjects with diabetes compared to 4.5% of control subjects met criteria for a DSM-IV eating disorder (OR=2.4, CI 1.5-3.8). All of these disorders were bulimia nervosa

or ED-NOS; no cases of full-syndrome anorexia nervosa were identified. An additional 14% of the diabetes group and 8% of the control subjects were engaging in disordered eating behavior that met criteria for a subthreshold disorder (OR=1.9, CI 1.3-2.8).

This study is the first to have a large enough sample size of females in the age of highest risk for eating disorders to adequately address the question of prevalence. Of note, the prevalence rates of eating disorders in the diabetes and control groups in our study were similar to those reported elsewhere.^{23,24,26-29} However, the previous studies lacked the sample sizes, and thus the power, to achieve statistical significance for observed differences between groups.

iii. Pre-Teens and Early Teens With Type 1 Diabetes

Eating attitudes and behavior have been little studied in pre-teen girls with diabetes. To date, only the studies reported by Striegel-Moore et al.²⁵ and Peveler et al.²⁴ included girls younger than 12 years of age, and both had very small numbers of subjects in the younger range.

We are presently carrying out a study of eating attitudes and behavior in a group of girls with diabetes aged 9–13 years. Preliminary analysis of

the first 90 subjects suggests that weight- and shape-related body image disturbances are very common in this group, reported by almost half the subjects. In addition, although clinical eating disorders are very uncommon in this age group, almost one in six girls reported at least one current disturbed eating behavior, including dieting, binge eating, insulin omission, and intense, abnormal exercise for weight control.¹²

Summary

The question of whether eating disorders are more common in girls and young women with type 1 diabetes has been addressed in a substantial number of studies from research groups around the world. Many earlier studies showed an absolute increase in prevalence among young women with type 1 diabetes that was not statistically significant, likely due to small sample sizes. Combining the findings of the seven published studies that employed both a control group and a standardized diagnostic interview yielded an OR of almost 2.0. In addition, our large, multi-site, case-controlled study found both clinical and subthreshold eating disorders to be more than twice as common among adolescent girls with diabetes as in their age-matched peers.

In Brief

Eating disorders are often undetected in diabetes health care settings because clinicians may not be aware that disordered eating and weight-loss behavior can underlie noncompliance with the treatment regimen and unexplained impairment in metabolic control in their female patients. This section reviews the most common manifestations of disordered eating and weight-loss behavior in young women with diabetes, namely binge eating and deliberate insulin omission for weight control; the importance of screening for these behaviors; and their impact on metabolic control and short- and long-term diabetes-related complications.

3. Effects of Eating Disorders in Adolescent Girls and Young Women With Type 1 Diabetes

Primary contributor: Anne Rydall, MSc

The Diabetes Control and Complications Trial (DCCT),^{1,3,52} a 9-year, multi-center, randomized controlled trial of more than 1,400 individuals with type 1 diabetes, provided the most conclusive evidence that the risk of diabetes-related microvascular complications is closely linked to the level of long-term metabolic control. With intensive diabetes management, the DCCT¹ clearly demonstrated that the onset of retinopathy can be significantly delayed by 76%, its progression slowed by 54%, and the development of proliferative and severe non-proliferative retinopathy reduced by 47%. In addition, intensive treatment reduced the occurrence of microalbuminuria and clinical nephropathy by 39–54% and clinical neuropathy by 60%. Furthermore, the DCCT found that the cohort receiving intensive treatment during the trial continued to show a significantly lower risk of progression of retinopathy and nephropathy 4 years after conclusion of the study, compared to those who had received conventional treatment.⁵³

i. Disordered Eating and Compensatory Weight-Loss Behavior

Disordered eating behavior, such as binge eating, as well as inappropriate compensatory behaviors, such as deliberate insulin omission or dose manipulation to induce glycosuria, are common among adolescent girls and young women with type 1 diabetes.^{7,8,10,22} Other behaviors commonly associated with eating disorders, such as excessive exercise, laxative abuse, and self-induced vomiting, are less common findings in this population.^{7,10}

In a study of adolescent girls aged 12–18 years (mean age 15 years) with type 1 diabetes,¹⁰ we found that 45% of subjects admitted to binge eating, 38% to dieting for weight control, and 8 and 2% to self-induced vomiting and laxative abuse, respectively. Of note in this group, 14% admitted to deliberate insulin omission for the purpose of inducing glycosuria as a means of controlling weight. We re-evaluated this same cohort 4 years later (mean age 19 years at follow-up) and found significant increases in the percentage of subjects admitting to disordered eating and weight-loss behavior, including binge eating (now 53%), insulin omission (now 34%), and dieting (now 54%) (Figure 2).

(a) Deliberate insulin omission for weight control

Individuals with type 1 diabetes have a unique weight control method available to them, namely, the deliberate omission or reduction of insulin in an effort to induce glycosuria, a form of calorie purging. This has been recognized in the *Diagnostic and Statistical Manual of Mental Disorders* (Fourth Edition) (DSM-IV) eating disorder criteria⁴⁶ as an inappropriate compensatory purging behavior included under “misuse of medications for weight loss.” Individuals with diabetes are often aware that insulin therapy can lead to weight gain^{20,21,54} and that reduction or omission of their prescribed insulin dosage can result in weight loss.^{17,22} This extremely dangerous method of promoting weight loss or preventing weight gain is common among young women with diabetes,

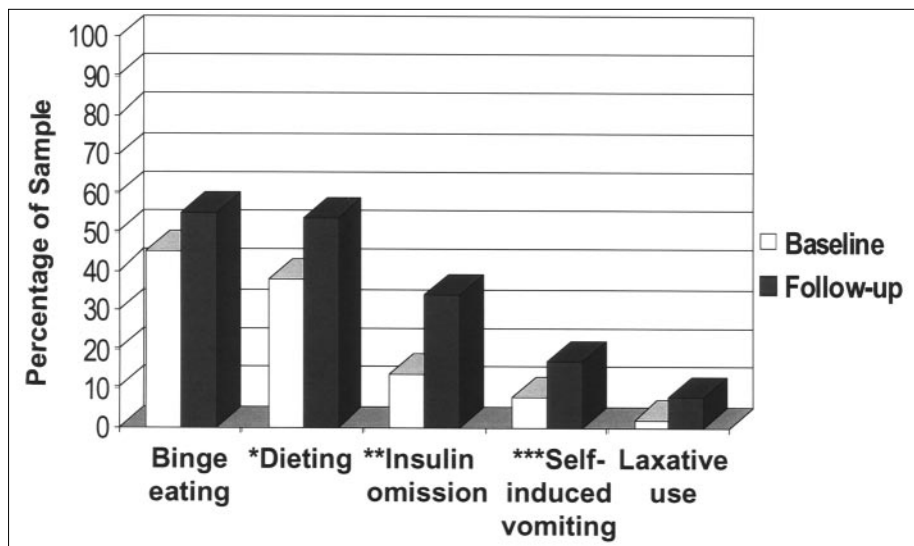


Figure 2. Prevalence of disordered eating behavior in 91 adolescent girls and young women with type 1 diabetes. McNemar's test for change in prevalence, baseline to follow-up: * $P = 0.01$; ** $P = 0.003$; *** $P = 0.06$.¹⁰

with reported rates ranging from 5 to 39%, depending on the age range of the samples studied.^{7,10,22-24,42,43,48,55,56}

In general, the studies that include a predominantly mid-adolescent cohort have yielded prevalence rates of insulin omission in the 11–15% range,^{7,10,22,24,25} whereas those including a somewhat older cohort (older adolescents and young adults) have reported considerably higher rates in the 30–39% range.^{10,11,23,55} Furthermore, in a preliminary study of pre-teen and early teenage girls with type 1 diabetes (mean age 11.8 years), we have found that insulin omission occurs with a frequency of only 1%.¹² Taken together, these studies suggest that insulin omission is a problem of increasing importance as these girls make the transitions from early to mid-adolescence and into young adulthood. Figure 3 shows the prevalence of insulin omission in these different age groups taken from the studies performed by our group.^{10,12}

Apart from dieting for weight loss, deliberate insulin omission is the most commonly employed weight-loss strategy among adolescent girls and young adult women with diabetes.^{7,10,22,23} The easy availability of this weight-loss method may explain the lower prevalence of other purging behaviors, such as extreme exercise, self-induced vomiting, and laxative or diuretic use, reported among young women with diabetes.^{7,17,22,23}

(b) Binge eating

Binge eating is defined in the DSM-IV criteria for eating disorders⁴⁶ as the

recurrent consumption of objectively large quantities of food in a defined period of time and is characterized by a feeling of loss of control during the eating episode. This behavior is common among young women in the general population⁵⁷ and has been reported in as many as 55–80% of young women with diabetes, depending on the method of assessment used and the definition of a binge episode that is employed.^{10,43,58} In our multi-site study of 356 adolescent girls with diabetes, one-third of the sample reported current binge eating.⁷

It has been suggested that the quantity of food consumed during a binge episode should not be considered of diagnostic significance.⁵⁹⁻⁶² This seems particularly relevant for individuals

with diabetes, for whom binges frequently involve the consumption of much smaller quantities of food than would normally be associated with an eating disorder.¹⁷ Even binges of smaller quantity can involve feeling a loss of control, guilt, self-loathing, and a desire to purge,⁶² and when associated with diabetes, are still likely to affect metabolic control. Furthermore, among some individuals with diabetes, binge eating may be triggered by episodes of hypoglycemia.

(c) Persistence of disordered behavior

In a 4-year longitudinal study of 91 adolescent girls with diabetes,¹⁰ we demonstrated high rates of disordered eating and weight-loss behavior at both baseline and follow-up (Figure 2). Subjects in our sample were classified as highly disordered, moderately disordered, or non-disordered, based on the presence and frequency of self-reported disordered behavior (i.e., binge eating, deliberate insulin omission for weight control, self-induced vomiting, or laxative use). Subjects were classified as highly disordered if they engaged in one or more behavior at least twice a week over the preceding 3 months; moderately disordered if they engaged in disordered behavior between twice a month and once a week; and non-disordered if they did not engage in disordered behavior at all or engaged in disordered behavior less than twice a month.

One-third of our sample reported highly or moderately disordered behavior at both assessments, and there was a significant tendency for disordered eating status to persist,

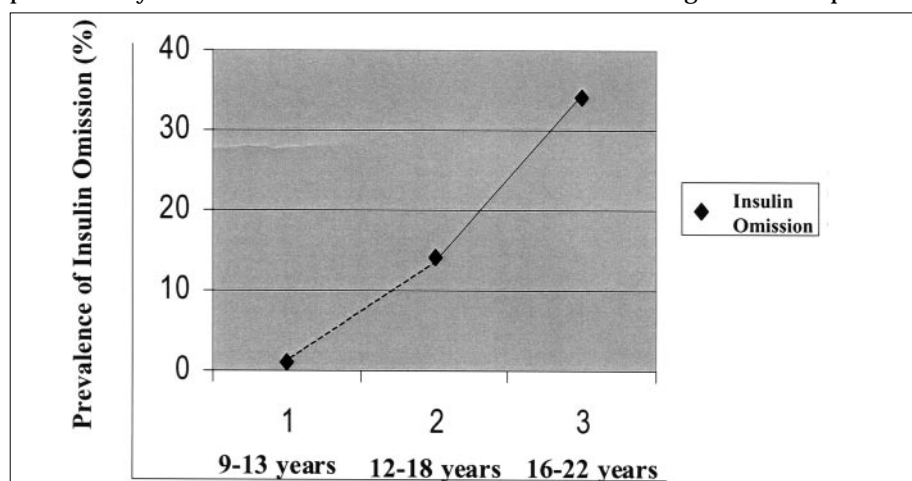


Figure 3. Age and prevalence of insulin omission for weight control. 1. Colton et al., 2000 ($n = 90$): 1% prevalence of insulin omission in pre-teen girls.¹² 2. Rydall et al., 1997 ($n = 91$): 14% in adolescent girls (baseline assessment).¹⁰ 3. Rydall et al., 1997 ($n = 91$): 34% in young adult women (4-year follow-up of baseline sample).¹⁰

with more than 60% of those with disordered behavior at baseline continuing to exhibit such behavior 4 years later. The behaviors present at baseline, including binge eating, self-induced vomiting, and dieting for weight loss, showed a significant tendency to persist. In addition, we found that disordered behavior tended to increase in frequency over time, which was not surprising given that our sample had moved further into the age of highest risk for eating disorders at follow-up (i.e., older adolescence and young adulthood).

ii. Screening for Disordered Behavior

Disturbances in eating attitudes and behavior that do not meet full psychiatric diagnostic criteria for an eating disorder may still have a serious impact on metabolic control, the clinical management of diabetes, and the subsequent risk of long-term complications.^{10,22,42,63} We¹⁰ found that screening for disordered behavior using the modified Diagnostic Survey for Eating Disorders,^{22,64} independent of an eating disorder diagnosis, allowed demonstration of a clear association between disordered behavior, impaired metabolic control, and an increased risk of microvascular complications.

We demonstrated that subjects with highly disordered behavior at baseline had a threefold increase in the presence of diabetic retinopathy at 4-year follow-up compared to those with non-disordered behavior. Those who reported moderately disordered behavior also showed complications at a frequency midway between the highly and non-disordered groups, suggesting that even less frequent disordered eating and weight-loss behavior may still increase the subsequent risk of complications.

We compared the value of self-report screening for disordered behavior with a diagnostic interview (the Eating Disorder Examination,⁵¹ modified by our group for diabetes) in 60 young women with diabetes from our longitudinal study.¹⁰ Among those who screened positive for one or more of the four disordered behaviors described above, there was 100% sensitivity and 74% specificity in identifying subjects who met DSM-IV criteria for an eating disorder based on the interview (kappa, 0.75, negative predictive value, 1.0, and positive predictive value, 0.68) (Unpublished data, AR,GR, MO, DD).

Given the prevalence of eating disorders and their subthreshold variants in teenage girls and young adult women with type 1 diabetes, we recommend that health care professionals in diabetes clinic or office settings routinely ask specific questions about eating and weight and shape concerns. Direct questioning about dieting for weight control, binge eating, insulin omission or manipulation, laxative abuse, and self-induced vomiting should be part of regular diabetes care. Early identification of such behavior would help in detecting those with previously undiagnosed clinical or subthreshold eating disorders, and in instituting measures to prevent progression from disordered behavior to more serious clinical disorders.

iii. Impaired Metabolic Control

Metabolic control, as measured by hemoglobin A_{1c} (A1C) levels, tends to deteriorate during adolescence,^{2,65} more so in girls than in boys. We suspect that this may be due, at least in part, to disordered eating and weight-loss behavior in a considerable proportion of the girls.^{17,22,66} This worsening of metabolic control during the adolescent period also coincides with the period of highest risk for eating disorders, from mid-to-older adolescence into young adulthood.^{46,67}

We and others have consistently shown that eating disturbances in association with diabetes lead to significant impairments in metabolic control.^{7,8,10,22,23,26,27,32,42,54,63,68} In an early review of 57 case reports in

which diabetes and an eating disorder were documented, Marcus and Wing⁶⁹ reported that more than 75% evidenced poor metabolic control.

In our longitudinal follow-up study of 91 adolescent girls and young adult women with diabetes,¹⁰ we documented the association of disordered eating and weight-loss behavior with impaired metabolic control, both at baseline and 4 years later. We found that A1C levels at baseline were significantly higher among those classified with highly disordered behavior (11.1%) than among those with moderately disordered (8.9%) or non-disordered (8.7%) behavior ($P < 0.001$). At follow-up 4 years later, those classified as highly or moderately disordered (9.7% and 9.6%, respectively) had significantly higher A1C levels than those in the non-disordered group (8.2%) ($P = 0.005$) (Figure 4).

We¹⁰ further divided our sample into groups based on good (A1C <8%), intermediate (8–9%), and poor (>9%) levels of control, as suggested by the DCCT findings.¹ We found that 100% ($n = 9$) of our subjects in the highly disordered group at initial assessment had A1C levels reflecting poor metabolic control, compared to 53% of the moderately disordered group and 38% of the non-disordered group. Not surprisingly, the 14 subjects who reported persistent highly or moderately disordered behavior (i.e., at both baseline and 4-year follow-up) had persistently poor A1C levels at both times (9.5 and 9.9%, respectively). While there was little change in

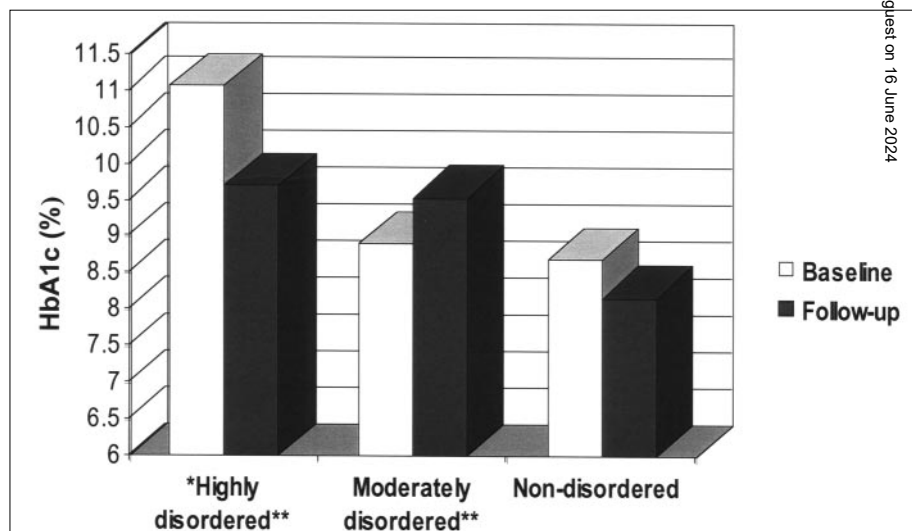


Figure 4. A1C by disordered eating status at baseline and follow-up. *A1C for the highly disordered group was significantly higher than for the moderately and non-disordered groups at baseline, $P < 0.001$. **A1C for the highly and moderately disordered groups was significantly higher than for the non-disordered group at follow-up, $P < 0.005$.¹⁰

A1C levels over time in the 43 subjects who did not engage in disordered behavior, there was both a statistically significant and clinically meaningful improvement in A1C (mean decrease of >2%; 9.7 to 7.6%, $P = 0.002$) in the nine subjects who showed improved eating status at the 4-year follow-up. Also, in the 11 new cases (i.e., those reporting highly or moderately disordered behavior at follow-up, but not at baseline), there was a trend toward worsening metabolic control, although this did not reach statistical significance (Figure 5).¹⁰

In addition, in our multi-site prevalence study of eating disorders in 356 adolescent girls with type 1 diabetes,⁷ we found that subjects who met criteria for a DSM-IV eating disorder had significantly higher A1C levels (9.4%) than those without an eating disorder (8.6%; $P = 0.04$). A1C levels for subjects with a subthreshold disorder (9.1%) were intermediate between those in the DSM-IV and non-disordered groups.

iv. Short-term Diabetes-Related Complications

Eating disorders may contribute to short-term diabetes-related complications, including hyperglycemia, recurrent episodes of diabetic ketoacidosis (DKA; invariably caused by deliberate insulin reduction or omission),^{11,55,68} hypoglycemia (due to food restriction after the administration of insulin),^{38,70} and frequent hospitalizations.^{32,43,71-73} In a recent study, Cohn et al.⁷⁴ reported that adolescent girls with diabetes had significantly more diabetes-related

hospitalizations, particularly for DKA, compared to their diabetic male peers. We suspect that this is largely due to the presence of unrecognized eating disturbances and disordered behavior, including insulin omission and binge eating, seen among teenage girls, but not boys, with diabetes.^{17,66}

Although the most common types of eating disorders found in this population appear to be bulimia nervosa and its less severe variants,⁷ there have been a number of documented cases of restricting-type disorders.^{8,32,38} These disorders may not present with impaired metabolic control,⁴ but rather with recurrent episodes of hypoglycemia precipitated by food restriction despite insulin administration.^{38,70}

In one of our studies,¹⁰ one young woman identified with highly disordered eating at follow-up (eating disorder not otherwise specified; anorexic-type), reported 20 episodes of severe hypoglycemia in the preceding year. Other complications can include delays in normal growth and pubertal development³⁸ and osteoporosis,⁷⁵ likely due to chronic food restriction and the inadequate administration of insulin.¹⁷

v. Long-term Diabetes-Related Microvascular Complications

Eating disorders in young women with type 1 diabetes have been associated with a significantly increased risk of the long-term diabetes-related microvascular complications, particularly retinopathy.⁸⁻¹⁰ In all likelihood, this is due to the impaired metabolic control resulting from persistent disordered eating and weight-loss behavior,

particularly binge eating and deliberate insulin omission for weight control.¹⁷

We demonstrated the relationship between disordered eating and weight-loss behavior and microvascular complications in our 4-year follow-up study of 91 adolescent girls with type 1 diabetes.¹⁰ These girls were 12-18 years of age at baseline, with a mean duration of diabetes of 8 years. A subset of our group at 4-year follow-up underwent a series of medical evaluations, including eye examinations and seven-field stereoscopic color fundus photography to detect diabetic retinopathy and 1- and 24-h urine collections to evaluate urinary albumin excretion rates, an indicator of early diabetic nephropathy. The most striking finding was that some degree of diabetic retinopathy (mild background retinopathy or worse) was present at follow-up in 86% of young women with highly disordered eating at baseline, compared to 43% with moderately disordered eating and 24% with non-disordered eating ($P = 0.004$; Figure 6).

Furthermore, disordered eating status accounted for more of the explained variance in predicting the presence of retinopathy at follow-up than did duration of diabetes, a well-established risk factor for the onset of microvascular complications.¹ Although there was a trend in our data toward more abnormal urinary albumin excretion results among individuals with highly disordered eating at baseline, the mean duration of diabetes at follow-up (11 years) may not have been long enough for incipient nephropathy to occur in sufficient numbers to be able to show a statistically significant association with disordered eating status (Figure 6).

Others have reported a similar relationship between eating disorders and microvascular complications in smaller studies of young women with type 1 diabetes, including case reports^{8,32,69} and small cross-sectional and case-controlled studies.^{9,11,47,48,75,76} Only one study⁵⁶ failed to find a significant association between eating disorder status or insulin omission and microvascular complications.

In an uncontrolled study, Steel et al.⁸ found microvascular complications in 11 of 15 subjects (73%), aged 16-25 years with clinically apparent eating disorders (12 anorexia nervosa, 3 bulimia nervosa). The mean dura-

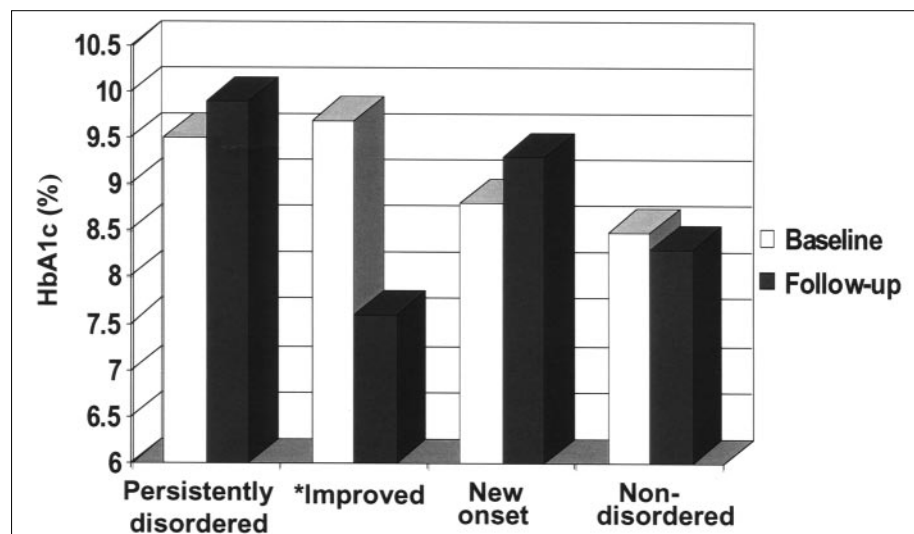


Figure 5. A1C at baseline and follow-up in 91 adolescent girls and young women with type 1 diabetes. Repeated measures analysis of variance (ANOVA): Group \times Time Interaction, $P = 0.01$. *Significant decrease in A1C, baseline to follow-up, $P = 0.002$.¹⁰

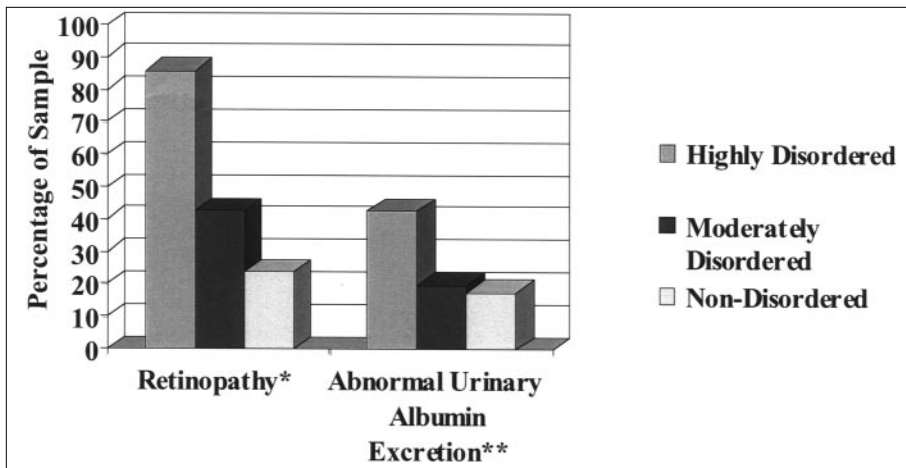


Figure 6. Disordered eating status at baseline and diabetes-related complications at 4-year follow-up. *Chi-square test for the association of disordered eating status at baseline and retinopathy at follow-up, $P = 0.004$ ($n = 71$). **Chi-square test for the association of disordered eating status at baseline and abnormal urinary albumin excretion at follow-up, $P = 0.32$ ($n = 72$).¹⁰

tion of diabetes in this group was 12.5 years, and the mean glycosylated hemoglobin level was 14.8% (range 11–18%). Sixty percent of their subjects identified with an eating disorder reported reducing insulin to control weight, and 67% reported bingeing and vomiting. Eleven of the 15 subjects had developed retinopathy, 6 had nephropathy as evidenced by persistent proteinuria, and 6 had peripheral neuropathy (4 with acute painful polyneuropathy). Although only those subjects with clinically apparent eating disorders were assessed, it was noted that only four of their 15 eating disordered subjects were free of microvascular complications. Two of the 4 subjects had only had diabetes for 1–6 years, suggesting that they may not have had diabetes long enough for clinical complications to become apparent.

Colas et al.⁹ reported more severe retinal lesions and an earlier onset in 29 patients with type 1 diabetes and an eating disorder (9 anorexia nervosa plus bulimia, 20 bulimia nervosa alone) compared to similar patients with diabetes who were matched for age, duration of diabetes, and age of onset of diabetes. The mean age of the eating disorder subjects was 26 years, and their mean duration of diabetes was 9 years. Those in the eating disorder group had higher A1C levels compared to the control group (10.8 vs. 8.1%, respectively), more retinal lesions (62 vs. 20%), and autonomic neuropathy (10 vs. 0%).

Polonsky et al.¹¹ surveyed 341 women aged 13–60 years (mean age

33 years) with type 1 diabetes (mean diabetes duration 15 years) to detect the presence of intentional insulin omission and its association with disordered eating attitudes and behavior, metabolic control, and long-term complications. Overall, 30% of this sample reported intentional insulin omission, with 8.8% reporting frequent omission, although only 13.5% admitted that this behavior was for weight-related reasons. In this study, insulin omission was not limited to the younger women, with 40% of 15- to 30-year-olds (16% reporting frequent omission), 30% of 31- to 45-year-olds, and 20% of 46- to 60-year-olds admitting to this behavior. Compared to non-insulin omitters, those omitting insulin for any reason reported more disordered eating, poorer glycemic control, more frequent diabetes-related hospitalizations, and higher rates of retinopathy (65 vs. 50%) and nephropathy (34 vs. 17%).

Ward et al.⁷⁵ presented findings from a retrospective review of a series of 17 of 21 subjects aged 21–46 years (median age 27 years) with diabetes, presenting to a hospital-based eating disorder unit over a 4-year period. Diabetes-related complications were reported in 11 (65%) of the 17 patients, including 7 with retinopathy (4 requiring laser treatment), 6 with peripheral neuropathy, and 1 with necrobiosis lipoidica. Of the five women who underwent bone densitometry, all had osteoporosis.

Cantwell and Steel⁴⁷ surveyed 147 women with diabetes aged 17–32 years and compared the 22 high scorers on

the self-report Eating Attitudes Test⁷⁷ to the 26 low scorers. This comparison revealed that high scorers (i.e., reflecting more disordered eating attitudes) misused insulin more frequently than low scorers (36 vs. 8%), and more had evidence of retinopathy (46 vs. 15%) and nephropathy (31 vs. 6%).

Takii et al.⁷⁶ compared a cohort of young women aged 16–36 years with type 1 diabetes who had been referred for eating disorder treatment (22 bulimia nervosa, 11 binge eating disorder [BED]) with 32 subjects with diabetes but without an eating disorder. They found significantly poorer metabolic control in those with an eating disorder compared to those without (average A1C levels were 12.3% in those with bulimia nervosa, 9.7% in BED subjects, and 6.2% in the non-eating disordered group). They also found that retinopathy and nephropathy were significantly more common among subjects with bulimia nervosa (41 and 46%, respectively) compared to those with BED (0 and 9%, respectively) and those in the non-disordered group (6 and 6.3%, respectively).

There is only one report in which diabetes-related complications were not associated with eating disturbances or disordered behavior. In an 8-year follow-up of 33 young women with type 1 diabetes (aged 11–18 years at initial assessment; mean age 15 years), Bryden et al.⁵⁶ reported that 46% of their subjects who developed complications omitted insulin for weight control. However, they did not find a statistically significant relationship between either disordered eating at baseline or insulin misuse and the onset of diabetes-related complications.

Conclusions

Taken together, these findings provide powerful evidence that eating disorders, including those of lesser severity from a psychiatric point of view, place young women with diabetes at increased risk for earlier-than-expected serious diabetes-related morbidity and mortality and that this risk is mediated by the poor metabolic control found in this group. Prevention efforts, early identification and screening strategies, and effective interventions are crucial in order to help reduce the risk of the potentially devastating microvascular complications of diabetes in this high-risk group.

In Brief

Eating disturbances in girls with diabetes are associated with: 1) maternal weight and shape preoccupation; and 2) family dysfunction, defined by inadequate family structure and personal support and by mother-daughter interactions that simultaneously constrain autonomy and emotional closeness in these relationships. Eating disturbances in girls with diabetes moderate the impact of the family on metabolic control. Findings are discussed in terms of their implications for treatment.

4. Contribution of the Family Environment to Eating Disturbances in Girls With Type 1 Diabetes

Primary contributor: Sherry Maharaj, PhD

A growing body of evidence has identified family functioning as a significant correlate of diabetes-related outcomes among teens with diabetes, as well as a potential risk factor for eating disorders in non-diabetic females. Problems with metabolic control and treatment compliance among teens with diabetes have been found in association with family environments characterized by high conflict and low cohesion, inadequate family structure and organization, impaired communication and problem-solving skills, and negative relationships defined by criticism and perceived rejection.⁷⁸⁻⁸⁵ Similar patterns of family disturbance have been identified in association with eating disorders in non-diabetic females. The families of young women with bulimia nervosa have been found to demonstrate a pattern of hostile, disengaged, and less nurturing behaviors that negate the girls' emotional needs.⁸⁶⁻⁸⁸ Although research has consistently linked family dysfunction with eating disorders among non-diabetic females, as well as with the adequacy of diabetes management among teens with diabetes, there has been little systematic investigation into the relationship between family functioning, eating disorders, and diabetes-related outcomes.

The etiology of eating disorders is multi-determined, likely arising from a complex interplay of biological, psy-

chological, and sociocultural factors.^{89,90} Families have been shown to have a significant influence on adolescents' overall psychosocial adaptation, as well as their adjustment to a chronic medical illness.^{91,92}

The family environment plays a primary role in the emergence and differentiation of an adolescent's self-concept. Family communications that support and validate teenagers' experiences and perspective are key to promoting the emergence of their self-identity^{93,94} and facilitating the process of individuation. The latter is considered to be the primary developmental challenge of adolescence.^{93,95}

Both clinical observation and theory have linked eating disorders in non-diabetic females to disturbances in the mother-child relationship, characterized by misattunement to the girls' emotional needs and failure to respond empathically to child-initiated cues.⁹⁶⁻⁹⁸ Failure to respond appropriately to a child's subjective experience may interfere with her ability to develop a separate and integrated sense of self and impair her capacity for individuation.^{96,98,99} Similarly, it has been suggested that a chronic medical illness such as diabetes may interfere with successful individuation among adolescents.^{100,101}

Diabetes self-care involves a complex, multi-component treatment plan that poses difficulties for many

teens¹⁰² and invariably requires a shared family effort.¹⁰³ A chronic illness such as diabetes may increase adolescents' dependence on family members at the very time they are struggling to achieve greater independence.¹⁰⁴ This dependence, coupled with parental anxieties about the illness, may heighten normal conflict in the negotiation of autonomy.¹⁰⁵ The added demands of diabetes may not only complicate the developmental challenges of adolescence,¹⁰⁶ but also strain the adaptive resources of vulnerable individuals and their families and lower the threshold for the expression of psychiatric disturbance.^{83,107}

A review of the literature during the past 15 years on the association between the family environment, eating disturbances, and diabetes outcomes among adolescent girls with type 1 diabetes revealed only three reports based on a cross-sectional study conducted by our research group.¹³⁻¹⁵ Participants in the study

included 113 girls with type 1 diabetes for at least 1 year [mean \pm SD age = 15 \pm 2.2 years; diabetes duration = 7 \pm 3.7 years; hemoglobin A_{1c} [A1C] = 9 \pm 1.4 %], attending the Diabetes Clinic at the Hospital for Sick Children in Toronto, and their mothers [mean age = 44 \pm 5.5 years]. Girls were classified as non-eating disturbed (n = 56), mildly disturbed (n = 37), or highly eating disturbed (n = 20), based on their self-reported disturbances in eating attitudes and behavior. Our major study findings will be reviewed here in terms of the quality of family functioning; the role of eating disturbances as a moderator of the impact of the family environment on metabolic control; and maternal weight and shape concerns.

i. Quality of Family Functioning

We found that eating disturbances in girls with diabetes are closely associated with the self-reported and observed quality of family functioning, with

more severe eating problems linked to greater levels of family dysfunction.^{13,15} Compared to non-eating disturbed girls, mildly and highly disturbed girls reported significantly poorer relationships with their mothers and fathers, defined by impaired communication, mistrust of their parents' responsiveness to their needs, and greater feelings of anger and hopelessness in reaction to this perceived unresponsiveness (Figure 7).

In addition, eating disturbed girls and their mothers described their overall family environments as more conflicted, with less personal support and inadequate organization and structure in the planning of activities and responsibilities. While these families are perceived to provide inadequate support and structure, they simultaneously emphasize high levels of achievement and behavioral independence.¹³

These self-reported disturbances in family relationships were corroborated by videotaped observations of mother-daughter interaction patterns among diabetic girls with and without eating disturbances.¹⁵ Eighty-eight mothers and daughters from our sample of 113 participants were videotaped engaging in two, 7-minute problem-solving tasks (one was diabetes-related, the other was a general parent-teen dilemma). The quality of mother-daughter interactions was rated using the Autonomy and Intimacy Rating System (AIRS)¹⁰⁸ which rates mothers' and daughters' communication patterns on 5 dimensions that reflect the ways in which autonomy (i.e., the experience of oneself as separate) and intimacy (i.e., the sense of relatedness to others) are negotiated in these relationships.

Our findings demonstrated that eating disturbances in girls with diabetes are associated with observed impairments in mother-daughter interactions that constrain both the teens' emerging sense of autonomy and emotional closeness in these relationships. Compared to mothers and non-eating disturbed daughters, interactions between mothers and eating disturbed girls were characterized by a negative mood and feeling tone with low levels of emotional attunement and genuine empathic support and misattunement around diabetes-related needs. These mothers and daughters exhibited limited perspective-taking abilities, used defensive communi-

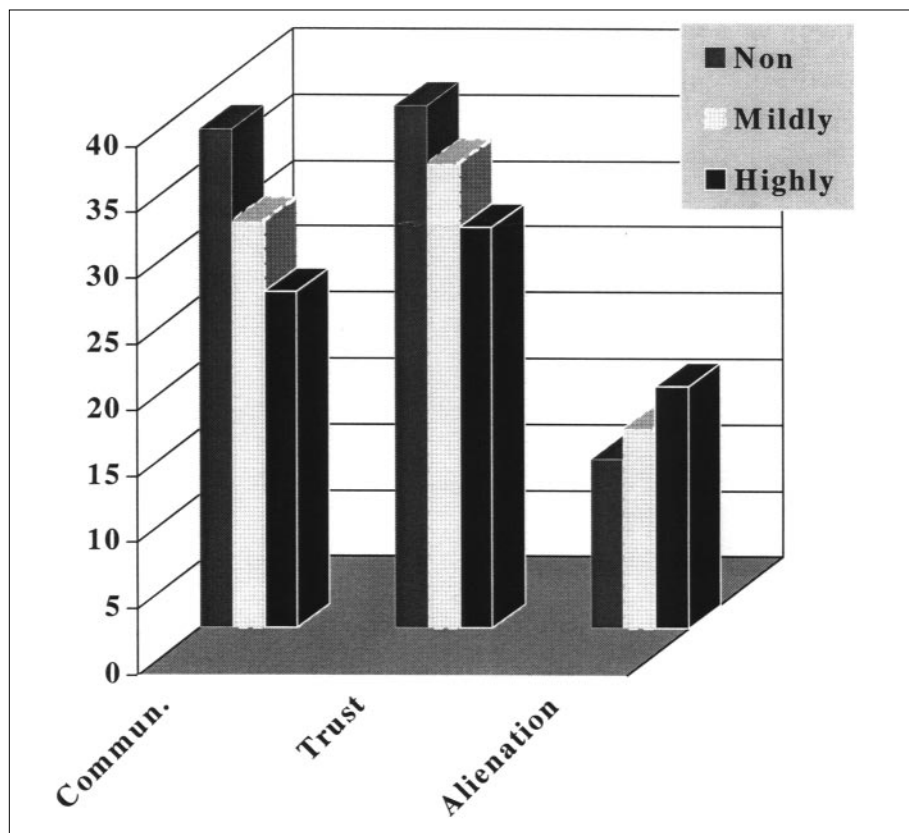


Figure 7. Perceived quality of relationships with parents. Multivariate analysis of covariance (MANCOVA) illustrated a significant group effect ($P = 0.0005$), with all groups differing from each other on perceived trust ($P = 0.005$) and communication ($P = 0.003$) with parents. Highly disturbed girls also reported more alienation from parents than did non-disturbed girls ($P = 0.0005$). There was a significant parent effect ($P = 0.0005$), with teens reporting significantly poorer communication ($P = 0.0005$) and greater alienation ($P = 0.01$) in their relationships with fathers than with mothers.¹³

cations that escalated conflict, and engaged in communication styles that tended to limit the teens' expression of thoughts and feelings.

Girls with eating disturbances demonstrated greater difficulties expressing themselves as separate, often exhibiting periods of withdrawal, confusion, or childish assertions (e.g., "I can take my insulin when I want, it's my life!"). While their mothers encouraged the teens' increasing independence around diabetes self-care, they failed to provide appropriate parental support (e.g., "I am not going to re-arrange my whole schedule when you should be the responsible one!"). While these interactional difficulties were found during the discussion of both problem-solving tasks, they were more pronounced during conversations about diabetes-related issues (Figure 8).

Optimal parental responsiveness to normal adolescent strivings for autonomy requires a balance between fostering independence and providing parental support.⁹³ For teenagers with diabetes, achieving this balance may be more difficult because the success-

ful management of diabetes requires increasing parental involvement.

Our research findings suggest that families of girls with diabetes and eating disturbances may be less able to appropriately balance the teens' simultaneous needs for independence and supportive guidance. These girls tend to live in family environments that are perceived to emphasize high levels of behavioral independence and achievement, while providing inadequate levels of personal support, structure, and organization.

Findings also suggest that these girls are not adequately supported in their efforts to develop independent thinking and self-determination in interactions with their mothers, nor are they provided with a supportive parental base from which to explore and validate their identity. These deficiencies may heighten feelings of helplessness and ineffectiveness among these girls and interfere with the development of an integrated, separate sense of self. Efforts to gain self-mastery and to bolster self-esteem through weight and shape control may be a consequence.

ii. Eating Disturbances, Family Functioning, and Metabolic Control

Studies have independently linked eating disorders and the quality of family functioning to the adequacy of metabolic control among adolescents with diabetes. The co-existence of diabetes and eating disturbances in young women, whether a clinical disorder or a milder subthreshold variant, has been consistently found to result in significantly higher A1C levels compared to those in diabetic females without eating disorders.^{7,10,22,23,48} Similarly, poor metabolic control among teens with diabetes has been found in association with family environments that are less cohesive and more conflicted, with poorer communication, lower organization, and less differentiation of family roles and boundaries.^{80,82,85,109,110}

Our group has demonstrated that the impact of family interaction patterns on metabolic control is moderated by the presence and severity of an eating disturbance in girls with diabetes.¹³ Among girls with no eating disturbances, we found that optimal metabolic control is associated with less rigidly controlled family environments that promote the open expression of thoughts and feelings. In contrast, good metabolic control among girls with more highly disturbed eating behavior is associated with family environments that are less affectively charged and more controlled and ordered (i.e., higher family control with less emphasis on behavioral independence). Thus, families of girls with diabetes must walk a precarious line between fostering adolescent autonomy and simultaneously providing supportive guidance appropriate to the needs of the individual girl.

iii. Maternal Weight and Shape Concerns

Mothers who model weight-loss behaviors and a preoccupation with bodily appearance may communicate to their daughters the importance of thinness for the female identity, as well as the strategies to attain it.³⁸ This can be particularly problematic for young girls with diabetes who are often heavier than their non-diabetic peers,⁷ due to the rapid weight gain often associated with insulin therapy.^{20,21} Girls with a vulnerable self-concept who are immersed in a family that values thinness and appearance may be more likely to translate feelings of inadequacy into "feeling fat"

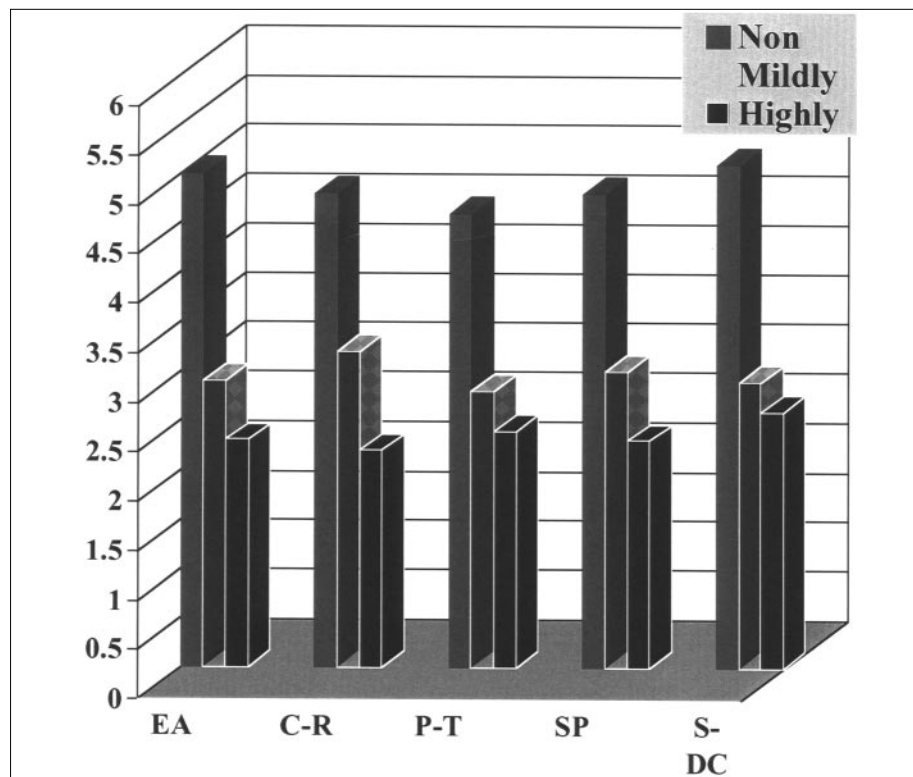


Figure 8. Observed mother-daughter interaction patterns. MANCOVA illustrated a significant group effect ($P = 0.0005$). Non-disturbed girls and their mothers exhibited higher emotional attunement (EA), conflict resolution (C-R), perspective taking (P-T), style of presenting concerns (SP), and support for diabetes self-care (S-DC) compared to mildly ($P = 0.001$) and highly disturbed ($P = 0.0005$) dyads. There was a significant task effect ($P = 0.0005$), with more impairment observed during diabetes-related discussions.¹⁵

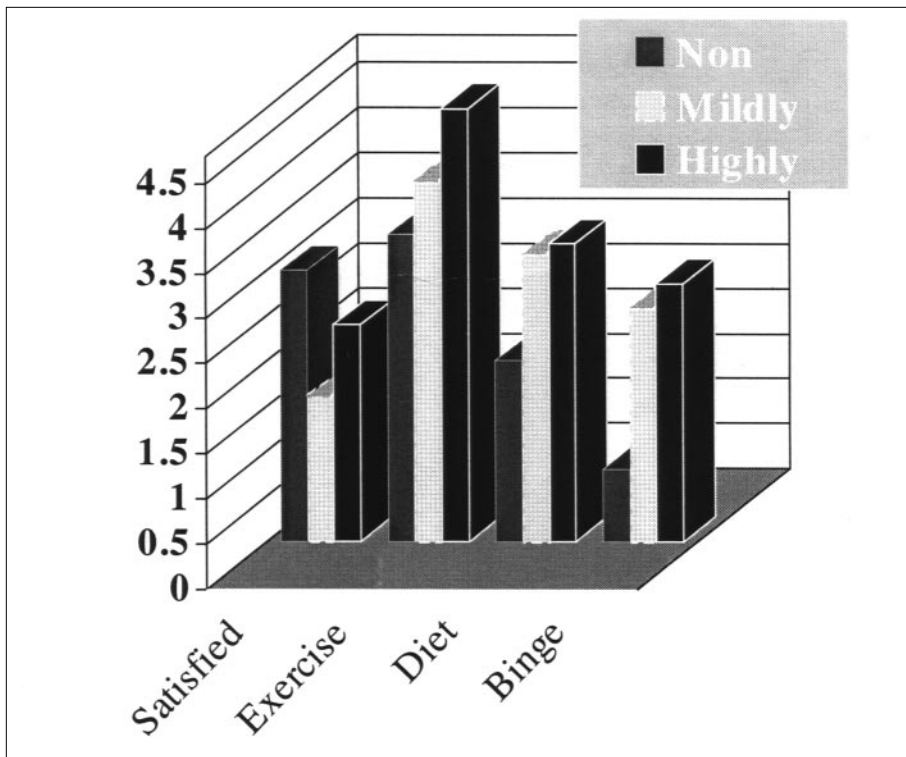


Figure 9. Maternal disturbances in eating and weight-loss behaviors. MANCOVA illustrated a significant group effect ($P = 0.03$), with mothers of eating-disturbed girls (highly + mildly) reporting significantly more weight dissatisfaction ($P = 0.01$), more dieting ($P = 0.05$), binge eating ($P = 0.02$), and exercise for weight control ($P = 0.02$) than mothers of non-disturbed girls.¹⁴

and to pursue thinness as the solution to identity confusion, interpersonal conflict, and low self-esteem.⁹⁰

Research in non-diabetic populations has demonstrated a significant association between problematic eating attitudes and weight-loss behavior in mothers and heightened body dissatisfaction, disordered eating, and weight-loss attempts in their daughters.¹¹¹⁻¹¹⁴ We have shown for the first time that eating disturbances in girls with diabetes are significantly associated with heightened weight and shape concerns in their mothers.¹⁴ Mothers of girls with eating disturbances reported more dissatisfaction with their own weight and were more likely to be on a diet, engage in binge eating, and exercise for weight-control purposes (Figure 9). Furthermore, maternal disturbances in eating and

weight-control behavior were found to be a significant and independent predictor of eating disturbances in adolescent girls with diabetes.

Implications of Family-Based Research Findings

Our study findings suggest that the family environment may enhance the risk for eating disturbances in girls with diabetes through two interrelated pathways: first, through family interaction patterns that fail to support the teens' complementary needs for independence and supportive guidance; and second, through modeling and reinforcing the value of thinness for the female identity. Furthermore, the family's impact on diabetes-related outcomes, such as metabolic control, is moderated by the presence and severity of eating disturbances in these girls.

We conclude from our findings that standard interventions designed to improve metabolic control, such as intensive diabetes management, are unlikely to be effective as long as eating disturbances and problematic family interactions persist. Effective treatment of girls with chronically poor diabetes control requires routine assessment of the presence of eating disturbances, as well as attention to goodness of fit between the characteristics of the family and the needs of the specific child.

Specifically tailored family-based therapeutic interventions are needed to improve disturbed family interaction patterns that may heighten the risk for eating disturbances and poor diabetes outcomes among girls with diabetes. For example, families that fail to provide the necessary structure, order, and control may contribute to feelings of helplessness among girls with more problematic eating disturbances and place these vulnerable teens at risk for poor diabetes management.

In such situations, treatment should include fostering appropriate structure and limit-setting within the family as a necessary concomitant of diabetes management. In addition, these mothers and daughters may benefit from learning to communicate in a manner that recognizes and supports individual differences while maintaining continued emotional closeness. In contrast, support for non-eating disturbed girls includes fostering a family environment without rigid rules and procedures and enhancing family support of the teenagers' development of self-expression and self-mastery in managing their diabetes and other age-appropriate tasks. Health professionals should also assist families in de-emphasizing the focus on appearance and thinness and facilitate parental support of their daughters' emerging self-mastery and self-esteem in multiple domains beyond weight and shape.

In Brief

Few studies have been conducted to evaluate the effectiveness of treatment interventions for young women with an eating disorder and type 1 diabetes, yet there is speculation that this group is hard to treat. An integrated approach to treatment is recommended. This section discusses specific issues related to motivation and psychological and interpersonal functioning and describes cognitive-behavioral strategies.

5. Treating Eating Disorders in Young Women With Diabetes

Primary contributor: Marion Olmsted, PhD

There is an extensive literature on the treatment of eating disorders, and comprehensive practice guidelines have been published by the American Psychiatric Association.¹¹⁵ Recommended treatments include cognitive-behavioral therapy (CBT), interpersonal therapy, and psychoanalysis; psychoeducation; group therapy; pharmacotherapy; day hospital; and hospitalization.^{116,117}

Until recently, there had been no controlled treatment trials involving individuals with type 1 diabetes and eating disorders.¹¹⁸ One small, uncontrolled study suggested that outpatient CBT is effective for women with bulimia nervosa and diabetes, although treatment was believed to be more difficult than for comparable non-diabetic patients.¹⁶ Based on this study and a few individual case reports,^{32,119} it has been suggested that eating disorders in women with diabetes may be more difficult to treat¹¹⁹ and more intractable¹⁶ than in those without diabetes. However, we believe that this view remains speculative, as it is based on uncontrolled observation of a small number of selected cases reported in the literature.

There is a real need to develop and evaluate effective interventions to treat eating disorders in adolescent girls and young women with diabetes because of the significant impact of these conditions on metabolic control

and diabetes-related health outcomes.¹⁷ With a focus on early intervention, our group conducted the first randomized, controlled treatment study for eating disturbances in adolescent girls with type 1 diabetes.¹¹⁸ Girls aged 12–19 years attending a large urban diabetes clinic were screened for evidence of disturbed eating attitudes or behavior, which are much more common than full-blown eating disorders.⁷ More than 60% of the girls who were screened met criteria for participation in the intervention phase of the study. The effectiveness of six group sessions of psychoeducation (PE) for the girls and their parents was compared to a “treatment-as-usual” approach to diabetes management.

PE was associated with reductions in dieting, body dissatisfaction, and preoccupation with thinness and eating, and these improvements were maintained at 6- and 12-month follow-ups. However, this brief intervention did not result in significant improvements in metabolic control, as measured by hemoglobin A_{1c}, or insulin omission for weight control. A more intensive, individualized intervention may be required to achieve this result. Participation in the intervention, which required coming to the hospital for six consecutive weekly sessions, was also a challenge for these girls, who were not actively seeking

treatment for eating disorders and often had only mild disturbances.

An Integrated Approach to the Treatment of Eating Disorders in Type 1 Diabetes

Individuals with diabetes who accept specialized treatment for eating disorders appear to benefit from established treatments.¹⁶ However, the effectiveness of these treatments may be enhanced in this population when they are modified to include attention to insulin omission, metabolic control, body mass index, diabetes-related dietary restriction, relationships with family and medical caregivers, and feelings about having diabetes.

Treatment for full-blown eating disorders is ideally provided by an eating disorder specialist who is fully informed about diabetes and the interplay between eating disorders and diabetes. Given their frequency, interventions for subthreshold eating disorders ought to be incorporated into routine diabetes care.

i. Motivational Issues

Individuals with eating disorders may fear that normalized, balanced eating from all food groups will lead to an unacceptably high body weight. For those with diabetes, adherence to an appropriate insulin regimen that helps to achieve good metabolic control virtually guarantees an increase in weight.^{20,21} Although treatment providers believe that improved metabolic control and the subsequent reduction in risk for diabetes-related complications justify weight gain, adolescents or young adult women with diabetes may not share this view.

Furthermore, pressure from well-meaning family members and health care professionals may increase conflict in these patients' environment without increasing their motivation for change. It can be very stressful for treatment providers and family members to allow young women the time to overcome their fears when short-term (hypoglycemia, diabetic ketoacidosis) and long-term (micro- and macrovascular complications) risks are so high. Caregivers must find a balance between promoting behavioral change and accepting the adolescents' difficulty in achieving dietary self-regulation.

ii. Cognitive-Behavioral Strategies

(a) Self-monitoring

In addition to recording food and

symptoms, young women with diabetes and an eating disorder need to record blood glucose levels, insulin taken, and insulin omitted, if any, to provide a complete picture of their clinical state. Insulin administration and balanced eating may be conceptualized as part of self-care, while insulin omission or underdosing should be framed as a purging or self-harm symptom.

Some patients object to measuring and recording blood glucose levels because this draws their attention to the increased risk for complications associated with high blood glucose. They can avoid becoming distressed by remaining uninformed. Others may resist out of a feeling that collecting the information about blood glucose levels involves a commitment to respond with an appropriate dose of insulin.

One goal served by self-monitoring is to increase patients' awareness of their situation and the connections among various behaviors. This can be taken alone as a preliminary goal, with no immediate pressure to alter eating or insulin administration, and may be stressful enough as a first step for some patients.

(b) Negotiating an eating/insulin protocol

Any improvement in metabolic control reduces the risk for diabetes-related complications, indicating that a harm-reduction model of intervention is appropriate. Although four daily insulin injections could lead to tighter control, two daily injections may be preferable if this is what a young woman feels she can manage. Similarly, the food plan should be one that she feels she can follow as a first step.

The long-term goal of balanced eating and good metabolic control may need to be reached through a series of steps, each of which is negotiated with the patient. For those who have binge eating episodes, it is essential that the food plan incorporate foods that are usually eaten during binges.

(c) Bingeing or overeating triggered by hypoglycemia

Many individuals with diabetes binge or overeat in response to hypoglycemic episodes. These patients may believe that they will feel better more quickly if they continue to eat at these times, or eating may distract them

from the unpleasant physical symptoms associated with hypoglycemia. In addition to addressing these beliefs, a very specific plan incorporating detailed coping strategies should be worked out with these patients for use each time they have a hypoglycemic reaction. An important early therapeutic goal is to separate disordered eating from diabetes management. This does not mean that these patients are to be expected to totally abstain from bingeing right away, but rather that emphasis should be placed on not bingeing specifically in response to hypoglycemia.

d. Preparation for possible weight gain

The weight gain that frequently accompanies improved metabolic control may be conceptualized as the avoided phobic situation. With significant support and preparation, patients may be willing to face this situation so that they can improve their health and move forward with other life goals. The exact amount of weight patients will gain cannot be predicted in advance, and each young woman with diabetes and an eating disorder can be encouraged to find out where her weight stabilizes and what effect this has on her life before making a decision about whether she can tolerate a higher weight if it indeed occurs. It is a mistake to underestimate the importance these young women attach to their weight. Although these issues need to be addressed in therapy, in the short-term, empathy and support for these patients' situations are critical.

iii. Psychological and Interpersonal Issues

An important goal of treatment in patients with eating disorders is to improve their capacity to identify and modulate emotions and to distinguish feelings of hunger and satiety from other emotional and physical states. Psychotherapeutic treatment can increase their capacity to tolerate a variety of feelings without resorting to binge eating or purging and to accept feelings of imperfection without attempting to diminish them through weight restriction.

There are also a variety of other psychological issues, that are more specific to or are amplified by the presence of diabetes. Body image concerns, which are a core feature of eating disorders, are often amplified by diabetes. Patients may feel that their

body is defective in terms of insulin production and in terms of weight regulation. They may be preoccupied with and enraged by the unfairness of this situation. They may struggle to be “in control” of their body and have difficulty accepting their biology. Good self-care may be equated with defeat in this battle for control.

Another common theme relates to feeling ashamed or stigmatized about having diabetes. The attention to body, eating, and planning to eat required for good diabetes care may be in opposition to the eating disordered beliefs that bodily needs are shameful and that denying oneself

food is morally laudable. Patients may feel angry that diabetes either prevents them from reaching their eating disordered goals or brings a price that those without diabetes do not have to pay. The fear of disability and premature death is an almost universal underlying theme, although it is frequently disguised by neglect of diabetes management and disregard for its consequences.

Both eating disorders and diabetes have an effect on interpersonal relationships. Negotiating personal autonomy and appropriate support is extremely difficult in families or relationships when the individuals with

diabetes and an eating disorder are very symptomatic and/or not engaging in good self-care. These patients may feel blamed for having diabetes and/or eating disorders and may feel blamed for being unable to resolve their issues and improve their health. Similar patterns occur in relationships with treatment providers, where it is not uncommon for patients to report feeling blamed and misunderstood. Because individuals with diabetes will require ongoing contact with treatment professionals, it is important for them to develop the skill to manage these relationships in a way that allows them to receive good health care.

6. Implications, Summary, and Conclusions

i. Implications

The available data strongly support the view that eating disorders, both clinical and subthreshold, are prevalent in adolescent girls and young adult women with type 1 diabetes, and that this co-morbidity has serious short- and long-term implications. It is imperative that health care professionals involved in the management of these individuals be aware of the association between diabetes and eating disorders and that effective methods to deal with this dangerous co-morbidity be developed.

In our experience, there are a number of indications that an eating disturbance may be complicating the course of a young woman's diabetes. Some of these are listed in Table 3. The presence of one or more of these indicators does not necessarily mean the presence of an eating disorder, but rather should alert health care professionals to the need for further investigation.

Detecting eating disorders in young women with type 1 diabetes requires both an awareness of the pathophysiology and epidemiology of this association and the ability to ask the appropriate questions of the young women in a non-judgmental, non-threatening manner. Often, young women with

diabetes and an eating disorder will only begin to reveal the nature and severity of their abnormal eating attitudes and behavior once they have established a trusting relationship with one of their health care providers. Health care providers must then establish the severity of the eating disturbance and its impact on diabetes management. For those in whom a full-blown eating disorder, as defined in the *Diagnostic and Statistical Manual of Mental Disorders* (Fourth Edition) (DSM-IV), is suspected or diagnosed, immediate referral to a health care professional with expertise in the management of eating disorders is essential. The serious nature of eating disorders and their high levels of associated morbidity and mortality demand such an approach.¹²⁰

For those with milder (subthreshold) degrees of eating and weight psychopathology, clinic-based approaches should be attempted before referral to eating disorder health professionals is required. This will require a multifaceted approach including attention to family dysfunction, as well as negotiation of a treatment regimen with which the adolescent girl or young woman in question feels comfortable.

The initial response of many health

care professionals is to increase the frequency of insulin injections and self-monitoring, as well as recommend referral for more in-depth nutritional counseling. Instead, what may be needed is a less intrusive management plan with less frequent insulin injections and self-monitoring and a meal plan that attempts to “normalize” the patient's eating patterns. The potential success of such an approach is not certain but does warrant further investigation.

ii. Summary and Conclusions

It is our view that the most pressing need in this area is the development and evaluation of early interventions to prevent or treat eating disturbances in this at-risk population. Our studies regarding the importance of the interactions among diabetes management, family functioning, and eating disorders suggest that family-based interventions may have a high likelihood of success. In addition, ongoing research is needed to determine the impact of newer and more flexible approaches to diabetes management on the occurrence and persistence of eating disorders. Furthermore, the interaction between eating disorders and mood disturbances warrants exploration.

Table 3. Common Manifestations of Eating Disorders in Young Women With Type 1 Diabetes

- 1. Manifestations of insulin omission**
 - i. Poor metabolic control as evidenced by high hemoglobin A_{1c} levels
 - ii. High blood lipid levels
 - iii. Recurrent episodes of diabetic ketoacidosis
 - iv. Refusal to allow parents or others to witness insulin administration
 - v. Admission to insulin omission or dose manipulation for the purpose of weight control
- 2. Manifestations of dietary dissatisfaction/manipulation**
 - i. Admission to dieting for weight control
 - ii. Admission to episodes of binge eating
 - iii. Frequent requests for changes to meal plan, e.g. low-fat, low-carbohydrate, vegetarian, vegan, or other diets
- 3. Manifestations of body dissatisfaction**
 - i. Refusal to be weighed at clinic visits
 - ii. Anxiety or upset at being weighed
 - iii. Frequent complaints about weight and shape
- 4. Manifestations of family dysfunction**
 - i. Family functioning manifested by high conflict, low cohesion, and poor organization
 - ii. Maternal preoccupation with weight and shape
- 5. Other manifestations**
 - i. Pervasive noncompliance with one or more aspects of the diabetes treatment regimen leading to poor metabolic control
 - ii. Smoking or other substance abuse
 - iii. Poor clinic attendance
 - iv. More frequent hospitalizations
 - v. Earlier-than-expected onset of diabetes-related microvascular disease (e.g., retinopathy, nephropathy)

The majority of research from our group and others has focused on eating disorders in teenaged girls. Further research should examine the early indicators of eating disturbances in pre-teen and early teenaged girls, as well as the longer-term impact in women as they progress beyond adolescence and into early adulthood. We would expect that innovations that lead to the replacement of the traditional insulin injection, blood monitoring, and dietary compliance triad will have a major impact on the expression of eating disturbances in these females with type 1 diabetes.

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