Chronic Illness and Disordered Eating: A Discussion of the Literature\textsuperscript{1,2}

Virginia M. Quick,\textsuperscript{3} Carol Byrd-Bredbenner,\textsuperscript{4} and Dianne Neumark-Sztainer\textsuperscript{5}

\textsuperscript{3}Eunice Kennedy Shriver National Institute of Child Health and Human Development, Division of Epidemiology, Statistics, and Prevention Research, NIH, DHHS, Bethesda, MD; \textsuperscript{4}Department of Nutritional Sciences, Rutgers University, New Brunswick, NJ; and \textsuperscript{5}School of Public Health, Division of Epidemiology and Community Health, University of Minnesota, Minneapolis, MN

ABSTRACT

This paper describes the prevalence of eating disorders and disordered eating behaviors, the reasons why these practices are endorsed, and the potential consequences in youths and young adults with selected diet-related chronic health conditions (DRCHCs) and provides recommendations for eating disorder prevention interventions and research efforts. Although it remains unclear whether the prevalence of eating disorders is higher in those with DRCHCs compared with the general population, overall findings suggest that young people with DRCHCs may be at risk of endorsing disordered eating behaviors that may lead to diagnosis of an eating disorder and other health problems over the course of their treatment. Thus, health care providers should be aware that young people with DRCHCs may be at risk of eating disorders and carefully monitor psychological changes and the use of unhealthy weight control methods. It is also important to develop and evaluate theory-based interventions and disease-specific eating disorder risk screening tools that are effective in halting the progression of eating disorders and negative health outcomes in young people with chronic health conditions. Adv. Nutr. 4: 277–286, 2013.

Introduction

Chronic illnesses are increasing and constitute a major public health problem (1). The increased incidence and prevalence of chronic illnesses is in part due to medical advances that have increased the life expectancies of young people with chronic diseases (i.e., 85% of children with congenital or chronic health conditions now survive to adolescence) (2). Chronic health conditions are defined as having a biological, psychological, or cognitive basis, as lasting or are expected to last for at least 1 yr, producing signs and symptoms that may limit function and activities, and requiring medical care or related services (3). Currently, 1 of 10 in-school adolescents have a chronic illness or disability that limits their ability to perform daily functions (4–6). Coping with chronic health conditions during the adolescent years, a time of rapid growth and development that accompanies key socialization and individuation processes, is a critical challenge for adolescents and their family members and health care teams (7). For instance, medical treatments may retard normal growth and result in shorter stature, delayed onset of puberty, and malnutrition (i.e., poor weight management) (2,6,7). Visible signs of illness may cause embarrassment, which can lead to body image disturbances that have harmful consequences, such as the development of disordered eating behaviors (8,9), eating disorders (10), and other harmful outcomes (9,11).

Treatment and optimal management of diet-related chronic health conditions (DRCHCs)\textsuperscript{6} [e.g., cystic fibrosis, type 1 diabetes, inflammatory bowel disease (IBD), irritable bowel syndrome (IBS)] necessitate that patients adhere to a prescribed dietary regimen, usually on a lifelong basis. Compliance with these regimens presents many pressures that may cause youths to develop destructive attitudes toward food and body weight as well as unhealthy eating habits. Individuals with these health conditions likely need to be more concerned about their body weights and/or dietary prescriptions than healthy peers if they are to engage in practices that protect their health (12). However, increased concern may precipitate disordered eating (e.g., binge eating, strict

\textsuperscript{1} Financial support: Kappa Omicron Nu Research Fellowship and the Eunice Kennedy Shriver National Institute of Child Health and Human Development Intramural Research Training Award to V. M. Quick.

\textsuperscript{2} Author disclosures: V. M. Quick, C. Byrd-Bredbenner, and D. Neumark-Sztainer: no conflicts of interest.

\textsuperscript{3} To whom correspondence should be addressed. E-mail: gingermquick@gmail.com.

\textsuperscript{6} Abbreviations used: DRHC, diet-related chronic health condition; BD, inflammatory bowel disease; IBS, irritable bowel syndrome.
dieting, purging) that may lead to eating disorders (13). It is important to delineate disordered eating from eating disorders. Eating disorders are defined as a “clinically meaningful behavioral or psychological pattern having to do with eating or weight that is associated with distress, disability, or with substantially increased risk of morbidity or mortality” (13). On the other hand, disordered eating behaviors are abnormal behaviors associated with eating disorders, such as re-straint eating; emotional eating; disinhibited eating; night eating; binge eating; weight, shape, and eating concerns; strict dieting; and controlling one’s body weight and shape through inappropriate compensatory behaviors (e.g., purging) that do not warrant a psychiatric diagnosis of an eating disorder such as anorexia nervosa or bulimia nervosa defined by the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (14).

A comprehensive discussion regarding the prevalence and risk factors for development of eating disorders in youths with chronic illness is lacking, which has hampered our ability to fully understand these issues. Given the high prevalence of disordered eating behaviors during adolescence and young adulthood (15) and the negative health implications that these behaviors may have for those with chronic health conditions, an increased understanding of the risk factors for disordered eating and eating disorders in young people with chronic illness could assist health care providers, as well as parents and other child caregivers, in their efforts to help youths develop and maintain a healthy concern for their overall health and disease management. This type of information is also important to guide the development of future interventions aimed at preventing disordered eating and eating disorders in youths with chronic illness. Thus, this paper describes the most recent literature on disordered eating and eating disorders in youths and young adults with certain DRCHCs (e.g., type 1 diabetes mellitus, celiac disease, cystic fibrosis, IBS, and IBD), and recommendations are made for future eating disorder prevention interventions and research efforts.

**Current status of knowledge**

**Type 1 diabetes mellitus and disordered eating**

Type 1 diabetes mellitus is an autoimmune disorder that can be diagnosed as early as birth, but can occur at any time in the life span (16). It has a prevalence rate of 3 to 4 children per 1000 in Western countries (17). In this chronic health condition, the pancreas stops producing insulin, which causes the body to be unable to use glucose normally (16). Thus, most individuals with type 1 diabetes currently must obtain insulin exogenously for the rest of their lives. Typically, this is achieved through insulin injections administered once or more daily. In addition to insulin injections, specialized exercise, diet (American Diabetes Association dietary guidelines), and weight maintenance plans are needed to keep blood glucose levels normal. Maintenance of normal glucose levels is important because uncontrolled levels increase patients’ risk of heart disease, hypertension, dyslipidemia, and diabetic nephropathy, neuropathy, and retinopathy (16), as well as coma and death (18).

Newly diagnosed type 1 diabetes patients frequently find it challenging to cope with this chronic health condition (19–21). A literature review examining the prevalence of psychosocial problems in the diabetes population revealed that individuals with diabetes may experience psychosocial problems and are at special risk of reduced physical and emotional well-being, especially immediately after diagnosis, which is generally regarded as a time of crisis (22). Before diagnosis, individuals usually drop weight unintentionally due to the nature of the condition. It is suspected that, at first, some patients may feel positively about this weight loss (18). However, once diagnosed and placed on an insulin regimen, patients tend to regain lost weight and fluids, sometimes gaining substantially more weight than was lost before treatment began (i.e., sometimes as much as 4.6 kg overnight) (23). This weight gain occurs because insulin prompts the body to reduce blood glucose levels, with 1 removal route being fat deposition (16). A large increase in weight in a short period of time may negatively affect the body image and self-esteem of some individuals with type 1 diabetes (24,25) and cause them to fear that they will be unable to control their weight.

A review examining eating disorders among young women with type 1 diabetes suggests the need to constantly follow a strict diet and frequently monitor blood sugar levels before each meal and snack may cause these individuals to become too concerned with their diets (26). Dietary management may be especially difficult for young children and adolescents when they notice friends and family members without type 1 diabetes are able to eat whenever and whatever they want. Over time, this constant awareness of one’s diet and disease treatment may lead to disordered eating (13).

In the general population, purging includes vomiting, misuse of laxatives, and excessive exercise. Those with type 1 diabetes also may purge by omitting insulin [i.e., diabulimia (27)] (28–31). It is estimated that ~30% of females with type 1 diabetes purposely omit insulin to induce weight loss (31,32). The side effects of continual misuse of insulin can be detrimental, leading to retinopathy, neuropathy, nephropathy, heart disease, and urinary tract infections (18).

A recent study examining characteristics of individuals with both an eating disorder and type 1 diabetes found that almost half reported withholding insulin for weight loss purposes (33). Additionally, 42% had other disordered eating behaviors (e.g., bingeing, vomiting, use of laxative, diuretics, excessive exercise) (33). It is important to note that misusing insulin, despite the negative health consequences, is not a formal eating disorder diagnosis but rather a disordered eating behavior along with other purging techniques. Interestingly, nearly all (93.8%) type 1 diabetes and eating disorder diagnosed individuals in this study were diagnosed with type 1 diabetes before an eating disorder diagnosis (33), suggesting that diabetes led to an eating disorder diagnosis rather than the reverse.
In recent years, researchers have explored the prevalence rates of eating disorders among those with type 1 diabetes (34). Some studies report that eating disorders are more prevalent and persistent among those with type 1 diabetes than in the general population (35–39), whereas other studies indicate the risk is no greater than in the general population (40,41). A meta-analysis of research with females who have type 1 diabetes mellitus indicated that the incidence of bulimia nervosa was the same as, and possibly higher than, that in the general female population (34). However, a review examining 12 empirical studies indicated that females with type 1 diabetes are not at an increased risk of the development anorexia nervosa or bulimia nervosa, but did suggest that eating disorders not otherwise specified are prevalent in this population (42). In general, disordered eating in type 1 diabetes patients is more common among girls than boys (32). Bingeing and purging tend to be the most common types of disordered eating practices found among girls with type 1 diabetes (28,35,43).

The varying findings related to the incidence of eating disorders among type 1 diabetes patients may be because of differences in the screening tools used that do not adequately assess disease-specific eating behaviors, along with the age at diagnosis, duration of type 1 diabetes at the time of assessment, the type of medical care received (e.g., general vs. specialized physician, nutrition counseling, psychological counseling), and salient psychographic characteristics not being taken into account. Some other limitations, as stated by Young-Hyman and Davis (44), may include the following:

- lack of weight matched control subjects when comparing the prevalence of eating disorders or subclinical disturbed eating behaviors;
- incomplete psychological characterization of samples, including psychological constructs such as...self-efficacy over blood glucose and weight; potential misclassification of behaviors and attitudes as reflecting disturbed eating behaviors when they possibly reflect skills and attitudes learned as part of diabetes care/self-management regimen; and the need for refinement of existing measurement tools and development of assessment methods that address diabetes-specific attitudes, concerns, and behaviors that are prescribed as part of treatment (44).

It is not clear why some young people with type 1 diabetes are at risk of eating disorders; however, Ismail (23) proposed that family psychiatric history, age at diagnosis, personality characteristics (i.e., perfectionism, impulsiveness), peer environment, stigma, diabetes-related fears (e.g., fear of insulin injection), and other factors are involved. In fact, previous work by Neumark-Sztainer et al. (45) found that increased weight concerns and less family cohesion are associated with disordered eating among female and male adolescents with type 1 diabetes; however, age, parental level of education, family structure, and race/ethnicity were not associated with the risk of disordered eating. Additionally, a qualitative study among 30 adolescent girls with type 1 diabetes revealed that a combination of low family meal structure (e.g., infrequent family meals) and high familial weight concerns (i.e., parents engaging in behaviors to lose weight and/or making negative comments about eating or weight) was more prevalent in families of girls who endorsed disordered eating than in families of girls not endorsing disordered eating (24). These findings suggest that family may play an important role in protecting against disordered eating in youths with type 1 diabetes. Other factors, such as bisexual or homosexual orientation, history of sexual abuse, and poor emotional well-being have also been found to predict disordered eating among youths with type 1 diabetes (46). Although it is uncertain whether the incidence of eating disorders is higher among those with type 1 diabetes than in the general population, disordered eating among those with type 1 diabetes is common and has potentially serious health consequences. More work is needed to understand the personal and environmental characteristics of those with type 1 diabetes who have disordered eating behaviors, which, in turn, will help to identify at-risk individuals and create care plans and interventions designed to prevent the development of disordered eating. Table 1 summarizes documented disordered eating practices among those with type 1 diabetes and lists the known risk factors associated with these practices in this population.

### Cystic fibrosis and disordered eating

Cystic fibrosis, an autosomal recessive genetic disorder characterized by dysfunction of the exocrine glands and production of abnormally thick, tenacious mucous secretions that obstruct glands and ducts, occurs in 1 of 2500 live births (16).

<table>
<thead>
<tr>
<th>Table 1. Disordered eating practices and risk factors for young people with type 1 diabetes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type 1 diabetes patients</strong></td>
</tr>
<tr>
<td>Types of disordered eating behaviors documented: binge eating and purging (including insulin omission) (28,35,43,46), fasting/dietary restriction, food preoccupation, use of laxatives, and excessive exercising (33)</td>
</tr>
<tr>
<td>Potential factors increasing risk of disordered eating</td>
</tr>
<tr>
<td>Age at diagnosis (i.e., mid-adolescent years) (23)</td>
</tr>
<tr>
<td>Sexual orientation (e.g., homosexual) (46)</td>
</tr>
<tr>
<td>Weight gain (possibly due in part from initiation of insulin (24,25,95,96))</td>
</tr>
<tr>
<td>Psychiatric history (e.g., depression, anxiety, sexual abuse) (23,46,97,98)</td>
</tr>
<tr>
<td>Personality characteristics (e.g., perfectionism, impulsiveness) (23)</td>
</tr>
<tr>
<td>Body image disturbance (24,25)</td>
</tr>
<tr>
<td>Poor emotional well-being (e.g., self-esteem) (46,96)</td>
</tr>
<tr>
<td>Skill and confidence in diabetes-related care (23)</td>
</tr>
<tr>
<td>Lack of coping skills (19)</td>
</tr>
<tr>
<td>Pressure to manage weight by exercising regularly to help control blood glucose levels (23)</td>
</tr>
<tr>
<td>Preoccupation with dietary management (counting carbohydrates) (13,26)</td>
</tr>
<tr>
<td>Diabetes-related fears (e.g., hypoglycemia, insulin injections) (23,99,100)</td>
</tr>
<tr>
<td>Stigma of health condition (e.g., insulin injections, insulin pump) (23)</td>
</tr>
<tr>
<td>Peer environment (e.g., social events involving food/beverages, weight comments from peers) (23,101)</td>
</tr>
<tr>
<td>Family environment (e.g., low family cohesiveness, infrequent family meals, parent comments about weight and shape) (24,46,96,102)</td>
</tr>
</tbody>
</table>
Respiratory organs, reproductive organs, sweat glands, salivary glands, and digestive system organs (i.e., pancreas, intestine, and liver) are affected. Thus, cystic fibrosis patients are at high risk of malnutrition due to malabsorption and malabsorption of food (16), bringing observable changes to the body such as short stature, low weight, and pubertal delay (47). Long-term treatment for these individuals includes increased energy intakes with 35% to 40% of total calories coming from fat, along with vitamin and mineral supplementation, pancreatic enzyme replacement therapy, and regular chest examinations (16). Sometimes oral and enteral tube feedings may be necessary if patients cannot meet the demands of nutrient needs from food sources (48). Additionally, 1 of 4 cystic fibrosis patients older than 20 y of age also experience the onset of type 1 diabetes, otherwise known as cystic fibrosis–related diabetes, which can make dietary management even more challenging (49). Hence, dietary management is of great concern in both the cystic fibrosis and cystic fibrosis–related diabetes populations.

Research has suggested that the intense dietary regimens followed by individuals with cystic fibrosis over the years may affect mental and physical health (50,51). Physically, growth and pubertal development delays occur (52), whereas mentally, quality of life declines (50). Some health-related quality of life domains that have been examined include social functioning, coping, emotional responses, concerns for quality of life domains that have been examined include socially (50). Interestingly, body image and eating disturbances among cystic fibrosis patients remain an understudied topic. A recent review article that critically evaluated 12 research studies examining body image among individuals with cystic fibrosis found that females had better body image compared with males given their preference for a low body weight and belief that being thin is attractive; however, the study authors noted this could compromise their survival (53). This review also indicated that males were more motivated to adhere to nutritional advice because they favored a larger body form (i.e., muscular, V-shaped body), but they also may be tempted to adopt risky behaviors, such as use of anabolic steroids, in their efforts to attain a socially sanctioned form (54).

Parents usually have a difficult time coping with treatment of children with cystic fibrosis (54). Parents’ views of their child’s dietary habits may be distorted by the emphasis and pressure that health professionals put on the importance of the child’s dietary intake and need for weight gain (55). Parents of children with cystic fibrosis tend to view their child’s behavior as more problematic at mealtimes and generally more stressful than parents who do not have chronically ill children (54). The problems that parents report that their cystic fibrosis child has include poor appetite, problems chewing food, reluctance to eat at mealtimes, taking >20 min to finish meals, and spitting out food (54). The cause of these problems and disordered eating behaviors is not well understood and can increase over time (54).

Few studies have examined the prevalence of eating disorders in those with cystic fibrosis; however, endorsement of disordered eating practices does occur (56). Disordered eating practices found in those with cystic fibrosis include atypical eating disorder behaviors such as spitting out chewed food (54), food avoidance, preoccupation with food, bulimic tendencies (57), bodily function distortions with regard to gastrointestinal function (e.g., feeling bloated due to medication), and misuse of pancreatic enzyme replacement therapy (56). These types of disordered eating practices in cystic fibrosis patients pose harm to their health (56,58) (Table 2).

Some studies report that individuals with cystic fibrosis are at increased risk of eating disorders (i.e., eating disorders not otherwise specified) (59), whereas other studies report that the prevalence rates of eating disorders in cystic fibrosis patients do not differ from the rates in the general population (60,61). These conflicting results likely are due to the same factors noted in the type 1 diabetes literature described earlier.

**Celiac disease and disordered eating**

Celiac disease (also called celiac sprue) affects 1 of every 120 to 300 persons in Europe and North America (62). This lifelong inflammatory condition affects genetically predisposed individuals. In celiac disease, inappropriate T cell–mediated immune response against ingested gluten results in inflammation of the small intestine (62). Individuals with celiac disease cannot tolerate gluten, a protein that contains amino acid sequences with prolamin fractions. Gluten-containing foods are found in those made with wheat, rye, and barley (62). Long-term ingestion of foods containing gluten causes...
mucosal malabsorption in the small intestine because intestinal villi decrease in number, thereby reducing absorptive surface areas and enzyme secretions (62). Distressing gastrointestinal symptoms include distended abdomen, flatulence, and diarrhea (62).

Diagnosis of celiac disease can occur at any age and often coincides with stressful life events, pregnancy, or viral infections (62). Long-term treatment of celiac disease includes a restrictive diet that is gluten free. The need for permanent dietary restriction of gluten-containing foods, along with distressing gastrointestinal symptoms, may affect eating attitudes and behaviors of patients with celiac disease (63). Additionally, celiac disease patients’ quality of life in various mental health domains may be lower than that of healthy individuals in the general population (64,65), especially among women with celiac disease (66). Recent evidence suggests that women report more difficulty managing feelings of deprivation associated with a gluten-free diet and greater desire to control the preparation of the food that they eat compared with men with celiac disease (66). An increased focus on food intake is needed for controlling symptoms of celiac disease; however, unintentionally, this may give rise to other aspects of consumption (e.g., overly concerned about calorie intake) that are characteristic of eating disorders.

Existing research examining associations between celiac disease and eating disorders is limited, with most previous work focused solely on case studies (67). For instance, a single case study of a 23- y-old woman indicated that she had celiac disease before receiving a diagnosis of anorexia nervosa. The authors reporting this case study indicated that the dietary regimen for treating celiac disease could have been the trigger for the eating disorder (67) because the patient had an extreme avoidance of food, had fear of abdominal pain, and was a highly restrained eater (67). In addition, she was unsatisfied with her body shape and feared gaining weight (67). Only 1 study to date, which was not a case study, could be found that examined associations between celiac disease and disordered eating in adolescents (68). In this large (N = 283) cross-sectional study of adolescents with a diagnosis of celiac disease, rates of eating disorders (i.e., anorexia nervosa and bulimia nervosa) among female patients with celiac disease were substantially higher than estimates for the general population (~2.4% in study sample vs. 0.5%–1% in Western countries (15,69)). Additionally, eating disorders were only found among women, and the onset of eating disorders typically followed the diagnosis of celiac disease (68). Disordered eating practices observed in celiac disease patients included dieting (i.e., for shape and weight reasons), excessive exercising, vomiting, overuse of laxatives, and binge eating (68). No other disordered eating practices in celiac disease patients could be found in the literature (Table 3).

### IBD, IBS, and disordered eating

Crohn’s disease and ulcerative colitis are 2 major chronic intestinal disorders of unknown etiology that are known as IBDs. IBD manifests during childhood and adolescence in 20% to 25% of patients (68). The incidence of IBD varies globally, but there seems to be a higher incidence rate in Northern Europe, Scandinavia, New Zealand, and the United States (0.3%–0.8%) compared with other countries (70). Crohn’s disease affects the gastrointestinal tract from the oral cavity to the rectum, whereas ulcerative colitis involves the mucosal tissue of the colon and rectum (63). In IBD, the gastrointestinal tract becomes inflamed, resulting in a number of complications such as abdominal pain and diarrhea. In turn, the inflammation and scar tissue causes temporary and permanent damage to the intestinal tract, resulting in malabsorption of nutrients from food. This may lead to malnutrition and delayed growth. Most patients with IBD have increased nutritional and caloric needs due to delayed growth or postsurgery recovery. Additionally, they may have low tolerance for certain foods due to the severity of the illness, so dietary management may include dietary restrictions, nutritional supplements, and/or, in some instances, intravenous total parental nutrition supplementation. Thus, management of IBD involves both a prescribed dietary regimen (i.e., avoidance of foods that cause gastrointestinal aggravation, dyspepsia, or indigestion or can result in intestinal obstruction) and usually a pharmacological agent (i.e., corticosteroids) (71). “The chronic, unpredictable gastrointestinal symptoms and complications that occur with IBD, along with the required treatments, all impose psychological and social stresses on young patients” (72). A qualitative content analysis of young patients with an ileal pouch–anal anastomosis revealed that living a “normal” life, physical limitations, food restrictions, availability of restrooms in social situations, and being dependent on medical care were emergent themes (73). For instance, many patients with an ileal pouch–anal anastomosis reported food restrictions and complained about “being unable to eat different kinds of food, having to bring their own food outside the home, worrying about food making them ill, and having to eat often to feel well” (73). Patients also reported avoiding certain foods such as milk and onions that had the potential to cause a blockage (73).

IBS is found in 15% to 20% of children and adults. IBS is one of the most common reasons individuals seek medical attention when experiencing gastrointestinal distress, with nearly 40% of them also having some form of lactose

### Table 3. Disordered eating practices and risk factors of young people with celiac disease

<table>
<thead>
<tr>
<th>Celiac disease patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Types of disordered eating behaviors documented: food preoccupation, dietary restriction, use of laxatives, purging (i.e., self-induced vomiting), excessive exercising, and binge eating (68)</td>
</tr>
<tr>
<td>Potential factors increasing risk of disordered eating</td>
</tr>
<tr>
<td>Preoccupation with dietary management (gluten-free diet) (65,66)</td>
</tr>
<tr>
<td>Weight and shape concerns (67)</td>
</tr>
<tr>
<td>Body image disturbances (67)</td>
</tr>
<tr>
<td>Fear of abdominal discomfort from eating food (67)</td>
</tr>
<tr>
<td>Poor emotional well-being (e.g., depression, self-esteem) (64,65)</td>
</tr>
</tbody>
</table>

Chronic illness and disordered eating 281

by guest on 24 April 2018
intolerance (62). Women are twice as likely to have the condition compared with men.

Diagnostic criteria for IBS include at least 3 months of continuous or recurrent symptoms of the following: abdominal pain or discomfort relieved with defecation or associated with change in frequency of stool or changed consistency of stool; 2 or more: altered stool frequency (more than 3 per day or less than 3 per week), altered stool form (lumpy/hard or loose/watery), altered stool passage such as straining/urgency/feeling of incomplete evacuation, passage of mucus in the stool or bloating and feeling of abdominal distention (62).

Dietary management of IBS includes encouraging regular eating patterns and avoiding offending foods, adequate fluid intake, and close monitoring for other food allergies or intolerances (e.g., dairy, wheat, yeast, eggs, gluten) (62). Dietary management is individualized to the patient needs and severity of IBS symptoms. As with IBD, the constant gastrointestinal symptoms and self-shame of having the condition (i.e., bodily shame), all can affect one’s quality of life (74).

Qualitative research has shown that youths 7 to 19 y of age with IBD struggle with food restrictions (e.g., “I have to think about every little thing I eat, while others do not”) (70). They tend to perceive themselves negatively and differently than their peers (e.g., “I’m thinner, paler, my hair is thinner. I don’t like how I look now. I look sickly. They’ve name called me to death saying ‘fat girl’”) (70). IBD patients are most distressed by their physical (e.g., energy level) and psychosocial (e.g., body image) concerns (75), which may be associated with disordered eating. Female adolescents with IBD tend to express more concerns about weight gain or cushingoid features (e.g., rounded face) associated with corticosteroid treatments (70,76). In fact, 2 cases of bulimia nervosa that were diagnosed after the onset of Crohn’s disease suggested that the stress of the illness and weight gain associated with corticosteroid treatments may have played a role (77). In severe cases of IBD in which surgery is needed, adolescents who receive proctectomy with an ileal pouch–anal anastomosis at a young age have acceptable functional outcomes, but at the cost of relatively high complication rates, poor body image, cosmosis, and a high rate of sexual dysfunction in women (78). IBS patients also experience body shame, which can have a major impact on one’s self-esteem, social behavior, and vulnerability to other psychological problems (79). There is little evidence to suggest that eating disorders are more prevalent in the IBD or IBS population (80,81) because this has been understudied, but disordered eating practices are known to occur (76,79,82) (Tables 4 and 5).

Conclusions: implications for research and interventions

Findings from the literature suggest that young people with chronic illnesses that require a dietary component, such as type 1 diabetes mellitus, cystic fibrosis, celiac disease, IBD, and IBS, may be at risk of adopting disordered eating practices that can develop into a full-blown eating disorder over the course of their treatment. In turn, those with DRCHCs are at high risk of jeopardizing their health when they are coping with dietary management and psychosocial problems related to their illness.

Currently, there is a limited understanding of how eating disorders develop in certain DRCHC populations, especially in patients with celiac disease, IBS, and IBD. Qualitative work such as conducting focus groups with health care providers of DRCHC patients and DRCHC patients themselves would help to increase understanding of how eating disorders develop in DRCHC populations and lead to a suitable theoretical framework for patient interventions. Findings from qualitative work also could inform the development of disease-specific eating disorder screening tools that could aid in early identification for those with disordered eating.

Development of disease-specific eating disorder screeners

To prevent eating disorders from developing, it may be important to detect potential risk factors for eating disorders early in treatment. Health care providers can play an important role in regularly monitoring their patients’ psychological status for these potential risk factors. For instance, a brief screening tool that assesses negative body image and disordered eating tailored to youths with chronic health conditions easily could be implemented by health care providers at regular, routine visits with patients. By consistently assessing key markers of negative body image and disordered eating, health care providers can intervene early before these negative attitudes and behaviors progress to a more serious health condition, such as an eating disorder.

Unfortunately, as can be seen in Table 6, there are few reliable and valid eating disorder screeners specifically tailored to those with chronic illness. Eating disorder screening tools used in the general population have the potential to misclassify eating disorder risk in those with chronic illness due to

Table 4. Disordered eating practices and risk factors of young people with inflammatory bowel diseases (Crohn’s disease and ulcerative colitis)

<table>
<thead>
<tr>
<th>Inflammatory bowel diseases (Crohn’s and ulcerative colitis)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Types of disordered eating behaviors documented:</td>
</tr>
<tr>
<td>Food preoccupation and dietary restriction (70,73)</td>
</tr>
<tr>
<td>Potential factors increasing risk of disordered eating:</td>
</tr>
<tr>
<td>Delayed growth and puberty onset (105)</td>
</tr>
<tr>
<td>Preoccupation with dietary management (avoidance of foods that cause gastrointestinal discomfort and blockages) (73)</td>
</tr>
<tr>
<td>Fear of abdominal discomfort from eating food (70,73)</td>
</tr>
<tr>
<td>Weight and shape concerns (e.g., weight gain from steroid treatments) (70)</td>
</tr>
<tr>
<td>Poor body image (i.e., presence of cushingoid features) (75,78)</td>
</tr>
<tr>
<td>Poor emotional well-being (e.g., depression, self-esteem) (72)</td>
</tr>
<tr>
<td>Disease severity (e.g., need surgery to remove part of the intestinal tract) (78)</td>
</tr>
<tr>
<td>Body shame (e.g., use of colostomy or ileostomy bag) (78)</td>
</tr>
<tr>
<td>Limited social functioning (70)</td>
</tr>
<tr>
<td>Impaired interpersonal relationships (peers and significant others) (72)</td>
</tr>
<tr>
<td>Physical limitations (decreased energy levels) (70)</td>
</tr>
</tbody>
</table>

Downloaded from https://academic.oup.com/advances/article-abstract/4/3/277/4591604
by guest
on 24 April 2018
the nature of the questions possibly reflecting skills and attitudes learned as part of disease management. For instance, a question such as “Have you tried to follow definite rules regarding your eating?” would not be appropriate because diet restrictions are health protective in those with DRCHCs. Thus, the refinement of existing measurement tools and development of eating disorder screener tools that address disease-specific attitudes and eating behaviors are needed. In fact, 1 disease-specific measure is the Diabetes Eating Problems Survey, which was developed to identify the risk of disordered eating among women with type 1 diabetes (83). The Diabetes Eating Problems Survey and its recently developed shorter version (84) are promising instruments with good psychometric properties, but need further validation in populations of young people with both eating disorders and type 1 diabetes as well as with males to ascertain their ability to predict eating disorder risk in youths with type 1 diabetes. No other disease-specific eating disorder screening tools could be located. Thus, it is imperative to develop disease-specific eating disorder screener tools that health care providers can use to identify these types of problems early in disease treatment when disordered eating is most treatable (85,86).

Training health care providers
In addition to screeners, health care providers need opportunities to learn about disordered eating treatment. A recent qualitative study of 20 health care professionals in England who regularly visit type 1 diabetes patients found that there is a general lack of training in the area of detecting disordered eating and treatment (87). For instance, health care providers were unclear as to what should be categorized as disordered eating among patients with type 1 diabetes, and they were uncertain about caring for these individuals given their limited training related to eating disorder treatment (87). Thus, future research should also aim to develop resources for health care providers on the topic of disordered eating and weight control practices among people with chronic illnesses, such as type 1 diabetes, and provide opportunities for developing expertise on this topic.

Development of eating disorder prevention interventions
Future research also needs to address the development of effective eating disorder prevention programs that health care providers can recommend and implement with their DRCHC patients. Interventions aimed at promoting a positive body image and preventing disordered eating should be incorporated into the health care treatment of young people with DRCHCs, preferably prophylactically before eating becomes disordered. Across DRCHCs, young people face similar physical and emotional challenges. For instance, the extended time away from their peers and the pain and physical side effects of their disease, including disease-related changes in appearance, may contribute to disruptions in normal social and identity development (88). These psychological stressors may place strain on young peoples’ emerging coping skills as they attempt to resolve the constraints of their disease with normal life as a young person (89).

Table 5. Disordered eating practices and risk factors of young people with irritable bowel syndrome

<table>
<thead>
<tr>
<th>Types of disordered eating behaviors documented:</th>
<th>Food preoccupation and dietary restriction (76)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Potential factors increasing risk of disordered eating</td>
<td>Preoccupation with dietary management (avoidance of foods that cause gastrointestinal discomfort) (76)</td>
</tr>
<tr>
<td>Fear of abdominal discomfort from eating food (76)</td>
<td>Poor emotional well-being (e.g., depression, low self-esteem) (74)</td>
</tr>
<tr>
<td>Body shame (gastrointestinal problems from health condition) (79)</td>
<td>Limited social functioning (74)</td>
</tr>
<tr>
<td>Impaired interpersonal relationships (peers and significant others) (74)</td>
<td>Physical limitations (decreased energy levels)</td>
</tr>
</tbody>
</table>

| Table 6. Eating disorder risk assessments used in diet-related chronic health condition populations |

<table>
<thead>
<tr>
<th>Eating disorder risk instruments</th>
<th>Type 1 diabetes</th>
<th>Cystic fibrosis</th>
<th>Celiac disease</th>
<th>Irritable bowel syndrome</th>
<th>Crohn’s disease or ulcerative colitis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nondisease-specific instruments</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eating Disorder Examination semistructured interview (106)</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eating Disorders Examination Questionnaire (107)</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Child version of Eating Disorders Examination semistructured interview (108)</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Structured interview for DSM-II (109)</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Structured interview for anorexia nervosa and bulimia nervosa (110)</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eating Attitudes Test (EAT-26) (111)</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eating Attitudes Test (EAT-40) (112)</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Children’s Eating Attitudes Test (113)</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eating Disorder Inventory (EDI) (114)</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bulimia Test (BULIT) (115)</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diagnostic Survey for Eating Disorders-Modified (35)</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diagnostic semistructured interview (Kiddie-SADS-E and Eating Habits) (116)</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disease-specific instruments</td>
<td>Diabetes Eating Problem Survey (83,84)</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>

1 DSM, Diagnostic and Statistical Manual for Mental Disorders.
There is a paucity of research exploring interventions for young people with chronic health conditions engaging in disordered eating. However, a recent systematic review of psychological interventions for adolescents and young adults living with chronic illness reveal that skills-based interventions delivered over multiple sessions may yield the most positive results in psychological health outcomes (89). Interventions that taught communication skills, incorporated practical components (e.g., role playing), involved at least 6 sessions, and spanned at least 3 mo in length achieved positive outcomes (90).

A review study that examined diabetes and psychobehavioral interventions found that a number of treatment approaches that reduce individual, social-familial, and environmental barriers that can interfere with self-management, clinical outcomes, and quality of life in those with diabetes were shown to be effective at having a positive impact on physical and emotional well-being (90). Behavioral interventions in treatments derived from a sound psychological theoretical base were found to be more beneficial in those with type 1 diabetes (91). For instance, the health belief model and social cognitive theory are models commonly used as a guide in behavioral interventions to improve diabetes self-management and have been shown to have indirect effects on clinical health outcomes (92).

Social influences such as family factors, peer relations, and social support are important influences on chronic disease management and are starting to receive more attention as being important to incorporate into psychobehavioral interventions. Additionally, targeting health care professionals in a health care provider–patient communication intervention may provide DRCHC patients with more social-environmental support. For instance, providing health care professionals with training in methods to increase patient empowerment may have positive effects on attitudes toward those with chronic health conditions (93,94). Thus, psychobehavioral interventions for those with chronic health conditions should be behaviorally focused and have a theory-driven approach that includes the individual, interpersonal (e.g., family and peers), and social-environmental levels because they may have the greatest impact on improving the physical and emotional well-being of young people with chronic health conditions. Lessons learned from the few studies of psychobehavioral interventions among youths with chronic health conditions (90) can inform the development of effective future interventions among young people with chronic health conditions that can lead to better management of disease and overall health outcomes for those with disordered eating; however, more research is needed to elucidate the constructs that help youths with DRCHCs manage their disease while avoiding disordered eating practices.

It is imperative that health care providers become aware that young people with DRCHCs may be at increased risk of eating disorders and endorsement of disordered eating practices that can have a substantial impact on their health outcomes. Researchers should develop theory-based, behaviorally focused interventions and disease-specific eating disorder risk screening tools that are effective at halting the progression of eating disorders and negative health outcomes in young people with chronic health conditions. Future research and effective interventions addressing these concerns are needed to aid in the improvement of health outcomes among those with DRCHCs.

Acknowledgments
All authors have read and approved the final manuscript

Literature Cited


