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OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

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*Pediatrics* 2003;111:e98-e108

DOI: 10.1542/peds.111.1.e98

The online version of this article, along with updated information and services, is  
located on the World Wide Web at:

<http://www.pediatrics.org/cgi/content/full/111/1/e98>

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American Academy of Pediatrics

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# Children and Adolescents With Eating Disorders: The State of the Art

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**ABSTRACT.** *Background.* Eating disorders in children and adolescents remain a serious cause of morbidity and mortality in children, adolescents, and young adults. The working knowledge of pathophysiology, recognition, and management of eating disorders continues to evolve as research in this field continues.

*Objectives.* This article builds on previous background and position papers outlining issues relevant to the care of the adolescent patient with an eating disorder.

*Methods.* The eating disorder special interest group from the Society for Adolescent Medicine recognized the need to update the state of the art published guidelines for the care of the adolescent patient with an eating disorder. This article was a multidisciplinary, group effort to summarize the current knowledge of best practice in the field.

*Results.* This article summarizes newer findings on pathogenesis and etiology, prevention and screening, risk factors, nutritional issues, care from the primary care clinician's perspective, appropriate use of a multidisciplinary team, and issues of managed care and reimbursement.

*Conclusions.* Primary prevention combined with early recognition and treatment helps decrease morbidity and mortality in adolescents with eating disorders. *Pediatrics* 2003;111:e98–e108. URL: <http://www.pediatrics.org/cgi/content/full/111/1/e98>; adolescent, child, eating disorder, anorexia nervosa, bulimia nervosa.

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ABBREVIATIONS. AN, anorexia nervosa; BN, bulimia nervosa; ED-NOS, Eating disorder-not otherwise specified; BMI, body mass index.

Eating disorders in children and adolescents continue to be a serious problem and may result in premature death or life-long medical and psychosocial morbidity. In 1995, the *Journal of Adolescent Health* published background and position papers outlining relevant issues in the care of the adolescent with an eating disorder.<sup>1</sup> This article provides an update on the state of the art for the child and adolescent with an eating disorder. Topics covered are pathogenesis and etiology, prevention and screening, risk factors, nutritional issues, aspects of care from a primary care clinician's perspective and goals for a multidisciplinary team, care in the inpatient and outpatient settings, use of clinical pathways, and issues of managed care and proper reimbursement.

## PATHOGENESIS AND ETIOLOGY OF EATING DISORDERS

Despite increasing awareness of the major eating disorders, a specific etiology for the pathogenesis of anorexia nervosa (AN) and bulimia nervosa (BN) remains unclear. Rather than single factor causal theories, eating disorders are now viewed as multifactorial disorders with the symptom pattern representing a final common pathway.<sup>2</sup> Interest has focused variously on the contribution of environmental and social factors, psychological predisposition, and biological vulnerability, with recent familial aggregation studies renewing interest in the contribution of genetic predisposition.

DiETING continues to be a common entry point in both syndromes, with the greatest risk being the group of severe dieters.<sup>3</sup> Not surprisingly, therefore, sociocultural and environmental factors as they relate to ideal body shape are thought to play an important role in the development of eating disorders. Reports of AN and BN are more common in industrialized nations where food is plentiful and where thinness for women is correlated with attractiveness. For example, the prevalence of AN in Greek girls living in Germany was double the rate for those girls living in Greece and Turkey where they remained less exposed to Western values equating thinness with beauty.<sup>4</sup>

The prominent physiologic disturbances in AN

have led to speculation that the abnormal behaviors are caused by a primary biological abnormality. Disruptions of the pituitary, hypothalamus, and various neurotransmitters have been postulated to be causal factors in the development of AN. However, most of these physiologic disturbances, and more recently, functional imaging studies, resolve with normalization of body weight, an argument against a primarily causal role.

However, recent studies of serotonin in particular have brought renewed interest in this area. The neurotransmitter serotonin is known to affect appetite control, sexual and social behavior, stress responses, and mood. Serotonin modulates feeding by producing the sensation of fullness or satiety. Serotonin antagonists that decrease serotonergic neurotransmission or block receptor activation increase food consumption and promote weight gain. Decreases in brain serotonin function are associated with depression, impulsivity, and aggressive behavior. The major serotonin metabolite, 5-hydroxyindoleacetic acid, is low in people who are underweight with AN, but then rises to above normal levels in those who have made long-standing recoveries.<sup>5,6</sup> One study<sup>7</sup> showed that patients with more severe binge eating have lower cerebrospinal fluid 5-hydroxyindoleacetic acid than do controls. It has been speculated that a premorbid disturbance in serotonergic function might be a risk factor for the development of both AN and BN. A putative allelic association between the B1438 A/G promoter polymorphism of the 5-HT2A gene and AN has been reported, but not consistently so.

Leptin, a hormone secreted by fat cells, seems less likely to play an important role in AN, despite its role in regulating body fat. People with AN or low weight have low serum leptin, consistent with their reduced mass of fat tissue, which increases with weight gain.<sup>8,9</sup> Interestingly, however, normalization of leptin levels seems to precede normalization of body weight, which may contribute to the difficulties experienced with attaining and maintaining normal weight in AN.

Neuroimaging studies using magnetic resonance imaging scans<sup>10,11</sup> and more recently, PET scans,<sup>12</sup> demonstrate subtle alterations of function as well as structure of the brains of those girls with AN but have not yet yielded any etiologic understandings.

Clinical and population studies of women have consistently demonstrated an increased association between major depression and AN,<sup>13</sup> with depression a risk factor for development of incident eating disorders in adolescence.<sup>3</sup> First-degree relatives of women with AN have elevated rates of major depression. Although it has been suggested that AN and major depression share a common etiology, it has also been suggested that the risk for AN is distinct from that of other affective disorders. However, many of the clinical features of depression can also result secondarily from starvation and improve with weight restoration.

Familial transmission of risk has emerged as an increasing focus of research attention. There are now multiple case-control studies designed to investigate

the familiarity of eating disorders, which demonstrate a higher rate of AN in relatives of probands with AN. The frequency of BN is also greater in the relatives of AN probands. The increased incidence of AN and BN in families is consistent with a range of observations, including 1) the coexistence of binge eating with AN, 2) development of both AN and BN that has been demonstrated in longitudinal studies, 3) the overwhelming predominance of common patterns of gender and personality traits, and 4) comorbidity with mood and anxiety disorders.<sup>14</sup>

In summary, the pathogenesis of eating disorders can be conceptualized in terms of symptoms reflecting a final common pathway with multiple developmental contributions. In terms of interventions, therapeutic implications can be derived best where there is consideration of the predisposing, precipitating, and perpetuating factors.

### PREVENTION AND SCREENING FOR EATING DISORDERS

Emerging experience suggests that recognition of individuals at risk and early intervention can prevent the development of full-blown eating disorders. Thus, for the primary care clinician, prevention of eating disorders rests on recognizing and addressing early risk factors, screening at-risk patients, and providing prompt and effective interventions to patients identified with disordered eating before frank eating disorders emerge.

Patients with disordered eating are less easily stereotyped than they have historically been. Once thought of as afflictions of affluent white young women, these conditions are now increasingly being seen in young patients, male patients, and patients of color.<sup>15-18</sup> Especially disturbing is the dramatic number of very young girls presenting with an obsessive overconcern about health and fitness, severe food restriction, significant weight loss, and even arrest of growth and development.<sup>19-24</sup>

Disordered eating, which does not meet the strict *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* diagnostic threshold for AN or BN, still represents a serious risk to health and well-being. Partial syndromes resembling both AN and BN are seen, with the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* category of "Eating disorder, not otherwise specified (ED-NOS)" used to capture the diverse spectrum of disordered eating. In some cases, disordered eating is simply the early presentation of what will eventually evolve into a full-blown eating disorder. In other cases, disordered eating is relatively static and does not progress in the short term. Adolescents engaged in pathologic dieting have been found to be 7 times more likely to develop disordered eating, and such dieting was a sensitive predictor of those who went on to develop eating disorders.<sup>3</sup> Other risk factors are seen in Table 1.

The diagnosis of ED-NOS should never be considered a low-grade disorder or undeserving of aggressive treatment. Rather, disordered eating and ED-NOS represent an opportunity to intervene in a potentially life-threatening pathologic process at an early stage that

**TABLE 1.** Risk Factors for the Development of an Eating Disorder

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Family history of eating disorder or obesity
Affective illness or alcoholism in first-degree relatives
Ballet, gymnastics, modeling, "visual sports"
Personality traits (eg, perfectionism)
Parental eating behavior and weight
Physical or sexual abuse
Low self-esteem
Body-image dissatisfaction
History of excessive dieting, frequently skipped meals, compulsive exercise

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may be more amenable to treatment. Failure to meet the strict criteria for AN or BN should never deter the clinician from offering early and comprehensive intervention. This is especially true in younger patients in whom earlier intervention is associated with a better long-term prognosis.

### SCREENING

Formal tools are available for the assessment of eating behavior and eating attitudes; however, these are not typically used by primary care providers. Simple screening questions can help to determine whether additional evaluation is required (Table 2).

When symptoms of disordered eating are recognized, a careful diagnostic interview should follow. It should establish the presence or absence of formal criteria for eating disorders including loss of weight, fear of weight gain, fat phobia, preoccupation with

**TABLE 2.** Useful Questions to Screen for an Eating Disorder

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History of present illness
Weight history
Maximum weight and when? Desired weight?
How does the patient feel about his/her current weight?
How frequently does she/he weigh him/herself?
When did the patient begin to lose weight?
What weight control methods have been tried?
Diet history
Current dietary practices? Ask for specifics, amounts, food groups, fluids, restrictions.
Any binges? Frequency, amount
Any purging? Frequency, amount
Abuse of diuretics, laxatives, diet pills, ipecac?
Exercise history: types, frequency, duration, intensity
Menstrual history: age at menarche? Regularity of cycles? Last normal menstrual period?
Review of systems
Dizziness, blackouts, weakness, fatigue
Pallor, easy bruising/bleeding
Cold intolerance
Hair loss, dry skin
Vomiting, diarrhea, constipation
Fullness, bloating, abdominal pain, epigastric burning
Muscle cramps, joint pains, palpitations, chest pain
Menstrual irregularities
Symptoms of hyperthyroidism, diabetes, malignancy, infection, inflammatory bowel disease
Psychological symptoms/history
Adjustment to pubertal development
Body image/self esteem
Anxiety, depression, obsessive-compulsive disorder, comorbid
Past medical history
Family history: obesity, eating disorders, depression, substance abuse/alcoholism
Social history: home, school, activities, substance use, sexual history, sexual abuse

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food, restrictive eating patterns, purging behaviors, body image distortion, out-of-control eating, and menstrual irregularity. Some patients with disordered eating or eating disorders will be unable to describe their behavior accurately or truthfully, making assessment more difficult. Additional information from family and friends can sometimes be revealing. Other information can help support the presumptive diagnosis of an eating disorder: preference for eating alone, extremely limited food choices, ritualized eating habits (eg, preference for a certain plate or bowl, eating foods in particular order, unusual food combinations), excessive fluid intake, excessive chewing of ice or gum, or recent vegetarianism. All patients with eating disorders should be screened for risk of suicide. Suicidal ideation can be present in any patient with disordered eating or eating disorders, but is especially common in patients with BN. When earlier identification of disordered eating has resulted in appropriate intervention, better prognoses are seen. Thus, concern over a patients' eating behavior should quickly lead to a coordinated plan that specifically addresses the problem. A "wait-and-see" approach is contraindicated.

The presenting symptoms of the eating disorders, such as loss of appetite, weight loss, amenorrhea, or unexplained vomiting, can be mimicked by a variety of medical conditions. When disordered eating is suspected, but the typical features of eating disorders are absent, alternative medical and psychiatric diagnoses should be explored while at the same time considering the possibility of denial or intentional deception. Medical diagnoses sometimes mistaken for eating disorders include inflammatory bowel disease, malignancies, thyroid disease, diabetes mellitus, chronic infections, and central nervous system disease. Psychiatric disorders can also be mistaken for eating disorders. Loss of appetite and a consequent weight loss are cardinal features of depression. Obsessive-compulsive disorder, substance abuse, and psychotic disorders are other conditions whose presentation may sometimes simulate that of a primary eating disorder.

### PRIMARY CARE APPROACH TO MANAGEMENT

The primary care provider is in the unique position to detect subtle clues to an eating disorder early on in its course when intervention may be easier. Rarely will an adolescent present with the complaint of an eating disorder. Sometimes an astute coach or school nurse refers the teenager, or a parent may become suspicious of an eating disorder. More commonly they seek help for a physical symptom such as dizziness, fatigue, headaches, heartburn, constipation, or amenorrhea, which result from weight loss or abnormal eating behaviors. The clinician needs to have a low threshold of suspicion.

When an eating disorder is suspected, a careful medical and psychosocial history needs to be taken and a thorough physical examination performed. Tables 2 and 3 outline questions to address in the history and potential findings on physical examination. In a busy practice, however, the answers to a

few key questions, asked in a nonjudgmental fashion, may help the clinician determine whether additional investigation is warranted: 1) How much would you like to weigh? 2) How do you feel about your present weight? 3) Do you or anyone else have any concerns about your eating or exercise behaviors/practices? When the concern about an eating disorder has been raised, a return visit in 1 month or less for follow-up weight and physical examination is prudent, even if the current weight remains in the healthy range, as any weight loss during periods of expected growth is concerning and may herald the onset of an eating disorder. The early AN patient feels victorious when a visit to the pediatrician results in her parents being told she is just fine; a humiliated or discredited parent may not keep a follow-up appointment. Therefore, it is important to explain the rationale for follow-up both to the patient and family. The patient who clearly has an eating disorder should be seen back within 1 to 2 weeks, with an initial treatment plan—"a contract"—in place. The purpose of the treatment plan is to set specific goals for the patient. The treatment plan is a work in progress that is evaluated on a regular basis by the treatment team, patient, and family to be sure it is helping the patient and family progress in treatment.

### Assessment

After eliciting the parent's concerns in the presence of the patient, the patient should be interviewed alone. History should be obtained in a nonjudgmental, empathetic fashion in an attempt to understand what the patient has been experiencing to determine whether or not there is a problem. Weight loss should be explored in greater detail for intentionality, methods used, and any resulting symptoms of compromised health. Physical examination may be normal; however, a number of clues may be uncovered if they are sought out (Table 3). Medical complications may be serious, irreversible, and even fatal. Every organ system may be adversely affected by malnutrition and weight loss. Of particular concern short-term are vital sign abnormalities and cardiac dysfunction; longer-term concerns include menstrual abnormalities and osteoporosis. Purging

**TABLE 3.** Possible Physical Exam Findings in Eating Disorder Patients

General appearance: emaciated; sunken cheeks; sallow skin; flat affect. May be normal weight or overweight with BN/ED-NOS
Vital signs: bradycardia, hypotension, hypothermia, orthostasis
Skin: dry skin, lanugo hair, loss of shine or brittle hair, nail changes, hypercarotenemic, subconjunctival hemorrhage (from vomiting)
HEENT: sunken eyes, dry lips, gingivitis, loss of tooth enamel on lingual and occlusal surfaces, caries, parotitis
Breasts: atrophy
Cardiac: mitral valve prolapse, click and/or murmur, arrhythmias
Abdomen: scaphoid, palpable loops of stool, tender epigastrium if vomiting
Extremities: edema, calluses on dorsum of hand (Russell sign), acrocyanosis, Raynaud's phenomenon
Neuro: Trousseau' sign, diminished deep tendon reflexes

HEENT indicates head, ear, eyes, nose, throat.

may result in severe abnormalities in electrolytes. A comprehensive review of medical complications can be found elsewhere.

### Assembling a Team

Although it may be ideal to have a formal eating disorders treatment team, an interested primary care physician who is willing to find and communicate regularly with a dietitian and therapist can do much. The primary care giver already has much of the necessary knowledge and skills, and, by teaming with these other key care providers, the patient can be treated effectively. Compliance may be improved by assembling a local team of providers if possible, rather than referring the patient long distance to a formal treatment program.

The registered dietitian should be experienced in working with children and adolescents, and be familiar with the significant calories necessary for weight restoration plus normal growth needs. She should be firm yet flexible in assisting the patient in setting up a food plan and teaching the exchange system to patient and parents. Discussion of specific calorie and fat gram content is useful for some patients and families but not helpful to others. She also needs to be able to confront the patient when excessive exercise, purging, or lack of adequate food intake is suspected.

A therapist should understand adolescent developmental issues and eating disorders and have experience working with children, adolescents, and their families. The therapist can also advise the physician and dietitian on strategies to utilize, as s/he understands the context of the eating disorder.

Psychiatric consultation may be beneficial, and sometimes necessary, for diagnostic questions, concerns about comorbid diagnoses (including depression, obsessive-compulsive disorder, or anxiety disorder), as well as pharmacotherapy decisions.

The primary physician monitors the patient's medical status through frequent visits (usually 1 or 2 times per week, more or less depending on the patient's response to treatment) that include history, physical examination, weight (always obtained in an examination gown, after voiding), vital signs, and laboratory evaluation as needed. Health education regarding the role of dietary fats, the need for adequate nutrient intake and restoration of menses to assure reaching optimal bone mineral density, the effects of starvation on the metabolic rate and the heart, gastrointestinal tract, and brain can be provided by the physician. Indeed, it is the primary physician who is viewed as the family's number one resource on the health effects of the eating disorder. The primary caregiver also monitors for adequate nutrition intake and/or recommends supplementary multivitamins, calcium, zinc, iron, or folate as needed. If delayed gastric emptying is impeding refeeding, cisapride or metoclopramide can be prescribed (with extreme caution if the patient is bradycardic, has prolonged QT interval, is extremely malnourished, or is on selective serotonin reuptake inhibitors). When esophagitis is present from purging or reflux, histamine-2 blockers and/or proton-

pump inhibitors can be provided. It may be appropriate for the primary physician to be the one to prescribe selective serotonin reuptake inhibitors for near normal-weight patients with BN or AN patients who have achieved target weight range. It is appropriate for the primary caregiver to take the lead in establishing a formal or informal contract for recovery with the patient, which can be a document or verbal care plan that should be reviewed by the entire team. This initial contract is often modified over time subject to the patient's progress as noted above.

It is critical for team members to communicate on a regular basis. Team members must support each other and consult one another before making significant changes to the plan. Taking the time to gather each other's input can help the team understand the dynamics of the situation better, avoid becoming the objects of "splitting" (an attempt to "split" the care team into divided factions to undermine treatment), and provide more effective treatment. When another team member's views are reported as differing from those of the physician, it is essential for the physician to take it up with the other member directly, avoiding any derogatory comments in front of the patient or family, and perhaps supporting the other member by saying something like, "I'm sure your therapist must have a reason for suggesting we proceed in this way; I'll call her so I can understand it better."

All members of the team can use opportunities to provide cognitive restructuring; that is, challenge assumptions, beliefs, attitudes, and myths held by the patient. The physician, for example, can encourage the poorly compliant patient to try an experiment for just 1 week to eat the entire food plan and find out what will really happen to her body, to show that her worst fears will not be realized. Additionally all team members can normalize, for patient and parents, the expression of negative affect (frustration, disappointment, sadness, anger) in a socially acceptable/respectful manner by validating the patient when she verbalizes negative affect and helping parents to see that this is healthy and important for recovery. Parents may need praise for appropriate limit-setting and may need encouragement to get their own support, read about eating disorders, and to support each other to avoid triangulation (a form of splitting) within the family.

#### **When There Is Lack of Progress**

Specific short-term expectations should be set by the team to help encourage progress as an outpatient. A target weight line with a slope of 1/2 to 2 pounds per week can be drawn (if not already done) by the physician and shown to the patient to make progress, or lack thereof, more concrete. Plotting percent body fat increase, or a graph following the decrease in malnutrition, may also be helpful tools. With younger children, parents may be instructed to prepare, assemble, and plate out all food, and supervise its consumption to assure adequate portions are being eaten. If parents are not initially involved in helping or supervising, failure to progress may necessitate getting them more actively involved in

meals. Psychiatric consultation should be obtained if this has not been done. Options for day treatment or inpatient hospitalization should be explored. For further management by severity of eating disorder, see Table 4.

#### **NUTRITIONAL CONCERNS DURING ADOLESCENCE**

The consequences of nutritional deprivation are related to the length, severity, and number of episodes of restriction and, very importantly for adolescents, the timing of those episodes in relationship to normal periods of growth and physical development.<sup>25,26</sup>

In acute and severe malnutrition all body tissues and organs may be affected. Damage to brain and bone tissue of adolescents with AN may or may not be totally restored to normal even with replenishment of nourishment.<sup>10,11,27</sup> In the brain it appears some compartments may be rehabilitated, whereas others are not.<sup>10</sup> Damage to most tissues and organ systems in the malnourished adolescent, however, have not been thoroughly studied. Although specific nutrients may be in short supply, the factor limiting systematic normality may actually be energy. With insufficient energy available, tissue maintenance and synthesis cannot occur even if the vital building blocks are present. Thus, the degree of osteopenia in malnourished adolescent females found to be related to total nutritional status as characterized by body mass index (BMI), eg, the proportion of total body weight for skeletal height.<sup>11</sup> Newer growth charts now incorporate the plotting of BMI over time with height and weight.

Both formally diagnosed eating disorders and disordered eating may result in serious nutritional deficiencies.<sup>28,29</sup> Adolescents may also develop serious nutrient imbalances as result of stressful lives and/or the need to manage their own dietary selection without proper education or supervision.<sup>30</sup> They may take nutritional risks as part of normal or exaggerated adolescent experimentation.<sup>31,32</sup> Adolescents with chronic diseases as well as those in competitive sports and dance are especially vulnerable.<sup>29</sup>

More sensitive nutritional status measures, and/or more situation-specific standards of application of commonly used measures are needed to monitor true changes in adolescent patients with AN. The application of indirect calorimetry has documented alterations in energy needs of adolescents in different phases of the disorder. Requirements are lower in the acutely malnourished patient than predicted by traditional equations and then increase strikingly during refeeding.<sup>33</sup> Investigators have also suggested that the most commonly used method of nutritional assessment during recovery, specifically the BMI ratio, yields less than helpful results when applied to adolescents with AN.<sup>34</sup>

Nutritional therapy requires ongoing assessment and monitoring, limit setting and goal establishment, and dietary prescriptions, as well as supportive counseling and education by the dietitian.<sup>35-38</sup> Assessment and monitoring of nutrient amount and balance of nutrient intake, fluid intake, food-related

**TABLE 4.** Suggested Guidelines by Severity of Eating Disorder

Mild or early eating disorder
85%–95% IBW and vital signs stable, full criteria may not be met
-Begin food plan of 3 meals and 3 snacks, usually with at least 1200–1500 calories/d (varies depending on patient's recent caloric intake), increasing amount once or twice weekly. Referral to dietitian can be very helpful.
-Refer to therapist experienced with teens and their families.
-Set a contract for expected rate of weight gain, target weight, a hospitalization weight, and consequences for failure to gain.
Draw target line. See at least every 2 wk until gaining consistently, then at least monthly till reaches target weight range.
-Communicate weight, vital signs, and any concerns to therapist and dietitian every few weeks.
-Add liquid supplements and/or restrict activity for failure to gain adequately. If bradycardic, restrict activity.
-See weekly and add parental supervision of meals for continued failure to gain. See "Moderate" category.
Moderate or established eating disorder
75%–85% IBW, may have changes in vital signs trending downhill, or minor laboratory abnormalities
-Dietitian and therapist should be mandatory.
-Restrict from physical activity until on gaining trend and vital signs remain stable.
-Short-term goal is for patient to reach weight at which exercise is safe.
-Set a contract for expected rate of weight gain, target weight, a hospitalization weight, and consequences for failure to gain.
Draw target line.
-See at least weekly until gaining consistently, then at least every 2 weeks till reaches target weight range.
-Communicate weight, vital signs, and any concerns to team members regularly.
-Consider liquid supplements to boost caloric intake.
-Discuss the possibility that hospitalization may be necessary if unable to reverse the weight loss.
Severe
<75% IBW, medically unstable, pulse <50, may be dehydrated
-Hospitalize. Here it is essential for nursing staff to be included in the plan of action, to take a supportive yet firm approach, not to bargain with the patient or keep information from the team.
-Restore nutrition through food trays planned by dietitian with expectation for completion. NG backup if patient unable or unwilling to take in prescribed nutrition. Give oral or NG supplement in an amount equivalent to uneaten portion of food.
Provide calories through 3 meals and 3 snacks over course of day. Calorie level should generally start at a minimum of 1200–1500/d and increase by 200 kcal/d until gaining weight, then by 200 kcal/d every 2–3 d until reaches expected calories.
Monitor closely for refeeding syndrome, fluid shifts, cardiac arrhythmias, and other serious acute medical complications.
-The patient should be closely monitored during and for 1 h after eating to provide support and assure compliance.
-Supervise time in bathroom for safety when orthostatic hypotension exists, and to deter exercise or purging.
-Having a therapist see the patient at least several times/wk in the hospital can be valuable. Because the patient often has difficulty processing information when acutely malnourished, this may be a time for primarily providing support. As nutrition and cognition improves, so will insight, and therapy can proceed. The patient can be asked to write a list of positive or healthy messages she can tell herself when the eating disorder is trying to convince her not to eat. She can learn relaxation techniques to utilize before and after meals.
-Hospitalization needs to be long enough to enable the patient to stop losing weight, establish a gaining weight trend, normalize vital signs and laboratory studies, and be able to eat adequately (with a fair amount of independence) to continue to gain weight as an outpatient.
Patients hospitalized on >1 occasion require higher weight goals for discharge. As health improves, the patient can be given greater input on the menu, choose meals from the cafeteria with her family, and eat some meals unsupervised.

IBW indicates ideal body weight; NG, nasogastric.

behaviors, ideas and beliefs, biochemical status, metabolic rate, body composition including fluid retention, feelings of hunger and satiety, and attitude toward adequate nourishment are key elements of successful therapy. Table 5 outlines specific dietary recommendations for different stages of recovery.

#### Treatment Guidelines and Clinical Pathways for AN

The development of treatment guidelines, protocols, and clinical pathways has increased because of 3 divergent forces in medicine.<sup>39,40</sup> First, professional organizations are supportive of structured approaches, because these treatment regimens help to ensure that patients receive quality care, as well as increase practitioner awareness of accepted approaches to the provision of care for a particular diagnosis.<sup>41,42</sup> A second influence that has contributed to the increased use of treatment protocols is the need to respond to the increased scrutiny of clinical practice by managed care organizations. These types of guidelines make treatment courses and outcomes more predictable. Third, the use of clinical guidelines helps to contain costs while also providing comparable outcomes that can be more accurately evaluated.<sup>43,44</sup>

The impact of these approaches to date has been limited for AN treatments. Still, AN would seem an ideal candidate for a structured protocol. Historically, guidelines, protocols, and clinical pathways are especially helpful when formulating care for costly or complex diagnoses, where many disciplines and a variety of services and interventions are required. This is certainly true for AN.

There are 2 guidelines for AN treatment that have been published. From a psychiatric perspective, the American Psychiatric Association has recently published a revision of its 1993 guideline. As a guideline, it is a consensus document and as such presents an overall review rather than a specifically tailored approach.<sup>45</sup> Interestingly, the American Psychiatric Association guideline includes recommendations for medical treatment as well as recommendations for treatment at different levels of care. The other guideline was published by the Society for Adolescent Medicine. This guideline focused on the specific medical problems of adolescents with eating disorders.<sup>1,46</sup> Taken together, these 2 guidelines could be used to develop a single national standard for the medical and psychiatric treatment of AN in adolescent populations.

**TABLE 5.** Key Aspects of Nutritional Care for Eating Disorders in Adolescents

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Goal establishment
Daily gain during life threatening phase of malnutrition 0.3–0.4 lb/d
Weekly gain in acute outpatient phase of malnutrition 1–2 lb/wk
Intermediary goals (10th, 15th, 25th, 50th percentile) until normal weight-for-height is reached, with normal menstrual status for pubertal stage
Dietary intake to support adequate gain and health
Dietary guidelines
Early stages—Educate and counsel to support patient normalizing food consumption—crisis stage plan menu or patient chooses food, determined by team approach to intensive treatment
Rehabilitation phase—enable patient to replace outside control with self management
Dietary prescriptions (above) are guides to nutrient needs at various stages of disorder
Food types and composition equivalents translate prescriptions into dietary patterns
Education
Nutritional supports for life and health
Principles of energy balance
Methods of healthy weight management
Food choices in any setting
Dangers of habits developed in AN and BN
Supportive counseling
Facilitating patient in nourishing self
Referral
To all members of interdisciplinary team if not in same institution
For dental care, especially if vomiting

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In order for guidelines to be practical, a further level of refinement is required. By providing increasing detail and attention to treatment processes, clinical pathways can be developed. Clinical pathways describe the optimal sequencing and timing of interventions by the treatment team (eg, medical, nursing, nutrition, mental health, and other staff). As such, they should minimize delays in care, monitor resource utilization, and maximize quality of care.<sup>47</sup> Thus, they should also reduce variation in the care provided, improve outcomes, reduce inappropriate lengths of stay, and improve cost-effectiveness.<sup>48–50</sup>

Clinicians at Lucile Salter Packard Children's Hospital at Stanford have published the first clinical pathway developed specifically for AN treatment in adolescents.<sup>51</sup> Using local treatment protocols and national guidelines for treating AN,<sup>46,52</sup> a team of adolescent medicine physicians, child psychiatrists, nurses, and dietitians collaborated to develop a clinical pathway. Key elements of the Stanford clinical pathway include medical, psychiatric, nursing, nutritional, and educational needs of patients and their families. The clinical path is built with a series of 3 stages that incorporate medical and psychiatric progress. During Stage 1, the typical adolescent is initially hospitalized on strict medical bed rest because of extreme medical fragility determined by vital sign instability or evidence of extreme malnutrition (ideal body weight <75%). Such patients are given a prescribed diet and their caloric intake closely monitored by experienced nursing staff. As patient vital signs stabilize and weight increases to a minimum of 75% of ideal body weight, Stage 2 of the treatment program begins. This principal feature of Stage 2 is a behaviorally reinforced monitored weight gain program. Target weight gain is at a rate of 0.2 kg per day. If a patient fails to gain this minimal amount, caloric consumption requirements are increased.

Along with the medically prescribed weight gain program, psychiatric evaluation and treatment of individuals and their families are initiated. The emphasis in the first stage is on building therapeutic rapport with the patient and family. The crisis of

hospitalization is often an avenue to help the therapist to increase awareness of the severity of the child's problem and to emphasize the need for action. Individual therapy with the adolescent is often confined to supportive therapy to help the adolescent accept the need to eat. Many patients are cognitively impaired at low body weights so little insight should be expected. As treatment proceeds to Stage 2, the therapist increases efforts to create cognitive dissonance between what anorectic behavior accomplished compared with other goals the adolescent may have (eg, school, friendships, athletic pursuits). Stage 2 may last well beyond discharge from hospital and often lasts 3 to 6 months. Stage 3 begins when patients are medically out of danger and able to participate more actively and appropriately in their treatment. Therapists encourage adolescents in this stage to come up with their own diet plans, weight gain programs, and monitoring programs. This stage may last from 6 months to several years.

It is clear that there are advantages for developing clinical pathways to assist in the treatment of AN in adolescents. General guidelines and local treatment conditions can come together to generate a more specific approach. In this way, the knowledge acquired through experience becomes formally structured and conceived. This permits for regularizing treatment, earlier identification of treatment problems, and comparisons of outcomes of patients similarly treated.

#### EATING DISORDERS AND HEALTH INSURANCE

Because the best treatment programs are characterized by being multidisciplinary and involving stages or phases over time, they may become quite expensive. Moreover, because treatment involves multiple care providers, and because severe cases may require longer-term care, sooner or later clinicians may find that their patients' insurance company is either denying payments altogether or instructing them to follow an incomplete, inferior treatment alternative. Faced with these choices, pa-



tients and families are then left in serious financial distress, including total ruin. In some instances, the effects on a distressed family can be destructive (including resentment of the patient, feeding into the resistance to treatment, and may also lead to the premature abandonment of treatment). Yet lack of or insufficient treatment may result in chronicity, invalidism and even death. Thus, it is important that professionals treating adolescents with eating disorders, patients, families, and the general public have an understanding of the barriers to care and how to approach them.<sup>53,54</sup>

Lawyers who have litigated lawsuits against health insurance companies have also acknowledged the need for a multidisciplinary team.<sup>17</sup> Health insurance companies have, for financial reasons, had an arbitrary division of medical and psychiatric benefits. Although coverage is often initially medical, it usually shifts to the less expensive and more time-limited psychiatric benefits in an effort to lessen spending. When to make this transition remains unclear because the problem is truly a multidisciplinary one with both psychological and medical treatment need as part of the treatment. State-of-the-art treatment can be delivered best with state-of-the-art coverage, which would entail treatment of adolescents with eating disorders with a multidisciplinary approach, both from a clinical and fiscal advantage.

#### Insurance Problems in the United States

The insurance issues for adolescents with eating disorders are not unlike those that affect the entire population of adolescents and young adults.<sup>55</sup> Many have no insurance because they no longer are eligible for their family plan. Most are underinsured, either lacking or having minimal mental health benefits. The situation has reached a crisis level, resulting in closure and/or reduction of services provided by eating disorder programs, pressuring practitioners to delay or forego needed admissions, advancing discharges and delivering crisis oriented treatment as opposed to focusing on rehabilitation and recovery.<sup>56-60</sup> There are 3 basic barriers to care that may preclude treatment for adolescents with eating disorders: 1) eligibility, 2) scope of benefits, and 3) reimbursement, or copayment and deductibles.<sup>53,56,58,61</sup>

#### Eligibility

One major reason why many adolescents and young adult patients are not eligible for coverage relates to the fact that many insurance groups are reducing the age up to which patients can continue under parental insurance. This lack of insurance occurs at the same time that partial employment or temporary employment in this age group is very high and affordability of insurance is limited. The situation is further complicated for new insurance holders by the preexisting condition clause, sometimes invoked in questionable ways. Although it is easier for college students to remain on their parents' insurance, they can only remain enrolled as long as they are in school. Therefore, if the eating disorder becomes severe and they have to leave college, they

will lose their health insurance at the time when they will need it most. The eligibility issue is the most serious one of all, because without health insurance the topic of scope of benefits and reimbursement will be moot.

#### Scope of Benefits (Coverage)

In many health plans, including health maintenance organizations and preferred provider organizations, the scope of benefits for treatment of eating disorders is minimal. For instance, the use of diagnostic-related groupings places additional obstacles for adequate hospitalizations. The diagnostic-related grouping for malnutrition is for 3 to 4 days. Needless to say, an inappropriately low discharge weight during a short stay has a much higher chance of ending in clinical deterioration. Even those patients who have 30 days of hospitalization in their health plans are not necessarily granted that time, as reviews, done every few days, may demand discharge the moment the patient's weight begins to improve, not taking into account other therapeutic issues. This trend does not affect only the rather costly hospitalization. Restriction of the number of outpatient visits to physicians and therapists is common. This trend is even more marked when it involves the need for simultaneous therapy approaches, such as is the case with individual, group, and/or family therapy.

A number of related problems have been repeatedly identified:<sup>52,55,57-59,62-64</sup>

- Designation of an adolescent medicine hospitalization as "psychiatric" as opposed to "medical," followed by denial of payment or acceptance of only the first couple of days for medical stabilization with denial for the remaining days of nutritional rehabilitation.
- Denial because the patient should have been admitted for a lower level of care (despite none existing in the community).
- The disclaimer phenomenon: insurers often state disclaimers at time of inpatient or partial hospital care, or just because days are certified does not mean that they will be paid by insurance. Clinicians and family act in good faith, but have no assurance that care will be reimbursed.
- Unfavorable reimbursement for outpatient or inpatient medical encounters if the diagnostic code includes a psychiatric diagnosis, such as AN.
- Unilateral review with criteria unknown to the clinician.

A complex array of methods for concurrent review of medical and psychiatric treatment can result in:

- Lack of coordination between reviewer and payer if different companies.
- Lack of coordination between different reviewers and the status of the file within 1 company.
- Lack of uniform criteria for adequate treatment of eating disorders so insurers pick and choose what they will cover.
- Difficulties with concurrent review and denial of coverage for hospitalization. If hospitalized, payers and/or reviewers have varying definitions of

**TABLE 6.** Predictors of Outcome

Favorable Outcomes	Poor Outcomes
1. BN better than AN	1. Long duration of illness
2. AN, purging type better than AN, restricting type	2. Low body weight at time of initial treatment
3. Short duration of illness	3. High creatinine (>1.5) levels
4. Higher discharge weight after hospitalization	4. Premorbid obesity (for BN)
	5. Premorbid asociality
	6. Compulsion to exercise
	7. Disturbed family relationships

**TABLE 7.** Outcome of Disease Course

AN	BN
1. Mortality: 5.6%	1. Mortality: 5.6%
2. Frequent weight fluctuations	2. 50% achieve full recovery within 2 y
3. 10%–31% with poor outcomes	3. Frequent relapses after recovery
4. Prolonged time to full recovery average time to first recovery 6 y	4. 20%–46% may have eating disorder symptoms 6 y after treatment
5. 50% may develop BN	5. 55% develop mood disorders
6. Increased incidence of depression, anxiety disorder, alcohol dependence	6. 42% develop substance use disorders
7. 45% never marry	

medical necessity for ongoing recertification for the need for hospitalization.

- Many payers have a process that allows posthoc review, which can then disallow payment despite previous approval.
- Mental health carveouts creating fragmentary care for follow-up. Often there is a lack of specialization in the field of eating disorders within an agency or network providing the care. Carved out provider might be unaware or uninterested in working with the medical provider.
- Insured benefits under mental health provider network may be unaware or unwilling to provide intensive care in programs with expertise in eating disorders.

#### *Copayments and Deductibles*

This issue relates to the increasing out-of-pocket expenses for those services that are covered. These expenses may be extremely high in the case of hospitalization. Many companies establish lifetime coverage or other forms of limiting payments of care. An indirect way in which this limit setting affects the care of patients with eating disorders is a structure of inequitable payment for different types of care, emphasizing rewards for technical procedures rather than anticipatory guidance or counseling. Thus, to the very visible nonreimbursed services, one needs to add the more subtle destructive influence of low reimbursement rates for psychological services rendered by clinicians; the net result is that, as time goes by, fewer qualified persons are able to continue the care for adolescents and young adults with eating disorders. At the end, patients will suffer and health care costs will nonetheless increase since eventually, with the advent of complications such as osteoporosis, care will eventually have to be delivered at a higher price, under a different diagnosis, and over a long period of time.

The regulations established by the health insur-

ance industry may affect the quality of the treatment and outcome of AN and BN by playing into the resistance.<sup>61</sup> Many patients, for whom weight recovery is a frightening and anxiety provoking experience, can now avoid or escape treatment by using the excuse of the cost, their desire not to be a burden to the family, and other reasons. This may reach the point of the patient waiting out behavioral treatment in the knowledge that once insurance runs out there is nothing they can do to her. In other words, the vagaries of reimbursement, the lack of a unified policy, and a pennywise, pound foolish attitude can unwittingly reinforce the brooding, obsessive, addictive part of the eating disordered patient, who may then sabotage even the best thought out treatment plan.<sup>61</sup>

#### **Insurance Solutions**

There have been some developments that offer hope. A victims' backlash is emerging. For instance, a lawsuit against an insurance company resulted in rejection of the psychiatric care exclusion in favor of complete medical coverage in the treatment of a malnourished patient.<sup>65</sup> Moreover, prevention continues to be viewed more favorably as a valid area for research efforts and dollars, with behavioral disorders included among areas in need of more primary prevention.<sup>66</sup> Patients with eating disorders could then be approached in more supportive ways, enhancing programs with early intervention, group therapy, day hospital programs, and other efforts.

Strong interest in evidence-based medicine and outcomes research currently exists. Eating disorder research faces certain challenges, as short-term studies of interventions may not address the chronicity of symptoms or evolution of disease over time in those patients with more chronic disease. Data collection can be methodologically difficult and expensive, as numbers in any 1 region may be small, depending on age group being evaluated.

In conclusion, insurance companies, physician and nurse reviewers, case managers, and families need to be educated about the unique characteristics of eating disorders as both a medical and psychiatric condition so that instead of placing obstacles in the way of recovery, insurers can approve for early and appropriate care for children, adolescents, and young adults with eating disorders. Simultaneously, families and patients need to be encouraged and empowered to challenge the current state of eligibility, scope of benefits, copayment, and deductibles, when it does not adequately address the medical and psychological needs of their children and family members.

## RECOMMENDATIONS

The goal for practitioners working with eating disordered patients above all is to help achieve the best possible outcomes, addressing both short-term and long-term health consequences. Synthesizing the information presented, there seem to be 3 key elements that can help to attain positive outcomes.

### 1. Early Detection

There is strong evidence that the longer the duration of illness, the harder it is to achieve recovery. Eating disorders need to be diagnosed early in the disease process in order for treatment to be as successful as possible. By the time a formal diagnosis of an eating disorder is made, the patient is already suffering from serious biopsychosocial problems. Intervention should occur at the first signs and symptoms of disordered eating. Awareness needs to increase at many levels. Early recognition of the disease process by parents, friends, educators, and coaches can facilitate evaluation by the health care system. Practitioners need to be sensitized to the possibility of an eating disorder developing even at a young age, and need better training to improve their recognition of the early stages of the disease process. Screening about body image, dietary changes and dieting habits, and assessment of growth patterns should occur yearly.

### 2. Early Intervention

Once an eating disorder is recognized, then families need to be willing to seek treatment. The earlier the intervention, the more likely a patient will recover. Expert help should be sought if patients are not progressing appropriately. A multidisciplinary approach should be used. The insurance industry can at times present obstacles to treatment, although there has been some acceptance in certain states that eating disorders fit into the parity laws for mental health. The sooner an insurance company is willing to support therapy, including psychological, nutrition, and medical, the sooner the disease process may be interrupted. This can potentially prevent serious morbidity and mortality that patients with eating disorders experience.

### 3. Restoration of Body Weight

Several studies indicate that weight restoration for patients with AN helps facilitate the recovery pro-

cess. Premature discharge from the hospital below a healthy weight predicts poorer outcomes. In the day treatment and outpatient settings, weight restoration goals should be clearly defined and monitored. If a patient is unable or unwilling to increase weight as needed, more frequent visits and/or more intensive intervention is warranted. In terms of preventing osteoporosis, weight restoration is essential. There are no known medical interventions to correct adolescent onset osteoporosis, which can be debilitating once women reach their 20s and 30s.

Achieving a healthy body weight in a timely way is difficult and often requires hospitalization or residential structure. This also requires more cooperation from the insurance industry, as this type of treatment can be costly. Tables 6 and 7 further outline predictors of outcome and disease severity in the adolescent population.

## CONCLUSION

Eating disorders in children and adolescents can be of long duration, potentially life-threatening depending on severity of illness, and with likely relapse if adequate alternative coping skills are not developed. A planned and skillful approach to treatment is necessary to obtain a cost-effective, healthy outcome. Patients require ongoing monitoring and treatment with a biopsychosocial perspective using a varied number of professionals, including a primary care clinician, therapist, dietitian, family therapist, and other team members as needed. Outcomes-based research in the field can further clarify ways to deliver cost-effective care in a variety of settings. Clinicians and families need to advocate for adequate coverage of both medical and mental health services for children and adolescents with eating disorders, especially because pathogenesis, medical effects, and necessary treatments all demonstrate the interrelatedness of the medical and psychological in this disease process. Specialized settings such as partial hospitalization programs, therapeutic use of community in a boarding school, and other innovations such as clinical pathways can help address the medical, nutritional, and mental health needs of these patients. Ultimately, the goals include primary prevention plus early recognition and treatment to prevent long-term sequelae.

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Sawyer, Marcie Schneider, Eric Sigel and Tomas Jose Silber  
*Pediatrics* 2003;111:e98-e108  
DOI: 10.1542/peds.111.1.e98

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