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House Bill Aims to Raise Eating Disorders Awareness

By **Mary K. Stein**
Managing Editor

A U.S. Congresswoman may have found a unique way to fund a nationwide program to help raise awareness of the existence and seriousness of eating disorders.

In mid-March, Congresswoman Judy Biggert (R-IL) introduced a bill designed to raise national awareness of eating disorders and to create educational programs to better educate students about the seriousness of eating disorders. The bill seeks to amend Title VI of the Elementary and Secondary Education Act of 1965, to help students with eating disorders receive a quality education and to "secure their chance for a bright future."

H.R. 3928 would amend a 1965 act

H.R. 3928, "The Eating Disorders Awareness, Prevention, And Education Act of 2000," would provide states, local school districts, and parents with the means and flexibility to improve awareness of, and to identify and help students with eating disorders. It amends Section 6301 of the Elementary and Secondary Education Act of 1965 with the following language: "programs to improve the identification of students with eating disorders, increase awareness of such disor-

ders among parents and students, and train educators (such as teachers, school nurses, school social workers, coaches, school counselors and administrators) on effective eating disorder prevention and assistance methods."

Dr. David Herzog, Professor of Psychiatry at the Eating Disorders Unit, Massachusetts General Hospital, noted that getting the Department of Education to use designated Title VI funds to underwrite the awareness program was a novel idea. Under Rep. Biggert's bill, states and local municipalities would be allowed to use federal funds to develop and design their own awareness and prevention programs. Such programs could include role modeling, teacher training, and mentoring. The funds would come from expansion of the allowable uses of the Innovative Education Strategic Block Grant program. Dr. Herzog also wrote a letter of support when the bill was being drafted.

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Update

Teaching Primary Care Providers About ED

A 12-month pilot program is helping staff members of medical clinics to better diagnose and treat persons with eating disorders in underserved neighborhoods. Valerie Gurney, PhD, and Katherine Halmi, MD, of Cornell University designed 4 flexible teaching modules for social workers that include diagnosis, course of illness, risk factors, comorbid disorders, assessment, treatment planning, medical complications, and psychotherapy. A separate medical management module was developed for internists, pediatricians, nurses and physician's assistants. The primary care curriculum is currently being implemented in 5 medical clinics in northern Manhattan. Six months after their initial training, the social workers had a significant increase in knowledge about eating disorders (a 20.4% mean increase from their previous scores). Also, by 6 months, the social workers were beginning to change practice behaviors, such as screening more patients for eating disorders. Attitudes toward patients with eating disorders remained positive throughout the study. The most common eating disorder among the patient population was obesity, a reflection of the study population, mainly recent immigrants from Puerto Rico and the Dominican Republic.

Educational funds would underwrite a nationwide program.

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Rep. Biggert has three daughters, and became aware of the seriousness of eating disorders when one of her daughters' friends developed an eating disorder.

Bill's language underlines the seriousness of eating disorders

The wording in the bill also cites statistics that underscore the seriousness of eating disorders. For example, it points out that an estimated 5

to 10 million women and girls and 1 million men and boys suffer from

eating disorders, including anorexia nervosa, bulimia nervosa, and binge eating disorder, as well as eating disorders that are not otherwise defined. It adds that 42% of 1st through 3rd grade girls want to be thinner and 81% of 10-year-old children are afraid of being fat. It also stresses that eating disorders can lead to death.

Finally, it notes that eating disorders can have a negative impact on the educational advancement of a student, a situation often overlooked and rarely addressed in U.S. schools.

NEA Endorses the Bill

In March, the National Education Association (NEA) endorsed Rep. Biggert's bill. In a March 17 letter, Mary Elizabeth Teasley, NEA Director of Government Relations, urged members of Congress to cosponsor H.R. 3928 to help local school districts address eating disorders. Teasley wrote, "These disorders impact not only health but also children's ability to advance educationally. Educators who spend considerable time with students on a daily basis are often in the best position to identify children suffering from eating disorders." Mrs. Teasley added, "In many instances, however, educators lack the training and resources to respond effectively to students in

need of help. H.R. 3928 will make available critical resources to help tackle this serious problem."

National study to follow

Within 18 months after the act becomes law, the National Center for Education Statistics and the National Center for Health Statistics will conduct a study on the impact eating disorders have on educational advancement and achievement. The study will attempt to

evaluate the extent to which students with eating disorders are more likely to miss school,

have delayed rates of development, or have reduced cognitive skills.

In addition, the Center will report on current state and local programs to educate youth about the dangers of eating disorders as well as to evaluate the value of current prevention programs. Finally, the Center will recommend measures that could be undertaken by Congress, the Department of Education, and state and local educational agencies to strengthen eating disorder prevention and awareness programs.

Public service announcements

The bill also calls for public service announcements, similar to the government's anti-drug media campaign, to improve public awareness and to promote identification and primary prevention of eating disorders. The proposed public service announcements would be developed and distributed nationwide by the Secretary of Education in cooperation with the Secretary of Health and Human Services and the National Institutes of Health.

The bill's status

In mid-March, H.R. 3928 was referred to the Committee on Education and the Workforce and the House Commerce Committee for further evaluation and debate.

Familial Transmission of Risk for Bulimia and Anorexia Nervosa

In what may be the largest case-control family study to date of the genetics of eating disorders, researchers have established familial links to the risk of developing anorexia nervosa and bulimia nervosa (*Am J Psychiatry* 2000; 157:393).

The subjects included 3 groups of Caucasian female probands (the individual with the disorder is called a proband) 18 to 28 years of age. The groups included 152 women with pure restricting subtype anorexia nervosa, 171 women with pure bulimia nervosa, and 181 women with no lifetime axis I psychiatric illness (controls). Information was sought on lifetime psychiatric histories of all first-degree relatives 12 years of age or older.

The 3 groups had a total of 1831 living or deceased relatives on whom information was obtained. Of the 1727 living relatives, 1561, or 90.4%, were interviewed. Ninety-five relatives, all female, were diagnosed with either a full or partial eating disorder

Diagnostic criteria for partial anorexia nervosa

The researchers stipulated that a diagnosis of partial anorexia nervosa required, in a person of normal body weight, unequivocal anxiety about body weight that was judged to be extreme or irrational and the concurrent presence, for at least 3 months, of at least 2 of the following characteristics:

- (1) distraction from daily chores or life demands because of anxiety about weight;
- (2) a seemingly unshakable conviction of being overweight and the belief that losing weight could reduce discomfort or frequent monitoring of weight, driven by anxiety about weight or shape; and
- (3) marked distress brought on by eating meals believed to be of

normal or below-normal size, or composed of foods the subject believed were "unsafe," or extreme distress upon minor fluctuations in body weight, extreme or rigid adherence to exercise regimens, or use of laxatives, diuretics, or anorexic agents.

Familial risk factors

The study offered new evidence of the importance of familial factors in the risk for anorexia nervosa and bulimia nervosa. Whereas anorexia nervosa was rare in families of the comparison subjects, full and partial syndromes of anorexia nervosa aggregated among female relatives

of both anorectic and bulimic probands.

The age-specific risk for anorexia nervosa in female relatives of probands with anorexia nervosa was 11.4 times as high as the risk in relatives of normal probands. By comparison, the risk of bulimia nervosa was 3.7 times as high among female relatives of probands with bulimia nervosa as in relatives of normal subjects. The age-corrected risk for bulimia nervosa was 3.5 times as high among relatives of anorectic probands as among relatives of comparison probands, whereas the risk for anorexia nervosa was 12.1 times as high among relatives of bulimic probands. Further, milder forms of anorexia nervosa and bulimia nervosa also showed a tendency to run in families. The authors noted that the cross-transmission in families suggests a common, or shared, family diathesis.

New evidence of the role of familial factors play

Overprotective Parents May Contribute to Child's Anorexia Nervosa

It's long been suspected that overprotective parents may play a role in the development of anorexia nervosa, but this has been very difficult to prove. Now, results of a controlled study suggest that overprotective parenting in early childhood is associated with development of anorexia nervosa (*Br J Psychiatry* 2000;176:132). Such high-concern parenting may be linked to unresolved grief.

After evaluating 40 consecutive adolescent girls referred with anorexia nervosa and matched controls, Drs. Philip Shoebridge and Simon G. Gowers found that mothers of anorectic teens had distinct characteristics. First, they rarely allowed others to care for their infants and children. They felt severe distress when they were separated from their children, and had high anxiety levels when they first allowed their daughters to spend a night away from home. Their daughters were also older than controls when they first stayed overnight with friends.

Earlier obstetric losses

Another component that distinguished families with anorectic daughters was a severe obstetric loss before their daughter's birth. In fact, 9 of the 10 daughters in the subgroup of severe obstetric loss were the next-born child after their parents had lost a child.

Five of the index patients and 8 control patients reported having a previous first-trimester miscarriage. Fifteen percent (6/40) of the index mothers had a perinatal or infant death prior to the birth of their child with anorexia nervosa, compared with 2.5% (1/40) of their matched normal controls.

The authors suggest that sympathetic questions about parental experiences that might have led to early and heightened concern about the next child should be included in the routine clinical assessment. Also, by explicitly acknowledging the early effects of these factors, clinicians may help families recognize and move away from excessive overprotection of their child.

Night-Eating Syndrome: A Unique Eating Disorder

The night-eating syndrome (NES) appears to be distinctly different from anorexia nervosa, bulimia nervosa, or binge eating disorder, according to results of studies in Norway and at the University of Pennsylvania (*JAMA* 1999; 282:657)

The night-eating syndrome is associated with morning anorexia, evening hyperphagia, and insomnia. Night eating is thought to be brought on by stress and is believed to affect about 2% of the general population (*Int J Eat Disord* 1997; 22:65), about 9% of obese patients, and about 27% of severely obese persons (*Psychiatr Q* 1959; 33:284).

Two studies look at behavior, endocrine changes

Two studies that examined the behavioral and neuroendocrine sides of this disorder have better defined this perplexing condition. The behavioral study, conducted by Dr. Albert Stunkard and his colleagues at the University of Pennsylvania, measured timing of energy intake, mood level, and sleep disturbances.

Subjects included 10 obese persons (8 women and 2 men) who met the criteria for NES and 10 matched controls who were observed in an outpatient setting. Four subjects with bulimia nervosa were added to the protocol as a comparison group. Twenty-four-hour food intake data were collected for one week.

The neuroendocrine study, conducted during a 24-hr period while subjects were inpatients at University Hospital, Tromsø, Norway, charted circadian levels of plasma melatonin, leptin, and cortisol. The study group included 12 night-eaters and 21 control subjects, all women.

Behavioral study: Half of calories between midnight and 6 am

The amount of food intake by night eaters and controls differed only moderately, but the night eaters had 9.3 eating episodes

during the 24 hours, compared with 4.2 eating episodes for the control subjects. The subjects with bulimia nervosa averaged 6.2 eating episodes per day. Furthermore, the patterns of day and night intake differed dramatically for the two groups.

During the daytime, the cumulative energy intake of the night eaters lagged behind that of the control subjects, so that by 6 pm they had consumed only 37% of their total daily intake, while the controls had consumed 74% of their total daily intake. While the food intake of the controls slowed markedly by 8 pm, the night eaters did not decrease their eating until after midnight. From midnight to 6 am, the night eaters ate 56% of their energy intake, while the control group consumed 15%.

During the 24 hours, the average mood of the night eaters was lower than that of the controls. Also, after 4 pm, the mood of the night eaters fell hour by hour, while that of the controls remained unchanged. The night eaters also had far more nighttime awakenings than the control group (3.6 vs. 0.3, respectively) and more than half of the nighttime awakenings were associated with food intake. They ate mostly carbohydrates (73% of energy) during these awakenings. The ratio of carbohydrate to proteins in their nighttime snacks was 7:1.

Neuroendocrine study: differences in plasma cortisol, melatonin

The Tromsø researchers divided the 12 night eaters into 7 nonobese (mean body mass index, or BMI, 23.1) and 5 obese (mean BMI: 36) subjects. Just as in the behavioral study, nighttime awakenings were far more common among the night eaters than the controls (3.1 vs. 0.1).

All the night eaters, obese and nonobese alike, had lower plasma melatonin levels from 10 pm to 6 am than did controls. Plasma melatonin concentrations were higher in the obese control group

than the normal-weight control group, but the concentrations were the same in the obese and nonobese night eaters. Plasma leptin levels were higher among the overweight subjects than among the normal-weight subjects in both night eaters and controls. The highest leptin concentrations did not differ between the obese and nonobese subjects.

Plasma cortisol was not significantly different between obese and nonobese subjects or controls. From 8 am to 2 am, plasma cortisol levels were higher among the night eaters than the controls. Preprandial and postprandial blood glucose and plasma insulin levels did not differ between the night eaters and controls in either the obese or normal-weight groups.

The carbohydrate-rich nighttime snacks (70.3% of kilocalories) and especially the high carbohydrate-to-protein ratio, suggest that night eating is designed to restore the disrupted sleep of the night eaters.

The night-eating syndrome also seems to differ from the “nocturnal sleep-related eating disorders reported by sleep disorder clinics and characterized by eating upon awakening from sleep, often due to sleepwalking and related sleep disturbances.

If this is a new syndrome, how can it be treated?

According to the authors, the presence of a sleep disorder linked to attenuation of the nighttime rise in melatonin suggests that exogenous melatonin may be helpful to these patients. Because the subjects' ingestion of high-carbohydrate snacks may possibly be an attempt to improve sleep and mood by raising serotonin levels, selective serotonin reuptake inhibitors may also help. In addition, corticotropin-releasing hormone (CRH) receptor antagonists might be a helpful addition to psychotherapy.

All of these speculations will need careful clinical testing before any recommendations for treatment can be made.

Purging Peers and Media Influences

It might be like tilting at windmills, but if Dr. Alison E. Field and her colleagues had their way, television, movie, and magazine industries would immediately hire more models and actresses at healthy weights. Eventually, images of androgynous, underweight young women would disappear from print and screen.

The 'Growing Up Today' Study

The researchers assessed the relationship of peer and media influences on the risk of developing purging behaviors in a 1-year follow-up study of nearly 7,000 girls aged 9 to 14 (The Growing Up Today Study). Although questionnaires had initially been sent to boys, the analysis was restricted to girls because the incidence of purging was too low among the boys to conduct meaningful analyses.

None of the girls were purging when the study began (*Arch Pediatr Adolesc Med* 1999; 153:1184). The researchers used the McKnight Risk Factor Survey and the Youth Risk Behavior Surveillance System questionnaire from the Centers for Disease Control and Prevention. Seven McKnight Risk Factor Survey questions included overconcern with weight, importance of thinness to peers and adults, teasing and comments about weight by adults, social eating, and influence of the media.

One year later: 1% were purging

During the year of follow-up, 74 girls, or about 1%, started using vomiting or laxatives at least once a month to control their weight. Among the 74 girls, 54% purged less than weekly, 16% purged once a week, and 30% used vomiting or laxatives 2 or more times a week.

Personal, peer, and cultural factors were independently associated with the development of purging. Regardless of age, girls who were more mature physically were more likely than less devel-

oped peers to begin purging to control their weight. Both peers and popular culture, independent of each other, influenced the girls' weight control beliefs and behaviors. The more effort a girl made to look like females on television, in movies, or in magazines, the higher her risk of beginning to use vomiting or laxatives to control her weight. Finally, the more girls changed their eating patterns around their peers, the more likely they were to begin purging within the next year.

Ironically, a dual message

The authors report that despite the fact that women's magazines include articles on the dangerous and deleterious effects of severe dieting, bulimic behaviors, and maintaining a very low body weight, such issues also contain ads and features illustrated with pictures of excessively thin models. Thus, young readers get a dual message: excessive thinness can be dangerous but it is also be desirable.

Appetite Suppressants and Pulmonary Hypertension

The fenfluramines may be off the market, but they are back in the news. This time they have been linked to development of primary pulmonary hypertension, or PPH.

Dr. Stuart Rich and colleagues have reported an increased outbreak of cases of pulmonary hypertension traced to use of appetite suppressants, particularly to the combination of fenfluramine and phentermine ("fen-phen"). The trend was reported from the Surveillance of North American Pulmonary Hypertension (SNAP) study, which included cases from 12 large hospital centers in the U.S. and Canada (*Chest* 2000;117:870).

Dr. Rich and a group of pulmonary hypertension specialists organized SNAP to track cases of PPH linked to commonly used medications, especially appetite suppressants and chemically related

substances. Eventually 579 patients were enrolled in the SNAP study, including 205 with PPH and 374 with pulmonary hypertension from other causes (secondary pulmonary hypertension). The study was conducted between September 1996 and December 1997, a time when diet pill use was markedly increasing in the U.S.

Fenfluramines had the strongest association with PPH

Use of appetite suppressants was common in both groups but of all medications surveyed, only the fenfluramines showed a significant preferential association with PPH compared to SPH. The association was stronger with longer use and more pronounced in recent users than in those who had used the agents some time ago. PPH has been reported in fen-phen users after as little as 23 days. A high number—11.4% of patients with SPH had used appetite suppressants.

A pattern first seen in Europe

PPH is a relatively rare disease, but an epidemic of PPH occurred in the 1960s in Switzerland, Austria, and Germany in association with the use of the appetite suppressant aminorex fumarate. Later, the International Primary Pulmonary Hypertension Study discovered a strong association between PPH and the use of appetite suppressants, particularly the fenfluramine derivatives (*N Engl J Med* 1997; 335:602).

After the FDA approved dexfenfluramine for extended use as an appetite suppressant in the U.S., and with the growing use of "fen-phen," an unusually high number of cases of PPH began appearing. After the outbreak in Europe, use of appetite suppressants was limited to 3 months. In the U.S., however, there was no limit on duration of use. In response to concerns about other adverse effects, fenfluramine appetite suppressants were withdrawn from the market in September 1997.

Long-term Effect of Hospitalization for Adolescent Anorexia Nervosa

Teens with anorexia nervosa are hospitalized for a number of reasons, including life-threatening illness, family and professional concern, and resistance to intervention. In the short term, hospitalization makes it possible to complete physical evaluation and monitoring,

reestablish adequate caloric intake, and relieve family and professional anxiety. However,

until recently little was known about the long-term effects of hospitalization on adolescents.

According to a team at the University of Liverpool, for some patients the gains achieved in the

Weight gain alone was a poor predictor of outcome.

hospital are reversed over time (*Br J Psychiatry* 2000; 176:138).

These researchers measured a

range of presenting variables for 75 teens with DSM-III-R anorexia nervosa being treated at a regional adolescent center. The teens were then reevaluated 2 to 7 years after hospitalization and their outcome was rated.

Looking at outcome

At follow-up, 2 of the 75 girls had died. Of the remaining 73 patients, 21 who had inpatient treatment had a significantly

worse outcome than those who were never admitted to the hospital. (Of course, the hospitalized group was likely to have been more ill in the first place.) The outcome was rated as good if the girl had maintained weight above 85% of normal, if menstruation had resumed, and if social functioning was satisfactory. A poor outcome was assigned if the girl still had an eating disorder and in all cases where weight was maintained below 85% of normal levels.

Deaths due to anorexia nervosa are said to exceed those of any other adolescent psychiatric disorder, including depression, and there is a lethal outcome in up to 15% of cases (Herzog et al, 1992). Further, only about half of younger patients can be expected to make a full recovery. In this study, 34 patients (45.3%) had a good outcome, 23 (30.7%) had an intermediate outcome, and 15 (20%) had a poor outcome. Data were incomplete for 3 patients (4%).

The researchers found a clear association between the severity of the condition when the patient first presented for treatment and its medium-to-long-term outcome. The more underweight the patient, particularly when she was below 70% of expected weight, and the lower the score on the Morgan-Russell Global Assessment Score (MRGAS), the worse the outcome. Age, length

BOOK REVIEW

Clinical Obesity

(Edited by Peter G. Kopelman and Michael J. Stock. Malden, MA: Blackwell Science, 1998; 631 pp; \$189.00)

This distinguished international textbook focuses on clinical and practical aspects of obesity and its treatment, while not neglecting the biological bases of these conditions.

Among the 23 well-written, easy-to-read, and generally well-illustrated chapters, there are many highlights. One chapter concerns the assessment of obesity and body composition, discussing the limits as well as the values of the body mass index (BMI) and stressed the utility of other measures of fat reserves and fat-free cell mass.

Another highlight was an elegant review of animal models, challenging several previous theoretical pillars, including set-point theory and diet-induced thermogenesis (for humans).

Molecular genetics continues to reveal new genes relevant to obesity almost week by week, and, although providing an excellent introduction, a textbook chapter on genetics is inevitably outdated before it is even printed. Several chapters focus on "fat topography," the health implica-

tions of different patterns of fat distribution.

Direct clinical concerns are addressed in chapters related to cardiovascular disease, cancer, women's health, pulmonary function (particularly disordered breathing, daytime sleepiness and sleep apnea), childhood obesity, and diabetes. (Here's a take-home pearl: rates of non-insulin dependent diabetes are 80 times greater for individuals with a BMI >35 than among those with a BMI <23.)

Treatment sections respect real-world difficulties of achieving sustained improvement, and examine dietary, cognitive-behavioral, exercise, and pharmacological options (currently limited but very hopeful for the future), and increasingly safe and effective surgical methods for serious obesity.

A review of the benefits versus the risks of weight loss (one of whose authors is a Professor Lean!) concludes that benefits accrue from even modest weight loss, and there are few negative effects. The difficulties of promulgating pertinent public health programs at community levels bring us down to earth. Overall, this is an excellent text, although the price may be too rich for many students' diets.

—J.Y.

of illness, and presence of purging were not significantly associated with outcome.

Those treated as inpatients had a notably poorer outcome, but, again, they may represent a sicker group to start with. Weight restoration alone did not guarantee a good outcome; in fact, weight gain alone was a poor predictor of outcome.

How patients see hospitalization

According to the authors, not all patients view hospitalization negatively. In fact, patients find being hospitalized helpful or supportive, particularly when attention is given to the psychological aspects of the disorder.

The understanding and care of the professional staff sometimes exceed that experienced outside the hospital. In addition, the peer group and educational setting within the adolescent unit is perceived as a safe environment, far from the stresses of life in the outside world. In such a situation, discharge from the hospital may require tremendous adjustment, particularly in resuming responsibilities and obligations relating to eating. Discharge can also be viewed as a significant loss of support.

Authors advise considering the impact on outcome

The authors urge clinicians to consider the likely positive impact of a period of hospitalization on outcome of the condition. Some of the costs of hospitalization, beyond the actual cost for treatment, include disruption of education and family life. The decision to hospitalize may also send an unrealistic message to the patient and her family that anorexia nervosa is a condition that can be overcome by professionals "doing something" to the patient rather than supporting him or her in the patient's own decision to change behaviors and attitudes.

Obesity: A Connection to Climate?

Environmental factors around the time of birth may contribute to obesity later in life. Researchers in Great Britain and at Northwestern University believe that early exposure to cold, along with high birth weight, may make some individuals, especially males, susceptible to obesity in adulthood (*Int J Obesity* 2000;24:281).

Among 1165 men and 585 women in Hertfordshire, England born between 1920 and 1930, adult body mass index (BMI) was statistically related to the subject's weight at birth. The study population included Caucasian men and women who had complete health records and who had lived in East or Northwest Hertfordshire since birth. Trends to increasing BMI or prevalence of obesity with increasing birth weight were statistically significant among men born in years following a cold winter, but not among men born after a mild winter. Although weights at 1 year of age did not show statistically significant seasonal trends, the relationship between birth weight and adult obesity was more pronounced in men and women born

during the first 6 months of the year than those born during the last 6 months.

More clues to possible causes of adult obesity

Birth environment

The findings suggested that environmental factors at work around the time of birth are

associated with an increased prevalence of obesity in adulthood. This is not an entirely new concept: More than 150 years ago, a scientist proposed a general rule that body size among mammals increases from warmer to cooler climates (*Am Anthropol* 1953; 55: 311). And, nearly 50 years ago, Newman and Munro showed an inverse relation between weight for height and the average January temperature in the state of birth (*Am J Phys Anthropol* 1955; 13:1). The authors note that factors that are sensitive to both temperature and season, such as nutrition, may also be involved in the pattern of later obesity. However, they add that evidence from animal studies indicates that exposure to lower temperatures before and soon after birth promotes development of adiposity in the newborn (*Am J Physiol* 1998; 274:R398).

Strict Diets for Chronic Diseases May Increase Risk of an Eating Disorder

Clinicians who work with adolescents and young adult women with diabetes or phenylketonuria (PKU) should be alert for signs of disordered eating that might interfere with their patients' health. The strict diets required for diseases such as these may increase the risk of unhealthy eating behaviors, according to Joan C. Chrisler, PhD, and Jeanne E. Antisdel, of Connecticut College, New London, CT (*J Dev Behav Pediatr*, April 2000).

Disordered eating reported in more than 20%

When the two researchers evaluated 54 women with diabetes and 30 with PKU, 33% of the diabetics and 23% of those with PKU had eating-disordered behavior. Certain types of eating problems were more common with each group. For example, the diabetic patients were more preoccupied with avoiding fatty foods and with weight loss whereas those with PKU

were more likely to be preoccupied with self-control around food. Those with PKU were also more likely than the diabetic patients to perceive that others were pressuring them to gain weight. Those with eating problems showed poorer judgment as well as lower self-esteem. Diabetics with disordered eating also had lower self-esteem and a more negative body image than diabetics without such problems. They were also more careless about monitoring their blood glucose levels or following a meal plan and properly treating hypoglycemia.

Individuals with type 1 diabetes and PKU, a hereditary condition in which an amino acid in proteins cannot be properly metabolized, must adhere to strict diets. Deviating from the diet regimens leads to serious health risks. Persons with diabetes are at increased risk for vascular complications, such as heart disease, and those with PKU can develop brain damage.

Letter to the Editor

Prognosis in Anorexia Nervosa

In the "Update" section of the millennium issue (January/February 2000), mention was made of our longitudinal study of 61 patients with anorexia nervosa. We would like to provide additional information about our study and to add our perspectives on the issue of prognosis among patients with anorexia nervosa.

In our study, the length of follow-up was 6 to 10 years (mean: 8 years). The study included biological parameters and measurements of total body nitrogen and total body potassium, which were also correlated with bone density and outcome such that patients who did not reach a body mass index (BMI) of 19 or more during index hospitalization were doing less well at follow up (Gross et al, *Annals of the New York Academy of Science* [in press]). The study supports the necessity for early, adequate weight restoration.

These results were strongly echoed by the 20-year follow-up study from Heidelberg reported by Zipfel et al (*Lancet* 2000;355:721). Here the seriousness of anorexia nervosa was demonstrated by the death rate of 16.7% and the persistence of full-blown anorexia nervosa in 10.4% of patients. A correlation between poor prognosis, duration of illness, and low BMI was also demonstrated, emphasizing the need for early intervention and adequate weight restoration.

These findings verify what all of us who treat patients with anorexia nervosa

have always known, namely that prompt, adequate weight restoration is the vitally important first step on the long road to recovery—whether this occurs in an inpatient setting, day program or on an outpatient basis. Yet there are those who would argue with this principle of treatment, even as we are becoming less able to convince funding authorities to provide appropriately for clinical services or research. In Australia the situation has been rapidly deteriorating, to the point where publicly funded services are inadequate and inaccessible and private eating disorders units are fighting for survival.

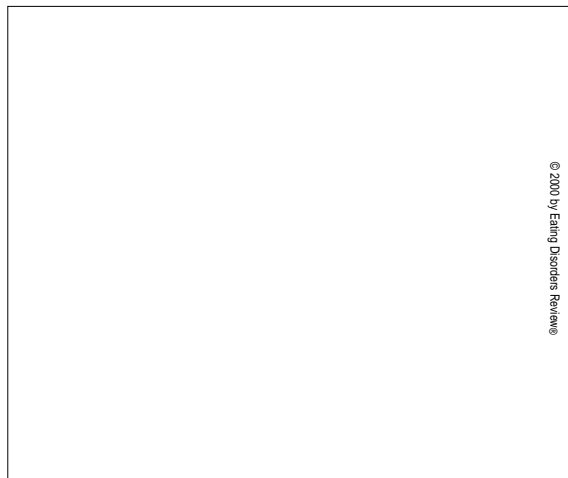
Outpatient treatment is excellent for patients who have not been ill for more than a year or so, particularly when they are treated with a multidisciplinary team, a user-friendly approach, and well-trained, involved general practitioners. These services come at a cost, can only be provided in the private sector, and are not readily available to those who cannot afford to pay for them. Not all patients fit into this early intervention category. Some inevitably require higher levels of containment and medical care. With very ill patients, of whom we still have many, we still do not know the optimal way in which to facilitate weight restoration. More research is needed and funding remains all but impossible to secure, at least in Australia.

Despite their high public profile, anorexia nervosa and other eating disorders are still not being taken seriously enough, particularly when the first essential goal of treatment has been so clearly demonstrated. The question is, what else can we do to get this message across?

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Nibbles, by Hunter



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At one time, "Hunter" aspired to be a professional pianist.

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Getting Coverage for Eating Disorders Treatment

By Pauline Powers, MD

Finding the medical coverage treatment of an eating disorder can be a real challenge, but having a plan makes it much easier to find the treatment you need.

1. Get an assessment so the diagnosis will be established. You will need an assessment so the disorder and its associated mental and physical problems can be properly diagnosed and documented.

2. Do you have mental health benefits? If you have insurance, you may also have mental health benefits. Often these benefits include an amount for hospital or residential treatment and an amount for outpatient treatment as well. Nearly all health policies include major medical benefits, which are typically much greater than the mental health benefits. Some companies provide Employee Assistance Programs (EAPs), and appropriate care is sometimes available through these programs. Read the booklet that comes with your insurance policy or call the phone number on your insurance card and ask about your benefits.

3. Obtaining your benefits. Although you may have what appear to be adequate benefits, the next issue is whether or not you can use them to obtain appropriate care. The three major types of health insurance policies are: indemnity, preferred provider organizations (PPOs), and health maintenance organizations (HMOs). Very few people have indemnity policies, but they are usually the most comprehensive and have the greatest flexibility. PPOs are usually much more flexible than HMOs. There is usually a deductible (a portion of the charge from the hospital, residential treatment center, or care provider that you pay). And, especially in the case of HMOs, there are reviewers (often untrained clerical personnel) who decide how much of your benefits will be available to you when a diagnosis is made. This decision may be made based on idiosyncratic rules that do not reflect current evidence-based treatment approaches and often do not reflect the consensus of professionals.

Determine health-care providers. It is also important to determine what the treatment center or care provider will need to help you obtain those benefits. This is not always easy to determine in advance. Ask your insurance company to send you a list of providers. If your professionals are on the list, call these professionals and let their office personnel know the results of your assessment, including the diagnoses, the type of treatment recommended and where it will be given, and estimated length of treatment.

If Your Provider Does Not Provide the Recommended Treatment

1. If your insurance benefits do not match the recommended treatment:

For example, if you have anorexia nervosa of the binge/purge type, and residential treatment is recommended for 60 days, your insurance benefits may only cover 10 days of residential treatment. In this case, first try calling your insurance company and ask to obtain your major medical benefits. It is logical to turn to major medical benefits because the semi-starvation that results from anorexia nervosa is a physiological complication and if untreated will likely result in hospitalization on a medical floor in a general hospital, which will ultimately be very expensive.

Eating disorders are medical illnesses and it is worthwhile to mention this fact to your insurance company. Typically, however, this will not result in any change on their part. The next step is to contact the personnel department of the company that purchases the insurance. Remember that insurance coverage is called a "benefit" but in fact it is a part of the compensation to the worker who has the insurance policy. **Insurance coverage is not a gift from the employer.** Furthermore, the insurance company is supposed to hold the funds paid by the employer on behalf of the employee and dispense them according to rules set down by the employer. Thus, the employer can decide to fire the insurance company (and ultimately the HMO or PPO).

The important point to remember is that it is actually your employer (or the employer of the person who has the insurance) who has power over what benefits are provided from the HMO or PPO. Thus, your personnel department can be helpful. You may find that the insurance company blames the employer or the employer blames the insurance company. Since the employer pays for the insurance benefits (which can include hiring an intermediary HMO), ultimately (although not immediately), the employer can choose to change insurance companies.

2. Despite your best efforts, your insurance company and personnel department are not helpful.

Although it is tempting to give up at this point, other steps can be taken. First, let your insurance company know that you have decided to call the insurance commissioner, and then call him. When you speak with the commissioner, tell him what has been recommended, what steps you have taken to obtain treatment, and the results of these attempts. Follow this up with a letter explaining the difficulties. Keep a copy of this letter for your files. If the insurance commissioner is not helpful, the next step is to contact your senators and congressmen and congresswomen. If they aren't helpful, contact the governor.

3. When efforts to obtain care by contacting your legislators and the governor are not effective:

Self-help groups may be the answer. For example, the Eating Disorders Awareness Program may be helpful (603 Stewart Street, Suite 803, Seattle, WA 98101). National information and the referral hotline is: 800-931-2237. The office number is 206-382-3587.

4. Try creative solutions.

Some families have been able to access help by contacting their attorney if benefits are available through an insurance company but the benefits are not available. Other families have gotten their insurance companies to make appropriate decisions by contacting the local newspaper or magazines and describing their plight. Others have called local help programs on radio and television.

5. Determine if you can afford care if your insurance company will not pay for it.

Once you know what care is recommended, who should provide it, and where this care should be provided, find out the stated total charges from the institution and/or professionals providing the care. Assess your own financial resources and negotiate a fee/charge you can afford.

If You Have Medicare or Medicaid Benefits

Although many hospitals and treatment centers accept Medicare and/or Medicaid, many have no staff members with experience in treating eating disorders. If the treatment center is a mental health center, which is funded in part by county, state, or federal funds, you can sometimes ask that appropriate care be provided and sometimes there are personnel at the center who are familiar with the treatment of eating disorders.

When You Have No Money or Insurance Benefits

Treatment programs do exist for people who have no money or benefits, but they are often hard to locate. Some agencies that receive public funds do provide treatment, and sometimes that treatment is outstanding. Another way to obtain treatment is through community agencies—sometimes treatment is provided at no cost or with a sliding scale fee. Counseling centers and student health services are another option if your patient is a student on a college or university campus. To get treatment at these locations, you usually pay a student health fee with your tuition.

Many departments of psychiatry within medical schools have low-fee clinics run by psychiatric residents (medical school graduates who have had two or three years of their psychiatric training and are supervised by experienced faculty members). Call the department of psychiatry within the medical school and ask if they have low-fee clinics run by residents and if they will accept a patient with an eating disorder. Be sure to ask about sliding-scale fees and ask about what supervision the medical resident has available to him or her.

No-Fee Research Treatments

Sometimes treatment can be obtained through a research program. For example, periodically Columbia University in New York has openings for patients willing to be part of an ongoing research program for patients with anorexia nervosa. The program is the Eating Disorders Clinic at New York State Psychiatric Institute at Columbia Presbyterian Medical Center in New York City. To ask about the program, call the research assistant at 212-543-5739.

A research study may be underway at a college or university near you, and the newspaper may run announcements of these programs. It is important to remember that although there may be no fee for part of the treatment, there may be fees for certain non-research portions of the study, and there are inclusion and exclusion criteria.

Final Thoughts

Keep trying to get better and trying to locate people to help you. Although you will encounter many barriers to accessing appropriate professional treatment, if you are committed to recovering, it can usually be accomplished. Care providers themselves are energized when patients want to recover and can often help you find the help you need. Many primary care physicians and pediatricians are relentless in trying to find help for their patients and your interest in recovery will encourage them to help you.

Facts to Know When You Seek Insurance Coverage

1. Your eating disorder diagnosis
2. Other psychiatric disorders
3. Physiologic complications of the eating disorder
4. Level of care recommended: outpatient, inpatient, partial hospitalization, intensive outpatient
5. Anticipated duration of recommended treatment
6. Professionals needed and their required expertise

