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Barriers to Care for Eating Disorders

Youth of color face extra challenges, including insurance coverage

There are many barriers to receiving eating disorder treatment. An important one is identifying the presence of an eating disorder in the first place. But, once identified, other barriers also exist. We often think of ambivalence about change as a key variable. The type of insurance and skin color are two major barriers to obtaining care for an eating disorder, according to a recent study at the University of California, San Francisco.

Researchers led by Dr. Ruby Moreno at UC-San Francisco performed a retrospective chart review of 1060 patients 11 to 25 years old who presented at an adolescent medicine specialty program between June 1, 2012, and December 31, 2019 (*J Eat Disord*. 2023. 11:10). All participants in the study had been diagnosed with malnutrition secondary to disordered eating. The primary outcome measure was whether a patient had been given recommended treatment within 6 months of intake. Patients with no visits within 6 months were considered lost to follow-up.

Insurance type and race/ethnicity

Racial and ethnic minority youth were less than two-thirds as likely to receive recommended treatment compared to white youths. In addition, anorexia nervosa (AN) took precedence: youths diagnosed with "other" eating disorders were only half as likely to receive recommended treatment as those with AN.

Stigma and cultural beliefs about mental health care may add additional barriers to eating disorder care for youth of color, but data are still mostly lacking in this area. Not surprisingly, barriers to therapy for this population led to worse outcomes. Across all models, hospital admissions for disordered eating within a month of intake significantly increased the likelihood of receiving recommended treatment. The authors also found that many publicly insured patients could not access family-based therapy, and instead relied on therapists with limited experience with eating disorders, who provided nonspecialized individual therapy.

Changes are needed

The authors correctly note that important changes are needed within the healthcare system to improve access to care, including addressing systemic inequalities that contribute to disparities in care for youth of color. The solution may involve a multidisciplinary approach to treatment, to help patients access appropriate levels of care. Future research would benefit from understanding perceived barriers to care for patients of color or those relying on public insurance, and their caregivers. According to Dr. Moreno and colleagues, the field of eating disorders is confronted with the need to understand institutional policies and public health initiatives, to improve health equity.

In an effort to help address health disparities among racial and ethnic minority populations, the Office of

Minority Health (OMH) of the Department of Health and Human Services provides support to agencies and organizations in the public and private sectors (**https://minorityhealth.hhs.gov/**). Largely through grant programs, OMH is currently implementing a disparity impact strategy, which identifies and addresses health disparities to promote health equity for racial and ethnic minority populations.

From Across the Desk: Diversity

Diversity is a word we hear and see everywhere. Diversity can be defined as **a range of human differences**, including race, ethnicity, gender, gender identity, sexual orientation, age, social class, physical ability, or attributes, religious or ethical values systems, national origin, and even political beliefs. Diversity may also interfere with care for an eating disorder.

One article in this issue centers on two barriers to getting treatment for an eating disorder: skin color and the type of insurance the family has (see "Barriers to Care for Eating Disorders" elsewhere in this issue). In another article, researchers led by Dr. Ruby Moreno of UC-San Francisco examined the distress and underlying burden of grief among parents of patients with anorexia nervosa (see "Helping Parents as Caregivers of AN Patients," elsewhere in this issue). The burden falls most heavily upon mothers of patients, who must learn ways of letting go of the adolescent the family knew before the illness, and finding a way to live with n accept their child as he or she is now. Fathers traditionally play a very small role in caregiving for AN patients or their children with other types of eating disorders.

—MKS

Day Programs for Children and Teens

Efficacy and benefits for this age group were proved in a review

Most day treatment programs for young patients with eating disorders involve 6 to 10 hours of treatment, and supervised meals for 3.5 to 5 days per week. These programs can provide more intensive treatment than outpatient therapy while avoiding some of the high costs of inpatient and long-term residential services. Day programs may be particularly helpful for young patients whose symptoms are too severe to be successfully treated by a traditional outpatient team, yet are not severe enough for hospital-based, inpatient, or residential treatment (*Child Adolesc Psychiatr Clin*. 2019. 28:573). The literature on such programs has grown. What does it show?

A recent paper by Krishnamoorthy and colleagues reported the results of a literature review of 21 day treatment program studies (*Eur Eat Disord Rev*. 023.31:199). The authors concentrated on the benefits and efficacy of day programs for children and teens, and used PRISMA guidelines to conduct the review. Most program were in the US; others were in Canada, Australia, Spain, Germany, the United Kingdom, and Italy.

The 21 programs involved 1366 participants. The individual programs involved from 19 to 160 participants, most of whom were female. Follow-up at 3 and 6 months showed that the participants maintained their gains and benefits.

The programs varied widely. For example, one program included motivational enhancement strategies (*Int J Eat Disord*. 2011. 44:29) and sibling psychoeducation sessions. Another program used telephone counseling between the therapist and parents, which involved talking about appropriate ways for the parents to handle meal support for their children over the weekends. In another program, parents were required to provide support when a patient refused to finish his or her meals. Most day programs included individual patient psychotherapy sessions, group counseling, individual counseling with a patient and at least one parent or parents' group counseling, and multi-family counseling. Most included at least two supervised meals and nutritional counseling each week. Parents were usually asked to attend at least one supervised meal a day; in contrast, another program allowed patients to have staff-supervised meals without their parents. A few programs included art therapy sessions, one included yoga classes, and six studies reported including school-based activities in the patients' daily schedule.

How effective are day treatment programs?

The authors reported that overall, the day programs they studied were effective for restoring body weight, reducing eating disorder symptoms, and for examining comorbid mental health concerns.

Of the nine studies that reported dropout rates, the average dropout rate was 21%. Most reasons given for dropout (when available) resulted from eating-disorder-related medical conditions. At follow-up, six studies noted that patients maintained their weight gain for 3, 6, 12, or 31 months after discharge. The authors pointed out that weight was measured and reported in various ways. Of all the studies, six calculated body mass index, or BMI, and seven studies evaluated changes in weight by BMI. The studies also used a wide variety of measures that assess eating attitudes and behaviors associated with AN and BN.

The authors reported that day programs produced significant improvement in eating disorder symptoms among children and adolescents. The effects ranged from small to large. The review did underscore the variations in low body weight that were measured and reported among the programs and studies. All studies used family-based therapy and a few added cognitive-based therapy, enhanced (CBT-E) and dialectical behavior therapy (DBT).

Suggestions for future programs

Krishnamoorthy and colleagues' literature review concluded that eating disorder day programs for children and adolescents are beneficial for promoting physical and psychological recovery. It remains unclear, however, which components of the day treatment programs contributed to recovery. Variations exist between the outcomes or components of these day programs, and these can be attributed to several elements. These elements include the differing clinical and demographic profiles of the clients, issues related to the existing mental health service infrastructure within the country in which the program was situated, inclusion of novel interventions, and lack of evidenceâ€based practices.

The authors suggested that day program research could be enhanced by reporting other physical health indicators, including heart rate and blood pressure. Such periodic physical health assessments may alert physical health professionals to possible comorbid health conditions. While specific expertise relating to family-based therapy and other specific interventions may be important, there is evidence to suggest that recovery-oriented interventions aimed at improving overall functioning rather than only focusing on the remission of mental health symptoms may be helpful for all patients (*Aust NZ J Psychiatry.* 2014. 48:1009).

Improving Early Intervention

Long waiting times and transient populations are just two elements that delay early intervention for eating disorders

Although intervening early to treat psychiatric disorders has many benefits, as many as 80% of persons with an eating disorder do not receive evidence-based treatment (*Int J Eat Disord*. 2017. 50:170), and early intervention is not well established.

What is early intervention? According to Dr. Karina L. Allen, of the Outpatients Service at Maudsley Hospital and the Maudsley NHS Foundation Trust, London, and a team of researchers, early intervention is detection of an illness at the "earliest stage" during the course of a diagnosed disorder. This is followed by stage-specific, targeted, evidence-based treatment–as long as it is necessary and effective (*JAMA Psychiatry*. 2018. 75:545). Dr. Allen and her colleagues surveyed early intervention patterns in the United Kingdom, Australia, Canada, and the US, and then developed suggested recommendations to improve early intervention (*Eur Eat Disorders Rev*. 2023. 31:32).

Key recommendations for early intervention

For services and policy makers, the researchers noted that in some countries, access to treatment depends on insurance or and/or other forms of "gatekeeping" around the diagnosis. Some of these processes may delay care and prevent treatment early in an eating disorder, particularly if symptoms are thought to occur "too early" or to be "too mild." Early intervention depends on having enough clinicians available to provide evidence-based eating disorders treatment. The COVID-19 pandemic increased the use of online treatment via video/telehealth, and this offers another option for flexible treatment delivery that could aid access to early intervention efforts.

Dr. Allen and her team highlight a major challenge in providing treatment services: often there is a division between child/adolescent (younger than 18 years) and adult services. In many settings there is a change of providers and treatment settings as one transitions to adulthood, and this can be disruptive to treatment and communication.

A few programs now in action

Because research into early intervention is in its infancy, multi-model neurobiological studies (including genetic, neuroimaging, and neurobiological studies) are needed, according to the authors. They also listed studies in Canada, Australia, and the United Kingdom that are analyzing and promoting early intervention in eating disorders.

Canada is studying early intervention through primary care settings. In the United Kingdom, the 4-year EDIFY Project (About EDIFY (edifyresearch.co.uk), begun in late 2021, is bringing together researchers, clinicians, and young people to develop a evidence-based, interdisciplinary project to learn how eating disorders develop and are maintained. The FREED project is using a pilot study of a FREED-on-Mobile (FREED-M) app to encourage young people with eating disorders to seek help. This app delivers youth-friendly psychoeducation through animation and downloadable resources, with the goal of encouraging youth to seek help for their eating disorders. In Australia, the Strategic Training Initiative for Prevention of EDs (STRIPED) (**www.hsph.harvard.edu/striped/**) calls for patient-centered and community-based access to care. Finally, the European ProYouth initiative (EPA-1485) is an ongoing online project that encourages help-seeking and promotes reducing eating disorder symptoms.

Food Avoidance: Another Tool to Measure Progression of AN

A recent study highlighted the importance of a balanced nutritional and psychiatric treatment team

Patients with anorexia nervosa typically limit their food intake, and high-calorie foods become a main target to avoid. Compared with healthy controls, AN patients indicate they have ittle desire to eat high-calorie foods. This pattern is seen in both restrictive AN (AN-R) or binge-eating/purging type AN (AN-BP).

Sophisticated procedures can detect this pattern of food avoidance. For example, an eye-tracking study highlighted that patients with AN avoided food cues, which potentially makes restrictive eating easier (*J Eat Disord*. 2019. 52:681). These underlying processes seem to particularly persist in weight-restored patients. In one study, patients' *explicit* (self-reported) desire to eat high-calorie foods was indeed higher than in currently underweight patients and similar to that of healthy controls. However, their *implicit* desire to eat high-calorie foods (assessed through reaction times) was as low as in currently underweight patients (*Am J Clin Nutr*. 2013. 97:463). [Of course, one wonders if persistent avoidance could relate to risk of relapse. Regardless, more knowledge is needed about this.]

The current study

A team of French psychiatrists led by Dr. L. Lodovico, of GHu Paris Psychiatry and Neurosciences, Paris, designed a multicenter, longitudinal study to determine how food avoidance can function as an indicator of severity of AN (*Eat Weight Disord*. 2023. 28:24).

The study included 130 female outpatients with AN, 11 to 53 years of age, studied in 13 AN specialty multidisciplinary treatment centers in France. The outpatients had AN for an average of 8 years, and an average body mass index (BMI, kg/mg^2) of 15.3. The participants were assessed before and after 4 months of care in the 13 centers. Avoidance of foods was assessed, in addition to BMI, severity of AN, severity of the eating disorder, levels of depression and anxiety, emotional state, degree of healthy life function, and body image perception.

All patients were offered at least one evidence-based form of psychotherapy for eating disorders (cognitive-behavioral therapy, interpersonal therapy, family therapy, or multifamily therapy). Psychotropic drugs (primarily antidepressants) were prescribed as needed.

The average time between the first and second evaluations was 132 days. Eating disorder symptoms were assessed with a French version of the *Eating Attitudes Test-26* (EAT-26). In this version, three subdivisions distinguish dieting, bulimia, and oral control. A score above 20 indicates problematic eating behavior and a high level of concern about dieting and body weight.

Food avoidance was assessed through an ad-hoc questionnaire constructed with a psychologist specialized in eating disorder patients' eating behaviors. Patients were asked to rate their levels of avoidance of 16 food items, including butter, starchy foods, french fries, cheese, pastries, cold meats, ham, red meat, white meat, and whitefish. The list also included low-calorie foods, such as nonfat dairy produce, green vegetables, tomatoes, fresh fruits (except bananas), dried fruits, and whole wheat bread.

Tools to measure depression and anxiety

To measure levels of anxiety and depression, as well as emotional state, conditions at work, and quality of life, the participants completed the *Hospital Anxiety and Depressive Scale* (HADS), a self-report questionnaire with questions devoted to depression and anxiety. Emotional state was measured with the *Positive and Negative Affect Schedule* (PANAS), a 10-part self-report questionnaire. Another questionnaire, the *Work and Social Adjustment Scale* (WSAS) questionnaire, measures the ability to work, home management, and social and private leisure activities (Br *J Clin Psychol*. 2004. 43:245). A body image perception test was based on a diagram representing a progression of 10 female silhouettes, each corresponding to a specific BMI. Patients were instructed to choose the silhouette that best represented their current body. Higher scores indicated perceived BMI, and by definition in this study equaled greater body image distortion.

Nutrition and AN

Food avoidance, especially avoiding high-calorie foods, was associated with severity of AN, shown by EAT-

26 scores, and with mood and anxiety scores. Those who developed AN at a younger age were more likely to have continuing food avoidance

One helpful observation among the researchers and the treatment team was that by restricting food, patients might include some higher-fat foods in their diets, but they also can restrict the amounts of these foods without reducing the appearance of dietary diversity. This was a true challenge for nutritionists and dietitians on the treatment team; in addition, little has been published about this behavior. Among the patients who reintroduced at least one high-fat food into their diets, EAT-26 scores were lower at baseline and improved during treatment. This confirmed that food avoidance is related to the severity of AN. A younger age at onset of AN was associated with stronger maintenance of food avoidance.

Avoiding calorie-rich foods is a well-known strategy used by AN patients to alleviate their anxiety; however, this can also have an important negative effect. Avoiding calorie-rich foods contributes to anxiety because of reduced dietary intake of micronutrients such as folate and selenium. Both affect neuronal function and have been linked to depression and anxiety (*Nutrients*. 2019.11:E792). According to the authors, the correlation between AN severity, nutritional status, and anxiety and depression underlies the concept that AN is a metabolic-psychiatric disorder *(Nat Genet*. 2019. 51:1207).

Dr. Lodovico and coauthors concluded that food avoidance could be an informative indicator of the severity of AN. There is a clear need for further study.

Examining Mortality Rates

An Italian study had much lower mortality rates from eating disorders than are normally cited

Eating disorders, particularly anorexia nervosa, have one of the highest mortality rates of all mental illnesses; there is extensive evidence of this effect. In a landmark meta-analysis of worldwide eating disorder mortality rates (*JMIR Res Protoc*. 2017. 6:e146), the standard mortality ratio, or SMR, of anorexia nervosa patients was 5.1 deaths per 1000 person-years. Young people between the ages of 15 and 24 years with AN have 10 times the risk of dying as their peers (*Curr Psychiatry Rep*. 2012. 14:406). People with eating disorders also have an overall worse quality of life, and their treatment costs are 48% higher than in the general population (*Curr Opin Psychiatry*. 2020. 33:521).

But, a recent study by Italian researchers has produced very different mortality rates for patients with eating disorders. In their study of 1277 persons with eating disorders, Dr. Giovanni Castellini and his colleagues at the University of Florence, Italy, found that the mortality rate of people with eating disorders did not differ from that of the general population. The 1277 people with eating disorders in their study included 368 with AN, 312 with BN, and 597 with BED. Twenty-two patients, or 1.72%, died during a median follow-up over 7.4 years (*Int J Eat Disord.* 2022. 17:122). The standardized mortality ratio, or SMR, was 1.19. Only among BN patients did the mortality significantly increase 10 years after clinical evaluation. The life status of participants, according to the authors, was determined through linkage with the Regional Mortality Registry.

Age was the most significant factor influencing mortality, according to the authors. Deaths occurred at the ages of 35, 57, and 64 years among the 3 AN patients; at the ages of 49, 72, and 82 years among the 3 BN patients, and at a median age of 64 years among those with BED.

Some possible explanations for the lower mortality rate

The authors suggest that the low mortality rate in persons with eating disorders in their study, compared to other published studies, could well be attributed to the eating disorders treatment network of the Florence area (EDTN), which they describe as a coordinated regional multidisciplinary treatment service.

The study also had limitations, according to the researchers. First, it did not include patients who used private care services; thus, the SMRs were not applicable to this group. And the SMRs were calculated considering gender, age group, and calendar time. To improve accuracy, according to Dr. Castellini and colleagues, future studies should add additional clinical characteristics of the patients and the type and duration of treatment.

Several other factors might be considered as contributing to the low mortality rates. Some are technical or statistical: the sensitivity and specificity (essentially, the "accuracy") of the mortality database was not described; it appears to be a regional rather than national database. The duration was relatively short for a mortality study, and the sample was relatively small. In addition, about half of the sample had been diagnosed with BED; as one might predict based on prior work, excess mortality was observed in those with AN or BN.

While those factors are probably critical to interpreting the results, they are nonetheless important in suggesting that higher mortality is common in those with eating disorders.

Treating Metabolic Disorders in Women with BED and BN

A Norwegian study compared CBT with a physical and nutritional approach

Binge-eating, with or without purging, may have impact on metabolic health, according to a report from a Norwegian team led by Dr. Therese Fostervold Mathisen, from Ostfold University College, Fredrikstad, Norway (*Eat Weight Disord*. 2023. 28:41). This recent study documents such effects, and examines whether treatment can help.

The study: two randomized groups

Dr. Fostervold Mathisen and her team designed a randomized controlled study that evaluated the effects of two 16-week treatment interventions for BN and BED. This program included two approaches: (1) physical exercise and diet therapy (PED-t), or (2) cognitive behavioral therapy (CBT). Fasting blood samples were collected at the beginning of the study, at 6 months, and at 12 months.

The final study group included 151 women diagnosed with BN or BED; the participants were 18 to 40 years of age, and had body mass indexes, or BMIs, of 17.5 to 35 kg/mg^2. Mean BMIs differed between the two groups. The women were randomly assigned to outpatient treatment with either group sessions of CBT or PED-t. Those in the PED-t group met weekly, with supervised, progressive resistance exercise, directly followed by dietary therapy and homework for two additional exercise sessions (one of resistance exercise and one featuring an interval running session). Those in the CBT group used Fairburn's individual CBT therapy, adapted for groups, and met weekly for 20 weeks.

How the type of treatment affected metabolic changes

In the current study, 32.5% and 39.1% of the participants had high levels of triglycerides and LDL-c, respectively. Low HDL-c levels were more common among women with BED (21.2%) compared to those with BN (5.1%). There was a favorable change overall in lipid profiles for both groups when pretreatment levels were compared with post-treatment levels. Changes in lipid and hormone markers, depending on pretreatment diagnoses, were significantly less favorable among women with pretreatment diagnoses of

BED than among women with pretreatment diagnoses of BN. The changes did not persist at follow-up.

More women with BED compared with those with BN had low HDL-c readings, which may be detrimental by increasing the risk of cardiovascular disease. The researchers had hypothesized that the PED-t treatment would have a greater effect on lipid levels, but this was not supported by the results. There were also only minor benefits to metabolic profiles from remission after treatment.

When viewed as a group, women with BN or BED had initial measurements that seemed to indicate healthy blood lipids, blood glucose, and thyroid hormone levels, but a significant number of participants had metabolic risk factors for cardiovascular disease.

These results make the case for efforts to understand the importance of lipid and glucose changes in those with BED and BN, and to develop appropriate ways to monitor and manage these effects.

QUESTIONS AND ANSWERS: Effects of the COVID 19 Lockdown

Q. One of my patients, a young adult with AN, reported that her symptoms, and her concerns about body shape and her increased anxiety and depression, worsened during the COVID 19 "lockdown." Is it just a passing reaction to the increased isolation she experienced? (*J.B., New Orleans, LA*).

A. The effects of the COVID lockdown, which began in spring 2020, have been reported widely among adults with eating disorders, especially those with feeding and eating disorders (FED). Several studies have shown a positive effect on patients' motivation to recover from their eating disorders.

One study that examined the conflicting results—motivation to recover, and negative effects from the isolation--stimulated Dr. Bianca Borsini and colleagues to design a study of FED symptoms. The study examined avoidant/restrictive food intake disorders (ARFID) symptoms during the lockdown among 45 young patients (11-13 years of age) and older patients (14-18 years of age). The researchers used open questions, multiple choice questions, yes/no questions, and a symptom checklist. The study was completed online (*J Eat Disord*. 2023. 11:71). Among the participants, 37 were females, and 8 were males.

About half of the participants (47%) reported that the lockdown had a positive effect on their symptoms, while 59% of those with AN reported having worsening symptoms during the lockdown. Better symptom improvement was observed among younger patients than among older ones. The lockdown was identified as the precipitating factor for FED among 61% of newly evaluated patients. The results paint a complex picture of effects from the pandemic on those with FED.

Among adults with FED, symptoms deteriorated during the lockdown, especially for those with AN, like your patient. There was also a favorable beneficial effect on intrafamilial relationships and motivation to recover or to comply with treatment.

The authors found that although the pandemic and the related lockdown precipitated FED for many patients, and worsened symptoms for others, it had a positive effect on some younger patients who were in treatment, but greater impairment among adults. Nearly all patients felt their treatment and care were satisfactory during the lockdown.

In another study, reduced access to eating disorder services, loss of routine, and heightened anxieties and eating disorder symptoms resulting from COVID 19 and lockdown measures presented challenges for adult AN patient (16 years of age and older) and their caregivers. AN patients were slower to adopt some of the measures. Increased remote support by ED services enabled treatment to continue, and self-management resources and strategies promoted self-efficacy in both patients and caregivers (*Eur Eat Disord Rev*. 2020.28:826).

To your question: Will these effects pass? The worsening of pre-existing symptoms may be more transient. For those who had a new onset of FED during the COVID pandemic, it seems very unlikely that the end of COVID-related public health emergency orders, or the transition from pandemic to endemic COVID-19, will signal the end of their FED. The increased need for eating disorders services is likely to persist into at least the near future.

—SC

Helping Parents Act as Caregivers

The burden was hardest for mothers of patients with AN

Parents are the most frequent long-term caregivers for people with AN, yet few studies have examined the burden of emotional distress such parents may have, along with underlying and unaddressed grief. To learn more about parental stress and grief, Dr. Jeanne Duclos of the Department of Psychiatry at the University of Lille, France, and a team of French researchers studied the role of burden among parents of AN patients (*Eat Weight Disord*. 2023. 28:16).

In their recent examination of 80 mothers, 55 fathers, and their adolescent children with AN (n= 84), the authors sought to explore parental and adolescents' characteristics that may be related to parental burden and grief in AN, and to identify links between the two. Before inclusion in the Evaluation of Hospitalization for Anorexia Nervosa (EVHAN) study, all participants had been hospitalized for an acute AN episode in a specialized French treatment center for life-threatening physical and/or mental conditions related to AN. The study group included people between 13 and 21 years of age who were living with their parents before they were admitted for AN treatment. Those who had another potentially serious underlying disease, such as diabetes, Crohn's disease, or other metabolic diseases, were excluded from the study.

Along with sociodemographic and clinical data, parental grief was assessed with the *Mental Illness Version of the Texas Revised Inventory of Grief* (MIV-TIG) (39). This inventory is ordinarily used to assess grief at the death of a loved one. In this case, it was modified to assess grief because of a relative's mental illness, instead of death, and the loss of that person as she/he was before developing mental illness.

Emotional distress for parents

Most participants (94%) were girls, and the mean age was 16. One-fourth of the sample was enrolled in primary school; 36% were in secondary school; 7% in higher education, and data were missing for 31. A few girls had been adopted, and some 29% had parents who were separated. Nearly half had one sibling, 31% had two, and 13% were only children. The mean sample had AN for nearly 2 years, a body mass index, or BMI (kg/m^2), of 14.3 on admission and a minimum lifetime BMI of 13.61. More than half of the adolescents met the criteria for restrictive AN; the rest met the criteria for purging-type AN.

According to the results of the French study, parents can suffer from feelings of burden with emotional distress, along with elevated levels of depression and anxiety. Parents caring for a patient with AN may describe a sense of "living loss" and grief. Some may feel that they have lost their child's "former self," along with their relationship with him or her, and their hopes for the future become disrupted. These feelings are particularly strong in the case of AN, where this life-threatening disease may make it difficult to be supportive to their child or to fully engage with normal life. Caregiver burden has two parts: the first is disruption of family/household life due to the patient's illness; the second is subjective distress among family members.

Helpful steps for parents

The grief process in adolescent AN is particularly challenging and complex. The first step involves letting go of the adolescent as she/he was before the illness and of one's relationship with the "old" person of one's former dreams and expectations. Next, the caregiver or caregivers have to find a way to live with and accept the person as he or she is *now*. The authors found that one particularly painful task for parents of adolescents with long and enduring AN is accepting the irreversible loss of their child's normal adolescence. And, after the diagnosis they have to think about and work on who their child may be in the future. Parents also need to know that 50% to 60% of adolescents with AN will eventually improve or fully recover. Addressing parents' intolerance of uncertainty may be helpful at this stage of loss and grief work. "Negative uncertainty" can contribute to feelings of distress and uncertainty and undermines self-confidence and self-efficacy.

The authors note that it is essential to help parents with their emotional distress. While fathers need specific help in decreasing their levels of anxiety, mothers need to be given priority during the treatment sessions, paying attention to interrelated parental experiences. Fathers' attendance in family-oriented treatment is generally poor, and tends to decrease over time (*J Clin Child &Adolesc Psychol.* 2018. 47: S56). The authors point out that society and therapists often tend to accept the fact that fathers will be absent from family therapy over time and thus reinforce their absence, conveying to mothers that they are the main agents for change and perhaps the guilty ones to start with. This merely increases the mothers' burden.

They point out that it is possible to work on such cycles without blaming either of the parents. Fathers do play a key role in their adolescent's recovery, including ways in which their attendance in therapy is associated with improved treatment outcomes (*Clin Soc Work J.* 48:389). Both parents express more grief when their child's clinical state is more severe. In studies, the fathers' grief was related to their own levels of depression and anxiety, while mothers' grief was associated with their own levels of depression and alexithymia. The authors concluded that mothers might be more affected by their child's clinical condition than by their own psychological condition, whereas fathers feel a higher burden related to their own anxiety. The burden was explained by grief in both parents, by anxiety in the fathers and by the mothers' experience of the child's worsening clinical state.

Limitations to the study

The authors listed several limitations of their study. One was that the study was conducted purely in an inpatient setting, which may have biased the sample toward a more severe eating disorder population. Parents of hospitalized adolescents, who could not be managed on an outpatient basis or managed it at home with little or no additional professional help, may have felt a more acute sense of distress and failure than parents who were outpatient caregivers.

Dr. Duclos and colleagues report that future studies would benefit from larger samples of patients with both restrictive and purging AN, and may promote development and use of specific loss and grief programs for this clinical population. As a result of their study, the authors themselves were encouraged to include some components or parts of the non-death loss and grief-oriented theories in their multifamily therapy and parent group programs for adolescent AN patients.

In the Next Issue

How Artificial Intelligence (AI) May Transform Care for Eating Disorders Patients

Three Italian clinicians discuss how the introduction of AI-based tools may impact and transform care for patients with eating disorders, including prevention, support of treatment, and development of and development of new and personalized treatment strategies. Their editorial was composed with ChatGPT version 3.5.

Highlights of IADEP's Annual Symposium in Palm Springs
Also check access to the Virtual Symposium on the iaedp website

Plus

- **Endometriosis and Eating Disorders**
- **Bulimia Symptoms, Anger and Aggression Among Teens**
- **Preventing Eating Disorders in Genetically Prone, High-Risk Families**
- **And, much more**

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