Treatment of Patients With Anorexia Nervosa in the US—A Crisis in Care

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The United States is facing a crisis in the treatment of anorexia nervosa (AN)—a debilitating, expensive, and frequently fatal illness. Annually, eating disorders cost the US more than $65 billion.1 Despite scientific advances, treatments do not yet exist that target the core biology of AN. Moreover, the absence of standards of care has left a vacuum to be filled by programs offering untested interventions. Many academic medical center programs have dwindled or closed, functionally steering uninsured patients and families to private programs and limiting treatment access for the uninsured and underinsured. Herein, we describe the crisis and propose solutions.

Anorexia nervosa frequently requires prolonged hospitalization for weight restoration and medical and psychiatric stabilization.2 Relapse rates approach 50%, and the standardized mortality ratio is approximately 6,3 rendering it one of the most lethal of psychiatric disorders. Although empirically supported treatments in youth, such as family-based treatment, have moderate success, recovery is often prolonged, and the evidence base for treatment in adults is weak.4 Approximately 20% of patients with AN develop a severe and protracted illness. No US Food and Drug Administration–approved medications exist.2

How the Crisis of Care Has Grown

Few Treatments
As mentioned previously, evidence-based treatments for AN that are based on biology do not yet exist. Recent innovations in genetic and biobehavioral research elucidate neurobiological contributions to AN disease risk and chronicity but have yet to be translated into clinical interventions. In part, this lack of evidence-based treatment reflects gross underfunding of AN research relative to its disability-adjusted life-years.5

Loss of Academic Programs
During the past decade, eating disorders programs housed in academic medical centers have been closing or shrinking because of their inability to compete with the proliferation of freestanding treatment centers.6 Their demise compromises the ability of medical school curricula to address eating disorders adequately and limit its formative experiences that equip trainees from all health care professions with the skills necessary to detect and treat eating disorders across the health care system. Fewer emerging clinicians may be prepared to care for these patients, and more lives could be lost. The restricted recruitment pipeline for physician-scientists may further perpetuate the dearth of quality translational research.

Lack of Standards of Care

Binding standards of care for AN do not exist. Treatment of eating disorders is unregulated. In the absence of consensus on optimal treatment of the disease, many untreated but superficially appealing treatments are marketed direct to consumer and direct to clinician. Outcome data are rarely published. Marketing strategies are unconstrained by legislation and policy changes that limit the pharmaceutical industry.6 Fee-for-service approaches dominate, with value-based care a rarity.7 High health care use and high recurring costs reflect the price paid for the absence of evidence-based treatments and standards of care.

Insurance Coverage and Reimbursement

Patients with AN who have severe and enduring presentations and the uninsured or underinsured are at a life-threatening disadvantage. Clinicians and facilities with expertise in caring for individuals with severe and enduring AN are lacking, as is reimbursement for their care.8 Medicaid coverage for eating disorders is highly variable, and Medicare does not cover medical nutrition therapy, a central pillar of eating disorders treatment. Private programs often reject patients with high acuity or inadequate insurance; therefore, individuals in greatest need can no longer access care. Repeated treatment failures, insurance denials leading to premature discharge, revolving-door experiences, and clinician burnout potentially contribute to a worrying pattern of opting for palliative care or hospice for the chronically ill. This pattern may reflect a failure to translate science into successful interventions and barriers to developing and disseminating innovative treatments focused on disease management and improving quality of life.

How Can We Address the Crisis of Care?

Translation of Research Into Effective Therapeutics
A lack of a mechanistic understanding of AN has thwarted efforts to develop evidence-based interventions. Advancing knowledge of genetic and neurobiological mechanisms could offer insight into perplexing behaviors associated with AN, thereby informing more treatments for restrictive eating, driven physical activity, distorted body image, and anosognosia (ie, the inability to recognize the seriousness of the illness).

Treatment of AN is unique in that it requires nutritional rehabilitation and weight gain, necessitating innovative research designs beyond standard outpatient randomized clinical trials. Guidance on treatment staging based on illness severity is lacking. Large multisite studies are essential to achieve adequate sample sizes. In addition, interventions that address both the psychological and biological aspects of the illness; incorporate

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short-, medium-, and long-term outcomes; address adherence, dropout, and relapse prevention; and aim for a varied intervention toolbox are needed, with the understanding that a one-size-fits-all approach to AN cannot adequately address the needs of patients and families.

Early Detection and Referral

Individuals with AN are typically symptomatic for years before seeking treatment. This delay in treatment must change; early evidence-based intervention has been shown to yield better outcomes. Accordingly, training is needed for physicians on the front lines of detection (eg, pediatricians, family medicine physicians) as well as teachers, coaches, and parents, underscoring the critical need for academic eating disorder programs. Effective screening, brief intervention, and referral guidelines are important components of care and under development by the US National Center of Excellence for Eating Disorders (nceedus.org).

Development of Obligatory Standards of Care

Although guidelines for treatment implementation exist, they have not resulted in mandated standards of care that deliver evidence-based interventions. We believe that standards of care must be developed and adhered to for reimbursement by third-party payors. These standards need to address the types of evidence-based treatments delivered, the training required to deliver such treatments, and mandate a standardized data repository to monitor outcomes.

Serve the Underserved and Bolster Academic Programs

To stop neglecting the most vulnerable patients, improvement in access to care for patients with chronic, severe eating disorders and for those with public insurance is needed. The loss of academic programs has rendered treatment for AN a luxury commodity. Hospital-based programs are needed to treat patients with high medical and psychiatric acuity and are often the only ones that accept public insurance.

In addition, support for academic centers of excellence that combine research aimed at improving clinical care with training in evidence-based approaches could reinvigorate the field.

Proposed Changes in Care Models

With the goal of providing value-based health care, what is the best method for delivering treatment for AN? Successful eating disorder treatment necessitates integrated multidisciplinary care across development and levels of care and considers patients and their families. Establishment of clinical centers of excellence could define and consolidate delivery of standard care and build consumer trust. Coronavirus disease 2019 has accelerated innovation in mental health care delivery—especially the provision of mental health telemedicine services. Virtual therapy and incorporation of wearable technology could extend the work of physicians and allied professionals and deliver interventions in real time. Easing requirements for cross-state licensure could enable virtual follow-up by a known specialized treatment team.

Funding

Compared with other psychiatric disorders, AN receives relatively little funding in the US, which may explain slow treatment development and dissemination. The estimated financial value of medical research for eating disorders in 2018 and 2019 was $49.8 million ($9 per person with an eating disorder), compared with $239 per individual with Alzheimer disease, $109 per individual with autism, and $69 per individual with schizophrenia.

The closing of academic programs may further limit opportunities to engage and train the next generation of clinical researchers. An Academy for Eating Disorder Task Force that inspired this perspective seeks to engage stakeholders, including federal funding agencies, philanthropic organizations, patients and families, advocates, insurance companies, policy makers, and clinicians, to coordinate dialogue to set priorities for the field. We encourage an immediate engagement of these stakeholders to address this crisis in care.

References