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Insight

To Better Diagnose and Treat Latinx Males with Disordered Eating, We Need an Increase in Representation and Advocacy in Research

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Restrictive anorexia nervosa (AN-R) is a psychiatric illness with high morbidity and mortality that often begins in adolescence. While many treatment options exist, there is limited research on their efficacy, particularly for higher levels of care (HLOCs). Our recent literature review of the existing published research on HLOCs revealed a consistent overrepresentation of non-Hispanic white females, a demographic that does not reflect the diverse populations seen in clinical settings. As a result, the findings from these studies are inadequate for informing clinical practice. This insight highlights the systemic inequities experienced by Latinx patients who continue to experience disparities in the diagnosis and treatment of AN-R. We call for action across multiple domains to improve representation in research and expand access to care, and to ensure that essential treatment is available to all patients with AN-R.

Advocacy Focus and Impact on Health

How this work impacts health: We highlight the impact of inequities in diagnosis, treatment, and research representation among Latinx patients and men with anorexia nervosa (AN-R), a disease with high mortality and low recovery rates.
How this paper addresses advocacy/action: We highlight the need for advocacy in dismantling barriers faced by men and Latinx youth with AN-R. We propose mechanisms of change aimed at eliminating stigma within the public and medical community and increasing representation in research to ensure all patients with AN-R are included.
What this work adds to the field: This Insight underscores the lack of treatment efficacy data for underrepresented populations and calls for higher-quality, inclusive research. These efforts could change the current standard of care, inform clinical practice, and improve outcomes for all patients with AN-R.
Next steps/needed action(s): Change will require a global approach in many areas, including policy, research, and practice. Key actions include expanding insurance coverage for Higher Level of Care (HLOC), increasing research funding, ensuring the inclusion of representative populations in this research, and eliminating provider bias through advocacy.

Our patient was an adolescent Latinx male with anorexia nervosa restricting subtype (AN-R) and public insurance who was hospitalized for the third time in six months. He cycled between outpatient family-based therapy (FBT) and inpatient hospitalization and was not getting any better. Although FBT is the most studied research modality for adolescents with AN-R, it may not be the most effective for all patients (Huryk et al. 2021). Given his persistent struggles, it was clear he needed more structure and support. We recommended a Higher Level of Care (HLOC) at discharge, but was this a feasible path to recovery?

AN-R is a mental health condition characterized in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) by intentional restriction of energy, fear of weight gain, and disturbed body image over the last three months that leads to low bodyweight with persistent behaviors that interfere with weight gain (American Psychiatric Association 2013). AN-R often begins in adolescence, but can continue into adulthood if not treated aggressively (Mitchell and Peterson 2020). With one of the highest mortality rates among mental illnesses and full recovery occurring in only a quarter of cases, evaluating the efficacy of all potential treatment modalities is critical to improving patient outcomes (Accurso, Buckelew, and Snowden 2021). Moreover, determining the appropriate level of care for an adolescent involves many factors such as current weight, illness duration, prior treatments, caregivers' ability to engage in providing care, language of therapist, geographic distance to treatment, and insurance coverage.

FBT centers on the role of the caregiver in supporting the patient. The first stage of FBT is focused on parental control of nutrition, which limits patient autonomy in meal choice and size. As disordered eating thoughts lessen, patients gradually regain autonomy. This can be done at home and typically extends over a 12-to-18-month period. FBT is considered the current standard of care because it is the most studied therapy for AN-R, offers flexibility, can be done in person or virtually, and is the treatment level that is most often covered by public insurance. Although FBT is the standard of care, fewer than 50% of patients achieve full recovery with FBT, often due to factors such as illness severity, complex medical needs, limited geographic access to outpatient treatment, and/or inadequate insurance coverage. In these cases, more support or HLOCs for eating disorder (ED) treatment are recommended.

In ED treatment, HLOC offer structured, multidisciplinary support. For example, these programs often offer medical checks by a pediatrician or adolescent medicine provider, psychiatric evaluations and medication support if needed, individual therapy, and support from dieticians who specialize in EDs. The main distinction of the different HLOC is the number of days and hours that multidisciplinary care is offered. Residential programs are the most intensive of the HLOC as they offer 24/7 care, while Partial Hospitalization Programs (PHPs) are in-person day treatment programs offered five to seven days per week, and Intensive Outpatient Programs (IOPs) are shorter day/afternoon programs typically offered three to five days per week, virtually or in person (Derenne 2019).

Because HLOC offer more intensive support than outpatient FBT, they may be more effective at reducing rehospitalization rates and expediting recovery (Essayli and Ornstein 2018), especially among those for whom FBT is not effective. However, they are often costlier, have limited availability, and may be further from a patient's home. Another primary difference and challenge are that they are only provided by privately-owned companies, which enables those institutions to set individualized admission criteria and makes them less likely to accept public insurance. However, despite multiple treatment options, limited data to support HLOC treatment efficacy further complicates providers' ability to recommend the appropriate level of care. These challenges became even more evident when we looked to select the best level of care for our patient.

Because our patient tried and failed outpatient FBT several times, we turned to the literature to identify a more effective level of care. Our search revealed that, to date, no published studies directly compared HLOC to outpatient FBT in adolescents with AN-R. We therefore aimed to conduct our own literature review to compare the outcomes of PHPs to outpatient FBT. We created two separate searches of PHPs and outpatient programs with the same inclusion criteria using the following terms: PHP/outpatient (as indicated) FBT programming, U.S.-based, adolescent population, and mention of adequate power in the Methods section. We identified several outpatient studies but only three focused on PHPs (Van Huysse et al. 2020, 2022; Rienecke and Richmond 2018).

Before even attempting to compare the reported outcomes of these modalities, we identified critical limitations in the PHP studies. The studies lacked long-term post-treatment follow-up, which is essential to understanding treatment efficacy in an illness that often has a long duration beyond initial treatment. More concerning were the demographics of those included or, more accurately, not included in these three studies: participants were overwhelmingly categorized as assigned female at birth (91.4, 92.2, and 96.2%, respectively) and non-Hispanic White (95.7, 93.1, and 96.2%, respectively) (Van Huysse et al. 2020, 2022; Rienecke and Richmond 2018). The studies did not clarify how race and ethnicity data were collected or if it was self-reported.

What was clear after reviewing these papers was that the populations enrolled in these HLOC studies varied greatly from our own. At our large, urban pediatric medical center in the Midwest, 20 percent of our patients with AN-R identify as male. Among our male population, nearly 40 percent self-identify as Latinx, and 50 percent have public insurance. Ultimately, not only did our literature review reveal that the patients included in the only published studies we identified did not match our patient of interest, they also did not represent many of the other patients we care for at our center.

Latinx male patients often present late in illness due to disparities in ED screening, driven by stereotyping across racial and gender identities. For years, AN-R has been perceived in the medical community as a "disease of affluence" (implying higher prevalence among those with higher incomes) that is strongly associated with women (Huryk, Drury, and Loeb 2021). Despite research showcasing that EDs impact people across all ethnicities, races, socioeconomic status, and gender, the stereotype that non-Hispanic white women are those mostly impacted by AN-R persists, as demonstrated in the recently conducted PHP studies we identified (Van Huysse et al. 2020, 2022; Rienecke and Richmond 2018; Rodgers, Berry, and Franko 2018). Men are estimated to be nearly five times less likely to be diagnosed with restrictive eating than women, and Latinx patients receive fewer or no ED screenings compared to patients identifying as non-Hispanic White (Moreno et al. 2023; Higgins and Cahn 2018).

Regarding insurance type, publicly insured patients with EDs were found to be only one-third as likely to receive the recommended treatment compared to those with private insurance (Moreno et al. 2023). In this same study, Moreno et al. found that most patients with public insurance identified as Latinx and that those identifying as Latinx were only half as likely to receive ED treatment compared to their non-Hispanic white-identifying peers, revealing that identifying as Latinx and having public insurance were independent barriers to accessing treatment (Moreno et al. 2023). While research continues to show that race itself is not a risk factor for disease but rather the driver of health inequities, institutional racism and implicit bias, both within and beyond healthcare, predispose our patients to the disparities they face in healthcare access including socioeco-

nomic, geographic, insurance, and language barriers (Vyas, Eisenstein, and Jones 2020).

Given the intersecting disparities Latinx men face in AN-R diagnoses and treatment, is it not surprising that they are largely or even entirely excluded from research studies? Determining appropriate treatment disposition for our Latinx male patients is challenging since even the standard of care was created using data that did not include them.

> *When the demographics of most of our patients are not represented in research studies used to determine the standard of care, how can we confidently propose treatment options to them?*

Our literature review brought us face-to-face with the reality that we were starting too many steps ahead in our analysis. Before we can compare treatment outcomes, we must focus our efforts on acknowledging and addressing inequities across multiple domains including policy, research, and practice to ensure the inclusion of Latinx adolescents and young men in research studies, which is necessary to improve their access to effective AN-R care (**Table 1**). Here we present some suggested solutions and actions in each of these domains to help address the barriers faced by our patients, and to achieve health equity for all patients.

POLICY

Policy efforts should focus on expanding Medicaid coverage, since many of our Latinx patients rely on public insurance. Additionally, we can push for stronger enforcement of the Mental Health Parity and Addiction Equity Act (MHPAEA) for EDs. This Act, passed in 2008, mandates equal equitable insurance coverage for mental health conditions on the same level as physical health conditions (Huskamp, Samples, Hadland, et al. 2018). However, since its implementation, treatment coverage has been inconsistent, weakly enforced, and often does not apply to HLOC (Huskamp, Samples, Hadland, et al. 2018; Dickson-Gomez et al. 2022). Partnering with ED advocacy organizations to file for parity may aid in expanding coverage of HLOC, making it available for all patients who may benefit (**Table 1**).

RESEARCH

To improve upon the generalizability of research findings, rating scales for funding decisions should require research to include diversity reporting. We also suggest that the researchers who led and authored the three studies we identified repeat their studies with a more inclusive demographic population to assess whether their findings are consistent across self-identified sex and race categories. Reducing both funding and selection bias in HLOC will help to promote more diverse patient study demographics. This also can be accomplished by requiring that investigators who conduct research at private centers are not affiliated with those centers or partner with a third-party to receive research funding. We also encourage researchers to utilize Community-Based Participatory Research (CBPR) practices. Since CBPR is a research approach involving collaboration between researchers, community members, and organizations, it may aid in the inclusion of neglected patient populations in research (Collins, Clifasefi, Stanton, et al. 2019).

However, these proposed improvements cannot occur without increased funding. To begin with, ED research funding is disproportionately low compared to other mental health conditions based on burden of illness (Streatfeild, Hickson, Austin, et al. 2021). Additional funding could enable higher-quality studies, including randomized controlled trials (RCTs) at multiple sites, which are essential to make headway in overall AN-R research. Findings from studies on the economic burden and mortality of AN-R, paired with patient cases, can be brought to the attention of local and federal representatives who can mandate proportional funding relative to disease cost, illness burden, and mortality. This research is critical to informing clinical practice (**Table 1**).

PRACTICE

Advocacy that reduces stigma is key to advancing policy, research, and practice. AN-R is often misperceived as an "illness of choice," and provider stigma has been shown to reduce empathy and quality of care (Bannatyne and Stapleton 2015). To create meaningful change, we must acknowledge and address bias at provider and institutional levels.

As clinicians trained in ED care, we witness first-hand how these barriers affect patient outcomes, making us the best advocates to raise awareness of AN-R in our own institutions. In the public sphere, we can utilize public health campaigns to reduce stigma and advocate for equity. Within the medical community, we can work to reduce provider stigma through peer discussions, publications that highlight gaps in care, and training in ED screening and treatment disposition. Providers should also implement systems that better track clinical outcomes based on gender, race, ethnicity, insurance type and other factors to identify discrepancies in care and outcomes. Sharing this data among clinicians can inform recommended treatment disposition and challenge care standards (**Table 1**). Ultimately, reducing stigma will lead more people to seek care, which will also result in stronger data to further support treatment choices, funding requests, policy change, and advocacy efforts.

It is now clear why our patient, an adolescent Latinx male with public insurance, was not improving. He was not only battling anorexia, but also a negligent system—one that does not include him in research studies and failed to cover the necessary level of therapeutic care we recommended. As clinicians, we make an oath to provide just care to all patients. We, as a society, and we as health care providers have much work to do to dismantle systemic racism within the health care system and beyond. Institutional change requires a multi-prong approach across policy, research, and clinical practice.

Here, we have outlined potential avenues to begin this work. We recognize that this is not comprehensive, and it can feel daunting, but action is necessary to improve out-

Table 1. Taking Action on Policy, Research, and Practice to Improve the Representation of Impacted Patient Populations in Research Studies and Insurance Coverage for Adolescents with Restrictive Eating

	POLICY	RESEARCH			PRACTICE
		Generalizability	**Funding**	**Content and Quality**	
ISSUE	*Patients who have public insurance have fewer treatment options, especially at higher levels of care (HLOC)*	*AN-R research studies lack diverse participants, making results difficult to apply to populations of varying race, gender, and socioeconomic status*	*Funding levels are disproportionate relative to disease burden, and there is not enough funding to make positive change*	*Little is known about AN-R treatment efficacies*	*Provider stigmatization results in limited screening and inequities in diagnoses, treatment, and inclusion in research studies that can inform care*
Suggested solutions and actions	• Partner with ED advocacy organizations to implement policy changes • Advocate for and establish Medicaid expansion for HLOC • Ensure enforcement of the Mental Health Parity and Addiction Equity Act (MHPAEA) to cover HLOC	• Require diversity reporting to receive funding • Change rating scores to incentivize inclusion of diverse patient populations; aim for 25% by race and gender • Repeat prior research studies to include diverse populations • Implement Community-based Participatory Research (CBPR) • Require that HLOC researchers are not affiliated with private centers and/or partner with a third party to receive funding	• Conduct studies on economic burden of AN-R • Mandate proportional funding for AN-R	• Conduct randomized controlled trials (RCTs) at multiple sites that include diverse populations	• Develop public health campaigns to increase awareness and advocate within communities for reduced stigma around eating disorders (EDs) • Advocate to peers through discussions, publications, and specialized training to reduce provider stigma • Acknowledge and address bias at provider and institutional levels • Track clinical outcomes based on gender, race, ethnicity, and insurance type to inform research and care decisions

comes for each patient in our care. While our patient was not given the care he deserved, we will continue to use our patient care experiences to fuel our advocacy—for him and for every patient navigating this broken system.

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DECLARATION OF COMPETING INTERESTS

The authors do not have any conflicts of interest to disclose.

AUTHOR CONTRIBUTIONS

AC is credited with the original idea and conducted the literature review for comparing FBT to PHPs as part of a capstone project. LN was an advisor on the original project and served as a mentor for transitioning this into an insight piece. Both authors participated equally throughout the writing and revision process.

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ABBREVIATIONS

AN-R, Anorexia nervosa restrictive type
FBT, family-based therapy
HLOCs, Higher Level(s) of Care
EDs, eating disorder(s)
PHPs, Partial Hospitalization Program(s)
IOPs, Intensive Outpatient Program(s)
MHPAEA, Mental Health Parity and Addiction Equity Act
CBPR, Community-Based Participatory Research
RCTs, randomized controlled trials

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