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The Overlooked Intersection: Autism, Ehlers-Danlos Syndrome, and Pain Perception in Women

Advocating for a More Inclusive, Evidence-based Approach to Pain Management

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Abstract

Pain is widely experienced but unequally treated, especially for women who are Autistic, have Ehlers-Danlos Syndrome (EDS), or belong to BIPOC or low-income communities. Research links Autism and EDS, as both affect connective tissue, sensory processing, and pain perception, yet women with these conditions often face misdiagnosis and inadequate care. Gender biases in medicine lead to pain dismissal, with women—especially Autistic women—struggling to communicate pain in ways doctors recognize. Racial and socioeconomic disparities further exacerbate this issue, as BIPOC and low-income women are systematically undertreated. EDS complicates pain management due to altered drug metabolism, yet existing biases make accessing appropriate treatment even harder. To address these inequities, healthcare must adopt neurodiverse-informed practices and personalized pain management strategies. Without systemic change, too many will continue to suffer needlessly.

Introduction

Pain is universal, yet its perception, acknowledgement, and treatment are anything but equal. For women, especially those who are Autistic, have Ehlers-Danlos Syndrome (EDS), or belong to BIPOC or low-income communities, pain is often dismissed, undertreated, or outright ignored. The intersection of these factors creates a perfect storm of medical neglect, leaving many to suffer in silence while the healthcare system fails to recognize their unique needs, leading to a cycle of inadequate care and mistrust in the healthcare system.

Emerging research reveals a strong connection between Autism and EDS, with both conditions involving connective tissue differences and neurological variances that impact movement, coordination, sensory processing, and pain perception. (CITE: Journal of Personalized Medicine) Studies suggest a potential genetic link between Autism and EDS, particularly in genes related to collagen production, connective tissue integrity, and neurodevelopment. (Journal of Personalized Medicine). Tragically, women with dual diagnoses often experience complex healthcare needs - due to the intersection of neurological and connective tissue symptoms - which contribute to frequent misdiagnosis, dismissal of symptoms, and inadequate care. Both conditions involve autonomic nervous system dysfunction, which can lead to issues like dysautonomia, sensory sensitivities, and difficulties regulating pain responses.

Additionally, women's pain is taken less seriously than men's pain. Women are less likely to receive adequate pain medication, leading to misdiagnosis, undertreatment, or dismissal of their experiences. (CITE Jones, D. (2019). *Hysteria: The history of a disease*. Springer). This can be traced back to centuries of gender assumptions in medicine, where women's complaints were often attributed to emotional instability, rather than legitimate physical conditions. For example, the term "hysteria" was historically used to describe a range of symptoms in women, from pain to depression, based on the outdated belief that women's uteruses were the source of emotional distress (Jones, 2019). Women are also more likely to be prescribed medications based on assumptions that their pain is emotionally driven rather than physically rooted (Green, 2019).

For Autistic women with EDS, this bias is magnified. Many struggle to communicate their pain in ways that align with traditional medical expectations. If a patient does not express pain in a way that doctors recognize, it is often ignored or minimized. Autistic individuals may experience atypical pain expressions, including difficulty verbalizing discomfort, reduced facial affect, or inconsistent pain responses due to sensory processing differences. As a result, their pain is frequently misinterpreted or dismissed by healthcare providers. In clinical settings, Autistic women with EDS may display muted or delayed pain reactions, which can lead doctors to underestimate the severity of their symptoms. Conversely, sensory hypersensitivity may cause them to experience minor symptoms as intensely painful, further complicating provider assessments. Additionally, Autistic women are also more likely to engage in masking behaviors, suppressing visible signs of distress to conform to social norms and camouflage their struggles. The lack of provider training on the Autism- EDS overlap further contributes to "diagnostic overshadowing," where symptoms are incorrectly attributed to Autism or psychological factors rather than the physical realities of EDS.

Pain disparities are even starker for BIPOC and low-income patients. Studies have repeatedly shown that black patients are systematically undertreated for pain, based on the false, racist belief that they have a higher pain tolerance. Women on Medicaid or without insurance are also less likely to receive adequate pain relief, leaving low-income women with EDS without proper treatment. BIPOC women are more likely to have their symptoms dismissed, particularly in emergency and urgent care settings. For women with EDS, who often require complex pain management strategies, these systemic biases can mean a lifetime of untreated suffering.

"As a Black Autistic woman with Ehlers-Danlos Syndrome, I've had to fight for my pain to be taken seriously. I can't count the number of times I've gone to the ER in excruciating pain, only to be dismissed, told it's 'just anxiety,' or accused of drug-seeking. I once dislocated my shoulder and was given ibuprofen, while a white friend with a similar injury was immediately offered stronger pain relief."

"When I gave birth to my son, I was in agony for hours before anyone believed me that the epidural wasn't working. These experiences aren't unique to me—BIPOC women are systematically undertreated for pain, and those of us with chronic conditions like EDS face even greater barriers to getting the care we need."

EDS complicates pain treatment because individuals with hypermobile EDS often metabolize medications differently, requiring higher doses of anesthesia and pain relief drugs. (Journal of Medicine). However, due to existing biases, women, especially BIPOC and low-income women, already receive less medication than they need. Standard doses of local anesthesia may be ineffective for EDS patients, leading to excruciating pain during procedures like dental work or surgeries. Many EDS patients have a paradoxical reaction to opioids, where low doses do not work, yet higher doses are difficult to obtain due to stigma around pain medication use. The lack of research on EDS, particularly in neurodivergent women, means that many doctors do not believe their pain is real or severe enough to warrant stronger interventions.

In a world grappling with opioid addiction, it is crucial to rethink how we address pain perception in women with Autism and EDS. The medical community must shift towards personalized, evidence-based pain management strategies that acknowledge the unique neurological and connective tissue differences in this population. To address these disparities, it is critical for healthcare systems to adopt neurodiverse informed care practices, which include sensory-friendly environments, communication accommodations, and trauma-sensitive assessments. Dedicated training to understand the unique pain profile and communication differences is essential for providers to ensure equitable diagnostic access and effective pain management for Autistic women with EDS.

Conclusion

Pain is real. Pain is complex. And pain should never be dismissed based on gender, neurodivergence, race, or socioeconomic status. The intersection of Autism, EDS, and pain perception in women, especially BIPOC and low-income women, highlights deep inequities in the healthcare system. Until these biases are addressed, too many people will continue to suffer needlessly.

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