The Squimbly* Support Plan: Bridging Awareness, Breaking Down Barriers, and Enhancing Frontline Recognition of Hypermobile Ehlers-Danlos Syndrome Through Education and Clinical Vigilance

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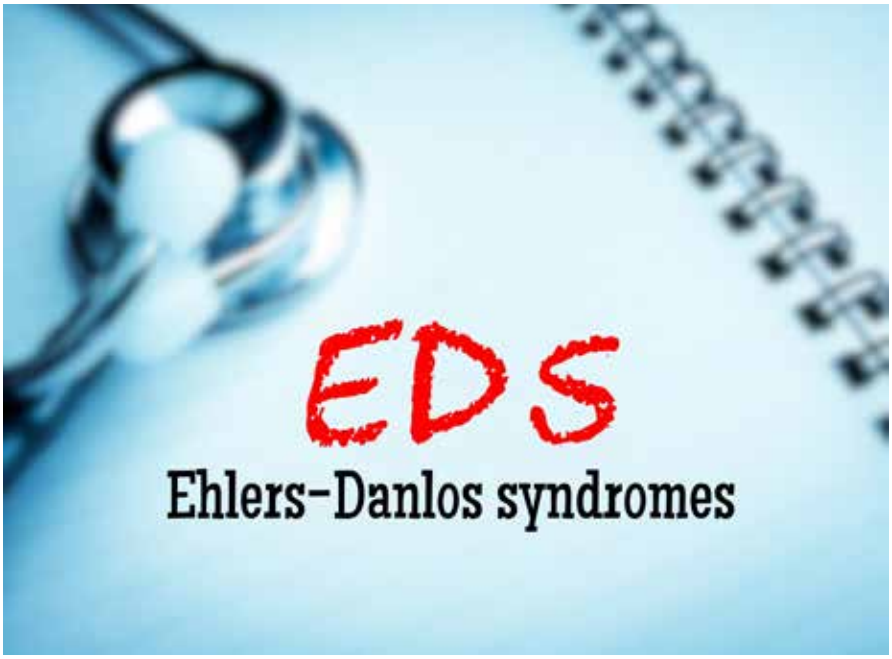

Ehlers-Danlos Syndrome (EDS) is an umbrella term for a group of thirteen connective tissue disorders that present similar symptoms, the most recognizable of which are joint hypermobility, tissue fragility, and skin hyperextensibility (Black et al., 2023a). At a basic level, people with EDS produce faulty collagen, and therefore lose strength in connective tissue throughout the body (Burkhart & Perkins, 2021). Symptoms often manifest unpredictably and are diagnosed late, leaving patients to self-manage. Primary Care Provider (PCP) support is limited by lack of education, resources, and confidence in treatment planning (Black et al., 2023b). On the patient side, there are also barriers present, such as Social Determinants of Health (SDOH), lack of recognition that there is a problem, and mistrust in healthcare due to poor experiences (Bell & Pearce, 2021). The average time to diagnosis for a patient with Ehlers-Danlos Syndrome - specifically the hypermobile variant - is ten years, which creates a significant delay in care, and consequently, worse patient outcomes (Black et al., 2023b; Harris, 2024a).

Definition

The Ehlers-Danlos Syndromes are a group of heritable connective tissue disorders, passed through an autosomal dominant trait with incomplete penetrance and variable expression (Van Dijk et al., 2023). All but the hypermobility type – the most common and seemingly hardest to treat – have a genetic marker (Black et al., 2023b). hEDS affects an estimated 1:2500 to 1:5000, with tens of thousands in North America (Black et al., 2023a; Burkhart & Perkins, 2021).

Barriers to Diagnosis

The road to diagnosis is often complex and obstructed on both the patient and provider side. A major barrier to PCPs providing care is a simple lack of education on EDS. This fosters skepticism, misdiagnosis, and uncertainty in diagnosis and treating hEDS. A 2025 study found 904.4% of the patients were misdiagnosed with a psychiatric condition before reaching the correct diagnosis of hEDS (Lee & Chopra, 2025). This damages trust and invalidates patient concerns. In a condition where early recognition and treatment are crucial, lack of awareness delays care and can lead to harmful treatment (Bell & Pearce, 2021).

Due to hEDS's complexity and comorbidities, PCPs often refer to a wide variety of specialists. Multidisciplinary approaches (MDA) require coordinated communication for effective treatmen. Additionally, referrals shouldn't replace provider education, as care responsibilities can become unclear (Black et al., 2023a).

In a 2023 study, a sample of providers indicated that the biggest barriers were knowing how to treat hEDS, who they needed involved in the care planning process, and knowledge of the disorder without exposure to EDS (Black et al., 2023b). The Ehlers-Danlos Society, a nonprofit that provides education and resources for

Abbreviations and Definitions

ECHO: Extension for Community Health Outreach
EDS: Ehlers-Danlos Syndrome
hEDS: Hypermobile Ehlers-Danlos Syndrome
MDA: Multidisciplinary Approach
PCP: Primary Care Provider
SDOH: Social Determinants of Health
***Squimbly**: A colloquial, compassionate term used to describe the lived experience of hEDS - including its diagnostic complexity, multisystem symptoms, and psychosocial impact. "Squimbly" encapsulates the bendy, unpredictable, and often misunderstood nature of the condition, offering a patient-centered shorthand for both the diagnosis and its ripple effects.

providers and communities, offers an Extension for Community Health Outreach (ECHO) program to bridge this knowledge gap.

Patients also have unique barriers that must be considered. As with any illness, one of the biggest barriers is Social Determinants of Health (SDOH), including economic and social factors. Families often struggle to afford care with limited diagnostic availability (Bell & Pearce, 2021). Accessible, informed providers can help address SDOH-related issues.

Another issue is fractured trust in the medical community, creating a need for psychosocial support as part of treatment (Bell & Pearce, 2021). Patients often become "self-experts" due to lack of support. When they do present to healthcare, there's often delayed diagnosis or psychiatric mislabeling (Lee & Chopra, 2025). Many patients stop seeing their PCP, believing care is futile. Without management, hEDS can worsen unexpectedly (eg: joint dislocations) (Quigley et al., 2024).

A more insidious issue with these patients is that many don't recognize a problem until symptoms disrupt daily life (Song et al., 2020). Thus, it is important to catch hEDS in childhood to prevent severe clinical progression and crisis (Tofts et al., 2023).

Abbreviations and Definitions

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helped build their confidence. While potential limitations included time constraints and the need for additional practice in adapting the Rule of Nines for various age groups, the project was a valuable addition to the curriculum, providing an immersive experience that brought theory to life.

This activity highlights the effectiveness of Tanner's Clinical Judgment Model in nursing education, mainly when applied to challenging, high-stakes scenarios such as pediatric burn care. By structuring learning around this model, nursing educators can help students build critical skills in a controlled yet realistic setting, ultimately preparing them for the complexities of real-world patient care ■.

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