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The Hidden Public Health Burden of Hypermobile Ehlers-Danlos Syndrome and Postural Orthostatic Tachycardia Syndrome: Epidemiology, Diagnostic Delay, and Health System Challenges

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ABSTRACT

Hypermobile Ehlers-Danlos syndrome (hEDS) and postural orthostatic tachycardia syndrome (POTS) are emerging as chronic multisystem disorders that are underdiagnosed and overburdened on the healthcare system and economic costs, especially for young women. Both conditions are highly underdiagnosed, with a length of time to diagnosis of a decade or more, multiple health service encounters, unnecessary investigation and poor quality of life. In addition, there is emerging evidence that there is a substantial overlap between hEDS and POTS, suggesting common mechanisms related to abnormalities in the connective tissue, impaired autonomic function, vascular dysfunction, and neuroimmune interactions. These disorders are widespread and have a significant disability burden, but are underrepresented in public health policies and in healthcare planning. This review discusses the epidemiology of hEDS and POTS, the consequences of delayed diagnosis, their impact on healthcare systems, and emerging strategies to improve early recognition, multidisciplinary care, and health policy responses.

Keywords: Hypermobile Ehlers-Danlos syndrome, Postural Orthostatic Tachycardia Syndrome, Public Health, Diagnostic Delay, Dysautonomia, Healthcare Utilization

1. INTRODUCTION

The most commonly occurring subtype of Ehlers-Danlos syndromes (EDS) is hypermobile EDS, defined by generalized hypermobility of joints, musculoskeletal pain, connective tissue fragility, and systemic effects involving multiple organ systems (Malfait et al. 2020). In contrast to the other subtypes of EDS, hEDS does not have a definitive molecular diagnostic marker yet, and currently relies on the clinical diagnostic criteria set in 2017. Hypermobile Ehlers-Danlos syndrome (hEDS) is a rare, inherited connective tissue disorder that involves generalized joint hypermobility plus classic musculoskeletal and systemic features. There is no definitive molecular diagnostic test for hEDS and uses the 2017 international criteria to make a clinical diagnosis. Do not consider generalized joint hypermobility the same as hEDS. The hypermobility spectrum disorders (HSD) are a group of conditions that individuals

with a hypermobility phenotype may be included in, if they don't meet the criteria for other connective-tissue disorders like hEDS (Malfait et al. 2017).

Postural orthostatic tachycardia syndrome (POTS) is an orthostatic intolerance syndrome which is a persistent condition of excessive sustained heart rate elevation. Current consensus guidelines recommend ≥ 30 bpm increase after standing or head-up tilting in adults, and ≥ 40 bpm increase in adolescents (12 – 19 years). There should not be a large drop in blood pressure upon standing up, and other causes of sinus tachycardia should be ruled out. Symptoms include dizziness, palpitations, fatigue, reduced exercise capacity, mental changes, and gastrointestinal (GI) symptoms (Olshansky et al. 2020).
Between 30-60% of patients with hEDS have autonomic dysfunction, and a large number of people who are diagnosed with POTS also meet criteria for generalized joint hypermobility and/or hEDS. These concurrent disorders often cause persistent disability, which is not well-known in healthcare systems (Novak et al. 2025).

The impact on public health is not just on people's morbidity but also on delayed diagnosis, healthcare costs, loss of productivity, mental health issues, and access to specialist care.

2. METHODOLOGY

The published data related to the epidemiology, delay in diagnosis, health system use, quality of life burden, economic burden and health system implications of hypermobile Ehlers-Danlos syndrome (hEDS) and postural orthostatic tachycardia syndrome (POTS) were reviewed. Literature searches were completed in databases actually searched, such as PubMed/MEDLINE, Scopus, Web of Science and Google Scholar and the relevant literature was retrieved. The following keywords were searched alone and in combination: Hypermobile Ehlers-Danlos syndrome, hEDS, hypermobility spectrum disorder, HSD, postural orthostatic tachycardia syndrome, POTS, prevalence, epidemiology, diagnostic delay, misdiagnosis, healthcare utilization, quality of life, economic burden, healthcare costs, multidisciplinary care and autonomic dysfunction. Studies were included if they focused on any of the hEDS, HSD, POTS or clinically relevant intersections of these patient populations and included data relevant to the central themes of this review. Clinical guidelines, consensus statements, systematic and narrative reviews, epidemiological studies, cohort studies, cross sectional studies and other relevant primary clinical research were taken into account. Studies that did not offer evidence relevant to the questions for the review, only addressed unrelated EDS subtypes, or did not provide enough information to support the claims for review were excluded. Initially, titles and abstracts were evaluated for relevance and then the full text of potentially relevant studies was examined. There is particular emphasis on consensus guidelines, population-based epidemiological studies, systematic reviews and larger condition specific studies. As this was a narrative and not a systematic review, no formal meta-analysis of the literature and quantitative risk of bias assessment was undertaken. If the evidence is not available, the fact that the evidence was limited is explicitly mentioned in the manuscript and conclusions are drawn in a cautious manner.

3. THE EPIDEMIOLOGY AND POPULATION BURDEN

The epidemiological estimates for hEDS, HSD, generalized joint hypermobility and POTS should be considered separately as they are separate clinical entities and have not been assessed on a one-size-fits-all basis across populations. Generalized joint hypermobility is a physical trait, and is not a diagnosis of hEDS or HSD. While hEDS is a defined clinical disorder diagnosed by specific criteria, HSD refers to symptomatic hypermobility that does not meet the criteria to diagnose hEDS or any other specific connective tissue disorder (Miller et al. 2020).

The numbers of individuals with hEDS alone are not known at the population level, as the diagnostic classification and the ways in which hEDS is ascertained have evolved over time. A national study of electronic health-records in Wales reported that the prevalence of Ehlers-Danlos syndrome and joint hypermobility syndrome in people who were diagnosed with either condition or both was about 194 per 100,000, a figure suggesting that these disorders may be more common than previously thought. This estimate is not to be taken as a prevalence estimate for hEDS, however.

POTS is a unique disorder of orthostatic intolerance. The consensus literature has reported its prevalence to be around 0.2%, but these figures vary depending on population, the approach used to diagnose it and the clinical setting. POTS is more common in women and often starts during adolescence or early adulthood. It is important to note that there are patients with both hEDS/HSD and POTS, but clinical overlap does not necessarily imply a prevalence of both disorders among patients (National Academies of Sciences et al. 2022).

4. CLINICAL OVERLAP BETWEEN HEDS AND POTS

There is a clinically significant relationship between hEDS/HSD and POTS, especially in specialist and referral cohorts. Higher levels of generalized joint hypermobility and hEDS have been found in patients with POTS compared to unselected populations. However, co-occurrence in the clinic does not imply one common pathophysiological mechanism.

There have been a number of proposed explanations for the association. Excessive venous pooling and impaired orthostatic vascular compensation may be a theoretical risk in select patients that have increased connective-tissue laxity. Other possibilities include autonomic neuropathy, changes in blood vessel regulation, relative hypovolemia and neuroimmune processes. However, at this time, there is no evidence that one mechanism is responsible for the correlation between hEDS/HSD and POTS in all people who have this type of disease.

It should be noted, however, that reported rates of overlap should be interpreted in the context of referral and ascertainment bias. Patients seen in specialist autonomic or connective-tissue clinics may be very different to the general population and shared clinical features, like fatigue or exercise intolerance, gastrointestinal symptoms, dizziness and functional impairment, may raise the chances of one condition

being studied after the other. Thus, population-based and longitudinal studies are needed to establish the strength and biological mechanisms of this association.

5. THE DIAGNOSTIC ODYSSEY

The most serious public health problem related to hEDS and POTS may be the long delay between onset of symptoms and diagnosis. Numerous patients have noted that several healthcare providers over the past several years did not provide a correct diagnosis. There have been published instances of diagnostic delays as long as 5+ years, especially for hEDS (Chaudhury et al. 2025).
Several factors contribute:

5.1 Lack of Awareness

Very little formal training is provided in primary care on connective tissue diseases or dysautonomia.

5.2 Heterogeneous Clinical Presentation

The symptoms include many organ systems such as cardiovascular, neurological, gastrointestinal, musculoskeletal, dermatological and psychiatric. The patient is therefore seen by several healthcare professionals in isolation.

5.3 Absence of Biomarkers

In contrast to vascular (vEDS) or classical EDS, there is no known genetic test for hEDS. Likewise, orthostatic testing of POTS is not regularly done in primary care and is not standardized.

5.4 Sex and Gender-Related Differences in Diagnostic Experience

EDS/HSD and POTS are reported more often in females in clinical groups. Data from large POTS surveys indicate that females may have longer diagnostic time than males and there are reports that many women feel their physical symptoms were first thought to be of a psychiatric or psychological nature. The observations may indicate possibilities for sex- and gender-related differences in healthcare encounters to influence diagnostic pathways. The data, however, do not definitively prove that gender bias is responsible for all delays or misdiagnoses, especially those in hEDS, and additional studies are needed to differentiate between biological sex differences, referral practices, access to health care, clinician awareness, and diagnostic bias (Petrucci-Nelson et al. 2025).

6. CONSEQUENCES OF DELAYED DIAGNOSIS

The delayed diagnosis has significant clinical and public health implications.

6.1. Increased Healthcare Utilization

When a diagnosis remains unclear, there can be multiple interactions with primary care, emergency care, and various medical specialties before it is reached. There is stronger evidence for the diagnosis of POTS

in cases of specific conditions. Patient surveys have shown that the diagnostic process can be long and tedious, with numerous consultations with physicians and visits to the emergency department before POTS is identified, and many misdiagnoses occurring before it is actually diagnosed. Healthcare utilization studies of EDS and HSD patients, also indicate significant contact with various parts of the health care system. Nevertheless, the frequency of individual investigations (MRI, CT, echocardiogram, endoscopy, neurological testing) has not been adequately documented in both the hEDS and POTS populations to discern that these are routinely and inexplicably repeated (Rauterberg et al. 2025).

6.2. Potential for Misdiagnosis and Inappropriate Management

Patients could be treated for other reasons for their symptoms before a correct diagnosis is made. A significant number of patients in the large community-based POTS survey had been misdiagnosed with other conditions, and many had been misdiagnosed as having psychiatric or psychological illness. These results illustrate the possible implications of under-diagnosis of autonomic disorders. There is still a lack of evidence, however, that undiagnosed hEDS or POTS often results in extended opioid use, unnecessary surgery or other particular inappropriate treatments. These effects should therefore not be seen as a proven part of the diagnostic process but as potential effects that may occur in cases of diagnostic uncertainty. (Neuman, Bateman, and Wunsch 2019).

6.3. Consequences of Prolonged Symptoms and Delayed Recognition

When no opportunities for proper recognition occur, symptoms may persist, be physically deconditioned, experience chronic pain, physical activity may be decreased, and functional disability may be experienced. Earlier recognition can help implement condition-appropriate management strategies, such as graded or condition-specific physical rehabilitation, fluid/salt management (as needed), compression garments and physical therapy. There are, however, limited data to support the idea that diagnostic delay is a direct driver of the progression of biological disease, and/or that early diagnosis independently changes the long-term disease trajectory in hEDS or POTS (Lau et al. 2026).

7. HEALTH-RELATED QUALITY OF LIFE

Patients often suffer from disabling deficits in several areas. Common limitations include: Failure to retain a job position, educational disruption, reduced social participation, impaired mobility, exercise intolerance, sleep disturbances, chronic fatigue. The impact on mental health will be: anxiety, depression, social isolation, reduced self-esteem. Importantly, these psychological effects may develop as a secondary consequence of chronic physical disease and diagnostic uncertainty, and not be a primary psychiatric illness. Additionally, hEDS and POTS can be linked to significant impairments in functioning in everyday life. Patients may have limited mobility, fatigue, exercise intolerance, sleep disturbance, chronic pain, less social interaction and challenges to full engagement with education or employment, depending on the severity of the disease. These disorders may be associated with psychological distress (anxiety or depression symptoms) or be affected by chronic symptoms, functional limitations, diagnostic uncertainty, and extended health care experiences. Physical signs should therefore not be considered as a psychiatric

symptom and should be evaluated accordingly. There is a need for further condition-specific longitudinal studies to establish the relationship between diagnostic delay, severity of the disease and the psychological and quality-of-life effects of treatment. (Grigoriou, Boris, and Dormans 2015).

8. ECONOMIC BURDEN

Three general categories of economic burden can be used to consider the economic impact of hEDS and POTS: direct health costs, indirect costs, and intangible burden. Direct costs can involve consultations, diagnostic investigations, emergency and hospital treatment, rehabilitation, medications, and continued specialist treatment. There is some evidence that patients with Ehlers-Danlos syndromes may have significant personal and health care costs but there are few studies specifically focussing on hEDS patients.

Potential indirect costs include lost work, lost occupational activity, disability changes in employment and unpaid care giving. With extreme symptoms in adolescence or early adulthood, there's also potential for disruption to education or for a decrease in future earning power, but these impacts have not been well documented in studies of the economic consequences of the condition, and these studies are condition-specific so the impacts of severe symptoms in adolescence and early adulthood are not well quantified.

The third component is the significant intangible costs related to chronic pain, fatigue, limited mobility, loss of independence and a compromised health-related quality of life. These consequences are significant for the patients, but are not always sufficiently conveyed by direct monetary appraisal. In general, health-economic data on POTS and hEDS are limited and additional longitudinal studies are needed to quantify direct health care costs, loss of productivity, burden on caregivers, and overall societal costs (Schubart et al. 2024).

9. HEALTH SYSTEM CHALLENGES

There are multiple barriers that are being faced by healthcare systems across the globe. There is often a lack of coordination within patients moving between cardiology, neurology, rheumatology, gastroenterology, psychiatric and pain medicine, and physiotherapy. The number of autonomic clinics is limited and is not sufficient to avoid the long wait. Variation exists in diagnostic pathways, treatment protocols, and referral practices. Better recognition in primary care may help to ensure better referrals and help minimise unnecessary health services contacts and investigations. But it is not yet proven that earlier recognition decreases the overall health care cost (Daylor et al. 2025).

10. PUBLIC HEALTH STRATEGIES

Addressing these disorders requires a systems-level approach.

10.1 Physician Education

Medical curricula should include connective tissue disorders, autonomic nervous system disorders, and recognition of multisystem disease (Cheshire and Goldstein 2018).

10.2 Screening Pathways

Simple tools such as the Beighton score, orthostatic vital signs, and standing heart rate measurements could facilitate earlier identification (Forghani, See, and McGonigle 2025).

10.3 Multidisciplinary and Interdisciplinary Care

Multidisciplinary care is a potential strategy for decreasing fragmented care and is a viable model for hEDS and POTS due to the involvement of multiple organ systems. Primary care physicians, cardiac or autonomic specialists, rheumatology services or genetics services, physiotherapists, occupational therapists, pain specialists, psychologists and others may be involved in the care of the patient depending on individual clinical needs. There are a few small studies that have explored interdisciplinary rehabilitation in adolescents with POTS and patients with hEDS/HSD, and have shown positive changes in functional disability and psychological and/or physical outcomes. Evidence of the effectiveness of multidisciplinary clinics in improving long-term outcomes or reducing utilization of health services, however, is relatively weak, with specific evidence of this benefit remaining inconsistent. Larger prospective studies are thus needed.

10.4 Patient Education

Structured educational programmes improve treatment adherence, self-management, symptom recognition, and quality of life.

10.5 Digital Health and emerging technologies

Digital technologies have the possibility of enhancing the process of longitudinal assessment and disease management in the future. Patient and clinician data of physiological trends and symptom-related changes over time can be recorded using wearable devices that measure heart rate and activity. However, there is not enough evidence yet to support their use as a routine diagnostic test to increase the accuracy or the timing of the diagnosis of POTS.

AI or machine-learning algorithms could eventually help uncover patterns in the longitudinal EHR or multiple systems symptoms that could benefit from further investigation. In the current state of affairs, however, the use of artificial intelligence to identify hEDS or POTS is not a clinical or public health approved tool, but a research opportunity. Further prospective analyses are needed before these

technologies are integrated into routine pathways to assess their diagnostic accuracy, generalizability, clinical utility, bias, and cost-effectiveness (Forghani, See, and McGonigle 2025).

11. FUTURE DIRECTIONS

Several priorities remain. Better epidemiological research is required to make accurate global prevalence estimates. Second, if markers of hEDS could be found, these markers would be objective markers for diagnosing hEDS and greatly enhance early recognition. Thirdly, longitudinal health-economic studies should provide the numbers on the cost to society of delayed diagnosis. Lastly, implementation research is needed to determine if multidisciplinary care models decrease healthcare utilization and increase patient outcomes.

12. LIMITATIONS

The results of this review should be interpreted with caution given to several limitations. First, prevalence and clinical burden estimates have changed over time as the definition of hEDS and HSD have changed and are not used consistently across studies and/or health care systems. Epidemiological studies are limited, and there are no population-based studies for hEDS or for hEDS/HSD. Second, most of the available evidence comes from observational studies, the specialist clinics, patient questionnaires or referral populations, leading to ascertainment, referral and selection bias. Results from these groups may not be applicable to the broader groups of people who have these conditions.

Thirdly, hEDS and HSD are sometimes included in the same published cohorts as different diagnostic categories, making comparisons and interpretation between different studies difficult. Like hEDS/HSD and POTS, no causal or common biological pathway has been demonstrated between the two conditions. Fourth, the literature on health economics is still limited, especially on indirect costs, caregiver burden, education impacts and long-term productivity. Lastly, the patho-physiology, diagnosis and management of hEDS and POTS is rapidly evolving. These limitations should be taken into account when interpreting conclusions about disease burden and the best models of care and should be revised as new, more reliable population-based and longitudinal data emerges.

13. CONCLUSION

Hypermobile Ehlers-Danlos syndrome and postural orthostatic tachycardia syndrome are emerging clinical syndromes to consider and may have significant multisystem symptoms, functional impairment and complex health care needs. Both disorders are often found together in some clinical populations but they are separate disorders and the biological mechanisms in the association are not completely understood.

There is existing evidence that patients, especially POTS patients, may have a long and complex diagnostic journey, multiple health service encounters, and may have been misdiagnosed. The impact of diagnosis timing on the long-term disease course, the indirect economic effects, and the burden of the disease on the population are less well quantified, however. Thus, statements from these results should be taken with a grain of salt.

Better clinician awareness, using consistent diagnostic criteria, making timely referrals, managing symptoms on an individual basis and ensuring multidisciplinary care are undertaken may enhance both patient experience and functional outcomes. Prospective validation is needed for emerging technologies, including wearable monitoring and AI, to be used for assessment and care. Longitudinal population-based and health-economic studies are needed in the future to more precisely characterize the burden of hEDS and POTS to define the models of early recognition and coordinated care that offer meaningful clinical and health systems benefit.

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