Beyond Joint Hypermobility: Investigating Bladder Dysfunction in Hypermobile Ehlers-Danlos Syndrome

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Background and Objective: Hypermobile Ehlers-Danlos Syndrome (hEDS) is the most common subtype of Ehlers-Danlos Syndromes, a group of heritable connective tissue disorders caused by collagen abnormalities. While musculoskeletal features of hEDS are well documented, its impact on visceral organs, including the bladder, remains underexplored. Despite frequent patient reports of urinary symptoms, a definitive link between hEDS and bladder pathology has not been established. This study aims to characterize lower urinary tract symptoms (LUTS) and urodynamic (UDS) findings in patients with hEDS to better understand potential mechanisms underlying bladder dysfunction in this population.

Methods: A retrospective chart review was conducted on patients with hEDS who underwent video UDS at a single tertiary-care center between 2022-2025. Inclusion criteria included age >18 years, confirmed hEDS diagnosis (2017 criteria), and completed UDS. Data were analyzed using Welch's t-test and Fisher's Exact Test.

Results: Among 27 patients, the mean age at hEDS diagnosis was 30.9 years (range 18-49), 92.6% (n=25) were female, and 92.6% (n=25) were white. Common LUTS seen in these patients included urinary frequency in 74.1% (n=20), urinary incontinence in 14.8% (n=4), frequent urinary tract infections in 25.9% (n=7), bladder pain in 33.3%(n=9), nocturia in 48.1%(n=13), and weak urinary stream in 51.8% (n=14) of patients. UDS findings revealed no evidence of detrusor overactivity, stress urinary incontinence, abnormalities in bladder compliance, or incomplete bladder emptying. Pelvic floor dysfunction was seen in 18.5% (n=5) with active EMG noted during emptying. Pelvic floor physical therapy was the most common intervention recommended, followed by beta-3 agonists for overactive bladder symptoms.

Conclusion: Our study shows that LUTS are prevalent in patients with hEDS, with findings suggesting pelvic floor and muscular dysfunction as primary contributors rather than classic bladder pathology. These results support a pelvic floor-focused approach to evaluation and management in hEDS patients.