Orthopaedic Manifestations in Ehlers-Danlos Syndromes

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INTRODUCTION: The Ehlers-Danlos Syndromes (EDS) is a collagen disorder that affects multiple organ systems, including the musculoskeletal system. It is crucial to understand the scope and burden of disease for any clinician providing healthcare for patients with EDS. With increasing education and awareness of EDS in recent years, we sought to determine the type and severity of orthopedic manifestations experienced by patients with EDS. The purpose of this study is to identify the most common orthopaedic manifestations in EDS patients and to examine the patient reported helpfulness for conservative and operative treatment modalities. It is important to note that collagen disorders, such as EDS, may affect the success rates of orthopedic intervention. Understanding the success or failure of treatment is not currently fully understood for this patient population.

METHODS: 1999 patients enrolled in an international EDS registry were contacted to complete a 260-question survey regarding their experience with both conservative and operative treatments for joint instability and/or pain. Participants were asked to report demographic variables, EDS diagnosis characteristics, symptomatic joints, conservative and operative treatments utilized, and their satisfaction with each treatment.

RESULTS: Over a 30-day period, 1096 responses were received. Participants were predominately female (95%), diagnosed with Hypermobile EDS (98%), and on average 40.9 years old (range: 18 to 77) at time of survey. The majority reported having their mental health affected by their musculoskeletal health every day (61%), followed by weekly (24%), monthly (11%), and never (4%). In comparison to those who underwent normal physical therapy (n=338), individuals who underwent physical therapy tailored to EDS (n= 610) more frequently reported that physical therapy improved posture (43% vs 79%; p <.001), greater helpfulness (p <0.001), and longer duration of attending physical therapy (p<0.001). 470 individuals who underwent at least one surgery for instability and/or pain reported 1174 primary and 273 revision operations. The reported complication rates were 36% and 39% for joint and spine surgeries, respectively.

DISCUSSION AND CONCLUSION: Patients with EDS represent a challenging patient population with multiple orthopaedic complaints that represent a chronic musculoskeletal disease burden for which additional research and treatments are necessary. EDS patients who undergo physical therapy for joint pain or instability may benefit from EDS tailored physical therapy in comparison to standard physical therapy. With more than 1000 survey participants, this new data should guide clinicians in treatment of musculoskeletal issues in EDS patients, as well as provide a threshold for further research in this area.

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