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Physician Perspectives Surrounding Hypermobile Ehlers-Danlos Syndrome

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Abstract

Background: Patients with hypermobile Ehlers-Danlos syndrome (hEDS) report difficulty obtaining a diagnosis and encountering health professionals who do not believe their experiences are related to their condition. This frustration affects the therapeutic relationship, leading to resentment, distrust, and hostility toward medical personnel on the part of patients. The purpose of this study is to evaluate the education and knowledge that clinicians have surrounding hEDS.

Methods: One hundred practicing orthopedists, rheumatologists, and geneticists were contacted via email to complete a confidential survey. The Patient-Practitioner Orientation Scale (PPOS) was administered, along with a set of questions relating to the diagnosis of hEDS and physician opinions surrounding the disorder. Answers were compared across physician type. Chi-square tests of proportions were used to compare hEDS knowledge by physician specialty and physician characteristics.

Results: No differences were observed in PPOS scores based on physician specialty. Orthopedic providers identified 35% of the comorbidities associated with hEDS, whereas rheumatologists identified 56%. No physician surveyed identified all associated comorbidities. Rheumatologists were more likely to believe that hEDS was overdiagnosed (58%) compared with orthopedists (17%). Overall, physicians' concerns centered on the limited treatment options for patients with hEDS and the unpredictability of surgical success in these patients.

Conclusions: Physician education focused on hEDS is lacking, but physicians as a whole want to learn more about the condition, highlighting the need for more clinical research to better understand the disease. Better-informed physicians will reduce the burden on patients and help re-establish patient-physician trust.

Categories: Rheumatology, Orthopedics
Keywords: ehlers-danlos syndrome, hypermobility, orthopedics, patient-practitioner orientation scale, rheumatology

Introduction

Hypermobile Ehlers-Danlos syndrome (hEDS) is a clinically variable and likely genetically heterogeneous hereditary connective tissue disorder characterized by joint hypermobility, tissue fragility, and connective tissue fragility [1]. For many patients, the prominent complaint is pain due to abnormal joint mechanics, which is often widespread and long-lasting [2]. Patients also present with a high rate of concomitant fatigue, headaches, autonomic issues, anxiety, gastrointestinal, and genitourinary complaints [3-7]. These symptoms significantly impact the quality of life of patients with hEDS [7]. Although hEDS is not curable, timely diagnosis, appropriate treatment, and symptom management can improve patients' quality of life [4].

The prevalence of these disorders in the British population, where hEDS has been more universally recognized, is estimated to be about 3%. This is a significant incidence rate, but the true incidence is likely much higher because the disorder is considered underdiagnosed due to its highly variable clinical presentation [5] and inadequate provider education [3,8], especially regarding its presentation in teens and older adults. While tests such as the Beighton scale and the 2017 International Classification criteria can assist with diagnosis, the disorder as a whole is often overlooked by providers, particularly in adult patients [5].

The initial phase of Ehlers-Danlos Syndrome (EDS) management involves clinical assessment and classification according to the current criteria available to providers. Many patients report difficulty with obtaining a diagnosis and encounter healthcare professionals who do not acknowledge their experiences with hypermobility [9], causing significant frustration [8]. This lack of knowledge among providers negatively impacts the therapeutic relationship, resulting in patient resentment, distrust, and hostility toward medical personnel [3]. This, in turn, contributes to the patient's psychosocial burden [1]. Strong patient-centered care has been associated with a range of positive outcomes, including increased patient satisfaction and medication adherence [10].

To facilitate effective treatment, a correct diagnosis is crucial, especially in the case of hEDS, the most common form of EDS [9]. Recent epidemiologic studies of hEDS in Wales have estimated its incidence to be approximately 1 in 500 people, far surpassing previous estimates [11]. Currently, hEDS remains a clinical diagnosis based on clinical presentation, family history, and the exclusion of similar disorders, as no consistent biological or genetic markers have been identified [1-3,7]. Unfortunately, patients with hEDS do not typically seek evaluation by a geneticist as their first point of contact [6]. Instead, they may initially consult a primary care provider, rheumatologist, or orthopedist.

Treatment for patients with hEDS is often multifactorial, involving physicians from many subspecialties. However, treatment recommendations for physicians are also lacking, with limited evidence data and few clinical practice guidelines available [1]. Unfortunately, this lack of guidelines may cause physicians to experience feelings of frustration, helplessness, and even failure as they attempt to treat these patients [12]. The development of evidence-based recommendations for the assessment and management of these disorders is crucial for improving patient health [1] and physician perceptions of their ability to treat patients with this disease [12].

The primary purpose of this study is to determine the level of education and knowledge that orthopedic surgeons and rheumatologists have surrounding hEDS.

Materials And Methods

This study is a multicenter, cross-sectional study conducted to understand the education and knowledge of clinicians with respect to hEDS. Institutional Review Board approval was obtained (HHC-2021-0242). Rheumatologists, geneticists, and orthopedists practicing at the Bone and Joint Institute and surrounding hospitals in Connecticut were contacted via email to complete a confidential survey using the secure web platform REDCap (Vanderbilt University, Nashville, Tennessee). There were 100 physicians available to be contacted. After providing consent, the Patient-Practitioner Orientation Scale (PPOS) (Appendices) [10] was administered, along with a set of questions relating to hEDS (Table *1*). In order to use the PPOS, permission was granted by Ed Krupat [10]. The questions regarding hEDS were divided into three parts: (1) provider demographics, (2) knowledge of diagnostic criteria for Ehlers-Danlos/hypermobility disorders, and (3) opinions on treating patients with Ehlers-Danlos/hypermobility disorders. These broad topics are similar to those examined by Vasant et al. and Hermanowicz et al., both of whom administered surveys to physicians to elucidate their opinions on disease management [13,14].

Demographics
1. How old are you? (Under 30, 30-40, 41-50, 51-60, above 60)
2. What is your gender? (Male/Female/Other/Prefer not to say)
3. What is your race/ethnicity? (American Indian or Alaska Native/Asian/Black/Hispanic/White/Multiple/Prefer not to say)
4. What year did you graduate from medical school? (Number input)
5. What is your specialty? (Fellow/Orthopedics/Rheumatology/Genetics/Other)
6. What is your primary practice location (HHCMG/OAH/CCMC/Other)
7. On average, how many patients do you see in clinic per week? (Number input)
8. What percentage of your time is spent on direct patient care? (50-66%, 67-84%, 85%+)
9. Type of practice (solo practice, small group practice, multispecialty group practice, HMO, preferred provider)
Knowledge
1. Do you remember learning about collagen disorders like Marfan's/Ehlers-Danlos/Osteogenesis Imperfecta in medical school? (yes, no)
1a. If yes, how much time was devoted to this disorder? (part of 1 class, 1 class, more than 1 class)
2. Do you have a special interest in the collagen disorders? (yes, no)
3. How often do you see patients with hypermobility in your practice currently? (daily, weekly, monthly, less than monthly)
4. How often do you see patients with Ehlers-Danlos Syndrome in your practice currently? (daily, weekly, monthly, less than monthly)
5. Do you think you are seeing more patients with these conditions now than you did when you started your practice? (yes, no)
6. How would you rate your knowledge of Ehlers-Danlos Syndrome? VAS 1-5 - 1) Highly Knowledgeable □ 5) No knowledge)
7. Are you familiar with the Beighton Scale, and do you feel comfortable administering it in your office? (yes, no)
8. What co-morbidities of Ehlers-Danlos Syndrome are you familiar with? (Check all: POTS/Dysautonomia, Mast Cell Activation Disorder, Aortic Dilation, Hollow Organ Rupture, Dental Issues, Dysmenorrhea, Pectus Excavatum)
9. What other manifestations are you familiar with? (Check all: Atrophic Scarring, Piezogenic Papules, Marfanoid Habitus, Myopia, Soft Tissue Lesions, Varicose Veins)
Opinion
1. Do you feel comfortable in diagnosing someone with Ehlers-Danlos Syndrome? VAS 1-5 - 1) Highly Knowledgeable □ 5) No knowledge
2. Do you feel comfortable treating someone with Ehlers-Danlos Syndrome? VAS 1-5 - 1) Highly Knowledgeable □ 5) No knowledge
3. What is the most challenging aspect of treating Ehlers-Danlos patients? (text box)
4. Do you think Ehlers-Danlos Syndrome is overdiagnosed or underdiagnosed? (Choice)
5. In your opinion, are Ehlers-Danlos patients difficult to treat? (yes, no) If yes, please explain why. (text box)
6. Would you be interested in attending a lecture to learn more about Ehlers-Danlos/Hypermobility Syndromes? (yes, no)
7. Would you be interested in a 1:1 interview (non-blinded) to discuss your opinions on Ehlers-Danlos/Hypermobility Syndromes? (yes, no)

TABLE 1: Questions asked to physicians on hypermobile Ehlers-Danlos syndrome (hEDS)

HHCMG: Hartford Healthcare Medical Group; OAH: Orthopedic Associates of Hartford; CCMC: Connecticut Children's Medical Center; POTS: Postural Orthostatic Tachycardia Syndrome; VAS: Visual Analogue Scale; EDS: Ehlers-Danlos Syndrome.

Knowledge of the diagnostic criteria for hEDS was based on the 2017 International Classification criteria. Each comorbidity listed within the criteria was assessed through a discrete question (knowledge subsection, questions 8 and 9). Perceived knowledge was determined from question 6 of the knowledge subsection.

Physicians were also provided with a downloadable copy of the 2017 International Classification criteria by

the Ehlers-Danlos Society after completion of the surveys, if interested.

Chi-square tests of proportions were used to compare knowledge of hEDS across different physician specialties and physician characteristics (e.g., age group, graduation decade, type of practice, etc.). Demographics were examined as categorical data and compared using chi-square tests. For demographic questions that are number inputs, categorical cutoffs were created. For responses in which ordinal data were collected (0-5 or 1-5 scale), the numbers were treated statistically as categorical data. For the comparison of multiple categorical variables, contingency tests were used. Student's t-tests were used to compare two groups of continuous data, and ANOVA tests were used to compare three groups, such as comparisons among subspecialties for questions regarding comorbidities.

For opinion questions for which responses could not be divided into categories, such as the most challenging aspect of treating patients with EDS or whether physicians find patients with EDS difficult to treat, the responses were manually evaluated to determine whether any patterns emerged in the text. Common responses were further characterized as categorical values.

All analyses were conducted using Microsoft Excel 2016 (Microsoft, Redmond, Washington) or Stata version 17 (StataCorp, College Station, Texas). All results with $p < 0.05$ were deemed statistically significant.

Results

Self-reported demographics of the physician population are shown in Table 2. Seventy percent (n = 18) of the physicians surveyed expressed a desire to learn more about hEDS.

Study demographics	n = 26
Specialty	
Orthopedics	50% (n = 13)
Rheumatology	35% (n = 9)
Other	15% (n = 4)
Gender	
Male	73% (n = 19)
Female	27% (n = 7)
Age range	
Under 30 years	4% (n = 1)
30-40 years	31% (n = 8)
41-50 years	23% (n = 6)
51-60 years	27% (n = 7)
Older than 60 years	15% (n = 4)
Race/Ethnicity	
White	84% (n = 22)
Asian	8% (n = 2)
Prefer not to say	8% (n = 2)

TABLE 2: Demographics of the provider pool

Data are represented as a percentage of the total, with the number of participants reported in each group in parentheses after the percentage.

No significant differences were observed with PPOS scores based on physician specialty (total score, p = 0.408, f-value). All physicians surveyed had similar total scores, as well as caring (p = 0.299, f-value) and sharing subscale scores (p = 0.645, f-value) (Figure 1).

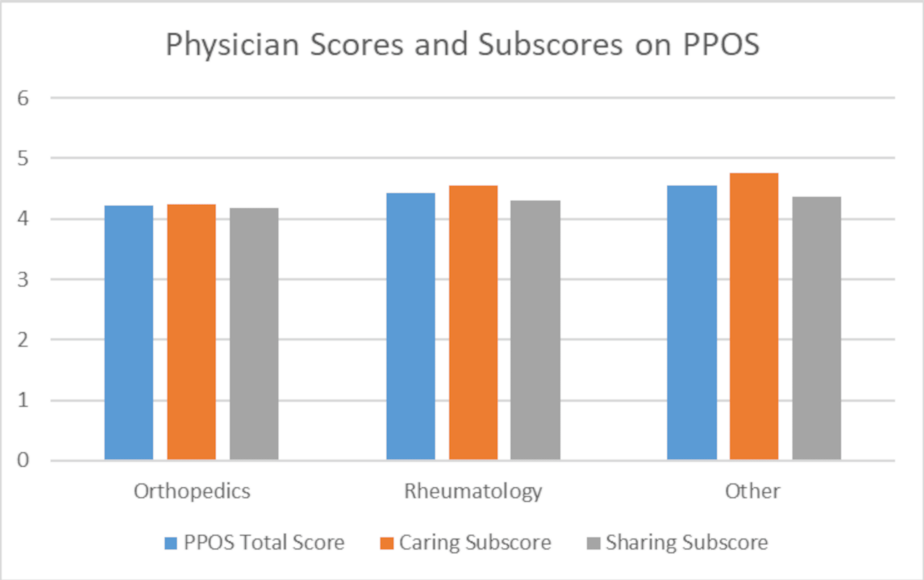


FIGURE 1: Physician scores and subscores as evaluated with the Patient-Practitioner Orientation Scale (PPOS)

Bar graphs showing physician scores and subscores (sharing and caring domains) for the PPOS are not statistically significantly different among orthopedic, rheumatologic, and other subspecialty providers. No one subspecialty showed a significantly higher total or subscore, with $p < 0.05$ considered to be statistically significant.

PPOS: Patient-Practitioner Orientation Scale.

Differences were observed among physician specialties in the identification of comorbidities associated with hEDS (knowledge subsection questions 8 and 9). Orthopedic providers identified 35% of the comorbidities associated with hEDS, whereas rheumatologists identified 56% ($p = 0.009$, t-value). No physician surveyed identified all comorbidities included in the 2017 International Classification. The most frequently identified comorbidities were aortic dilation and easy bruising. The least frequently identified comorbidites were piezogenic papules and dental overcrowding (Figure *2*).

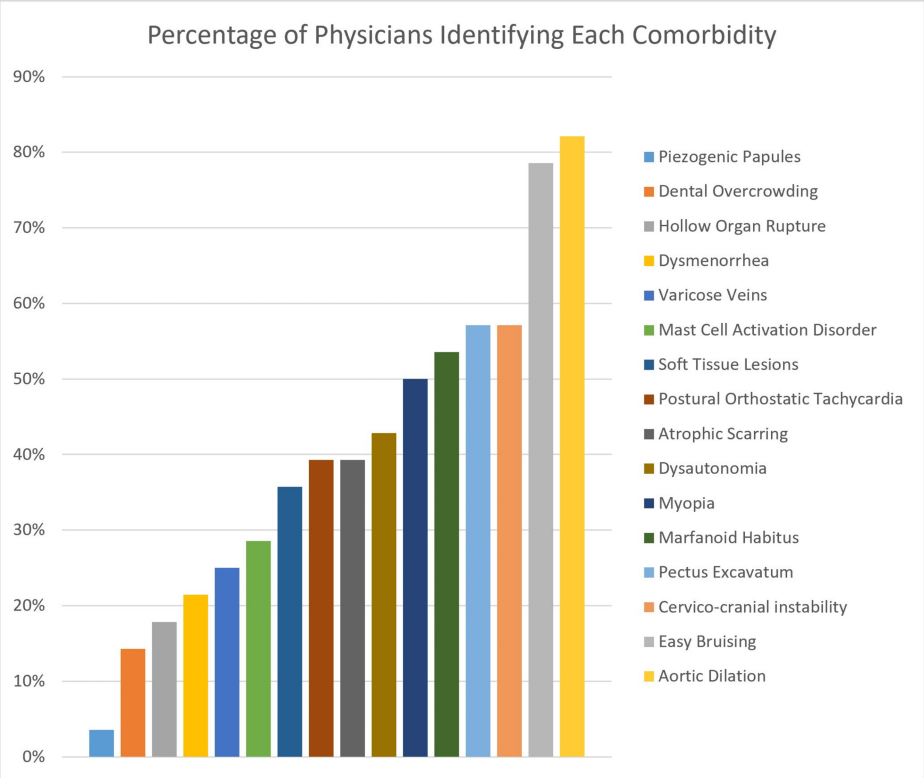


FIGURE 2: Percentage of physicians identifying comorbidities associated with Ehlers-Danlos Syndrome (EDS) (clinical diagnosis score)

Bar graph showing all comorbidities listed for EDS, as defined by the 2017 International Classification criteria. The percentage of physicians identifying each comorbidity is listed on the y-axis. The most common comorbidities identified by the physicians in our cohort are aortic dilation and easy bruising with about 80% (n = 20 or 21) of physicians identifying these conditions. The least common comorbidity identified is piezogenic papules, at 4% (n = 1).

EDS: Ehlers-Danlos Syndrome.

Orthopedists reported greater perceived knowledge of hEDS (Table *1*, knowledge subsection, question 6) but were less likely to identify all the comorbidities associated with hEDS. Rheumatologists had a lower perceived knowledge subscore but scored higher on the identification of clinical criteria and comorbidities (Figure *3*).

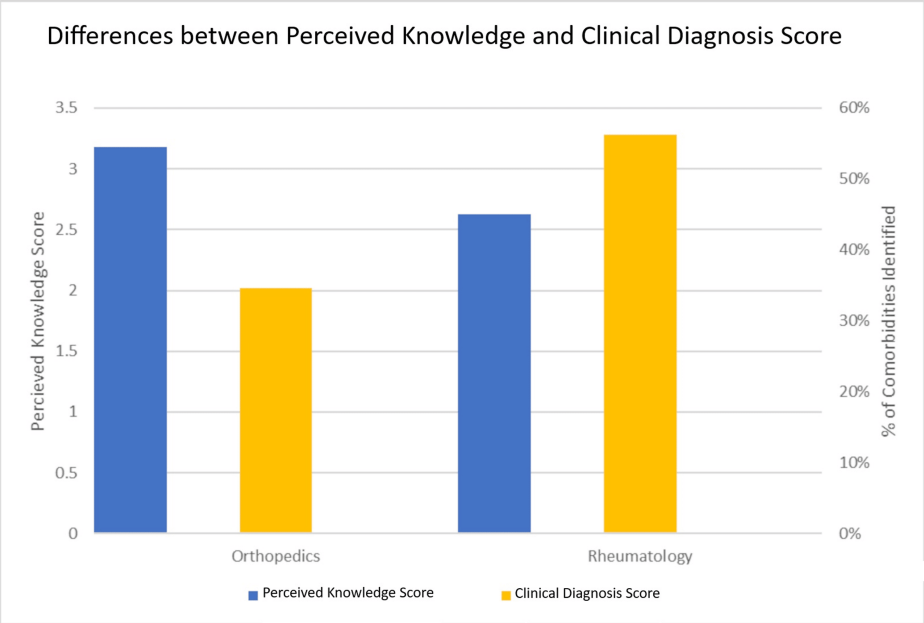


FIGURE 3: Comparison of clinical knowledge and perceived knowledge

Bar graph comparing the perceived knowledge score (blue), which shows how physicians rank their personal knowledge of hEDS, with the percentage of comorbidities identified (yellow), also called the clinical diagnosis score, which serves as a correlative measure of actual knowledge of the condition. Orthopedists have higher perceived knowledge compared to the percentage of comorbidities identified, whereas rheumatologists identified more comorbidities but did not feel their knowledge of the condition was as accurate.

hEDS: hypermobile Ehlers-Danlos syndrome.

Rheumatologists were more likely to believe that hEDS was overdiagnosed (56%, n = 5) compared with orthopedists (15%, n = 2) (Figure *4*). Overall, physicians' concerns with treating this population stemmed from the limited treatment options for patients with hEDS and the fact that surgical success in these patients was variable and unpredictable. A majority (85%, n = 22) of providers found hEDS difficult to treat.

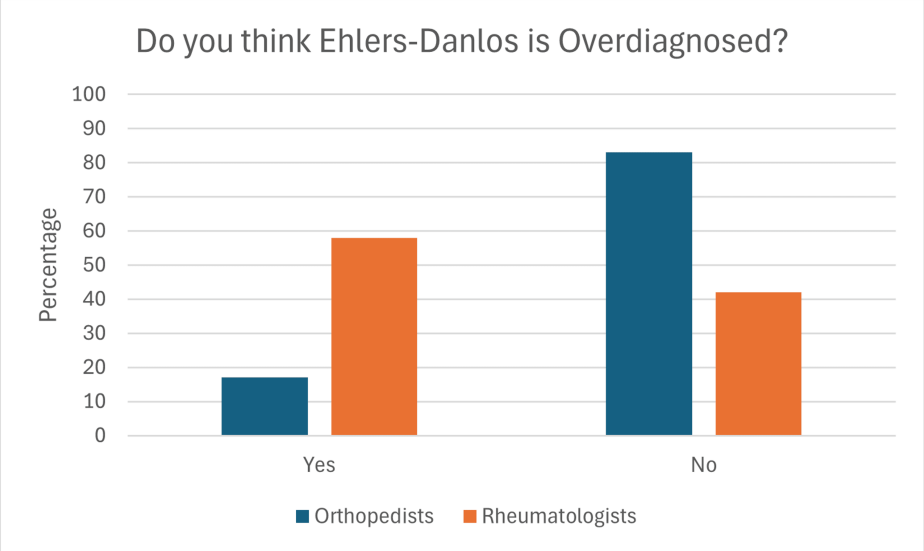


FIGURE 4: Physician opinion on the accuracy of EDS diagnosis by specialty

Bar graph showing the percentage of each specialty that feel that EDS is overdiagnosed. Blue bars represent orthopedists. Orange bars represent rheumatologists.

EDS: Ehlers-Danlos Syndrome.

Discussion

This study aimed to evaluate medical providers' perceptions and knowledge of hEDS for the purpose of improving patient care as it relates to the care continuum of those afflicted with the condition. Patients exhibiting symptoms of connective tissue conditions may be dismissed by multiple specialists in their efforts to get a diagnosis, leading to significant frustration. While hEDS does not have a single gene hallmark, some patients are asked to perform expensive genetic panels, which may not be covered by insurance, in order to receive the diagnosis of hEDS and rule out other disorders or EDS subtypes.

In addition to the barriers and challenges faced by patients to receive a proper diagnosis, misdiagnosis of hEDS is a growing concern as well. Suboptimal access to care for patients dealing with hEDS prompts the need for physicians to gain more expertise in diagnosing and managing these patients. The findings of our study revealed that a significant portion of physicians expressed a desire to acquire more knowledge about hEDS. Interestingly, orthopedists had a higher perceived knowledge of EDS than rheumatologists but demonstrated less aptitude in identifying hEDS comorbidities. As expected, physician concerns most commonly centered around the scarcity of treatment options and the futility of surgical interventions. To the authors' knowledge, this is the first study assessing physicians' perspectives on knowledge of hEDS and concerns regarding current treatment options.

The evidence-based framework that forms the basis of medical education does not encompass rare diseases like hEDS that lack sufficient data and knowledge [15]. This is unfortunate given that future physicians must develop the necessary skills to care for expanding populations of patients with rare and underrecognized conditions. As Domaradzki et al. report in one survey completed among medical students, 95.4% of respondents expressed doubts about whether they possessed sufficient knowledge about rare diseases, and almost 92.2% did not feel adequately prepared to care for rare disease patients [16]. In another survey, 46.6% of medical students and physician respondents believed that the medical curriculum should be supplemented with an additional rare disease course [17]. Additionally, recent evidence of the increased prevalence of hEDS provides an interesting perspective on rare disease classification and the importance of providing rare disease education in medical curricula. When conditions are misclassified as rare, often, their clinical presentations and comorbidities may not be emphasized in schooling, which may lead to further difficulty in the diagnosis and management of patients. Close to 70% of respondents expressed the desire to expand their training on hEDS. Collectively, these results demonstrate that additional medical education on rare and underrecognized conditions is wanted and warranted in selected populations.

Our study revealed notable discrepancies in comorbidity recognition between physicians of two different specialties, with rheumatologists displaying greater expertise in identifying hEDS symptoms (56%) compared to orthopedists (35%). Varying levels of knowledge on the topic of hEDS by different specialists may in part be due to their specific medical focus. The narrow scope of symptoms related to bones and joints

encountered by orthopedists on a daily basis represents a limited range of the comorbidities experienced by hEDS patients. In contrast, rheumatologists, who deal with the cardiovascular and gastrointestinal systems as well as autonomic functions, may possess a much broader understanding of the multisystemic hEDS symptoms. Rheumatologists are also better adept at diagnosing and managing other connective tissue disorders that share similarities with hEDS [18]. It is worth noting that for many hEDS patients, the first manifestations are often musculoskeletal in nature; therefore, they might see an orthopedist before the systemic aspects of the disease are apparent or bothersome enough for the patient to seek further treatment. Furthermore, it is possible that orthopedic specialists may have access to a referred cohort of hEDS patients who experience musculoskeletal manifestations severe enough to warrant a surgical consult, while many other hEDS patients may have their manifestations managed by their primary care team.

As for inconsistencies in perceived knowledge of hEDS comorbidities between orthopedists and rheumatologists, it is possible that confidence levels play a role. Meyer et al. reported that in one study, physicians presented with more difficult cases demonstrated increased levels of confidence and lower diagnostic accuracy, implying that overconfidence may hinder one's ability to recognize faulty diagnostic reasoning [19]. Given the complexity of hEDS cases, some medical professionals may be more susceptible to this phenomenon than others. Thus, increased knowledge about the consequences of diagnostic inaccuracy in hEDS patients, as well as improvement of education on hEDS for all specialties, could help to mitigate these risks. This could also partially be attributable to the Dunning-Kruger effect, a psychological phenomenon observed with specialists reporting less perceived knowledge when they are more experienced versus more perceived knowledge while they are less experienced in a particular subject [20]. In the context of medical care, orthopedists are a surgical subspecialty that may be less knowledgeable about the diagnostic criteria for hEDS and are less familiar with the symptomatology and comorbidities that constitute hEDS. Additionally, the diagnosis of hEDS can often be made prior to the orthopedic referral, and therefore, providers may not have a reason to further examine patients for diagnosis. For rheumatology, clinicians may manage many of the comorbidities as well and be familiar with the overlap of hEDS with other conditions. This may also explain why a higher percentage of rheumatologists surveyed in our study believed that hEDS is overdiagnosed (Figure *4*), as they encounter patients with presumed hEDS and approach the diagnosis more conservatively through utilization of their broad understanding of systemic hEDS manifestations.

Among the concerns listed by physicians in our survey, the most commonly reported apprehensions in 83% of respondents centered around limited treatment options available for hEDS patients, particularly with regard to surgical interventions due to the unpredictability of the outcomes. Successful surgery is contingent upon a correct diagnosis and realistic expectations. For patients suffering from painful joint instability or peripheral nerve compression, surgery may be warranted [21]. Unfortunately, hEDS patients undergoing surgery are vulnerable to bleeding complications, wider scars, and delayed healing, all of which contribute to a higher failure rate and decreased satisfaction [21]. Additionally, incorrect assumptions about the source of pain may result in unnecessary surgical interventions being performed in the first place. Limited and often unsuccessful treatment options for hEDS patients further denote the need for further awareness and education about hEDS [22].

Limitations

Although the study was effective in capturing physician perspectives on Ehlers-Danlos, there are several limitations that should be addressed. Firstly, the sample size is relatively small, with only 26 responses out of the 100 physicians surveyed locally. Therefore, these findings may not be generalizable to larger groups of medical professionals in other geographical regions. Additionally, the study failed to account for all physicians who engage with patients with hEDS and to differentiate between the levels of medical experience of the respondents. The study's reliance on self-reported data may have introduced bias, with respondents overestimating their knowledge of hEDS and providing more socially appropriate responses. A large percentage of physicians initially contacted did not respond, which may introduce non-response bias as well.

Given the high prevalence of hEDS, our results may also be heavily skewed toward the representation of physicians treating hEDS and less representative of treatment perspectives of the rare monogenic EDS variants. Furthermore, with a large portion of our providers being from rheumatology and orthopedics, our results may be best generalizable to providers of a certain cohort of hEDS patients that present with greater rheumatologic and orthopedic manifestations. Due to the small numbers, conclusions based on specialty may not be reproducible. Additionally, many providers may have their own ideas about what constitutes an EDS or hEDS diagnosis, and therefore, patient diagnosis based on clinical symptoms may vary by institution. With the vast heterogeneity of this condition, a greater number of specialties and stratification by EDS variants seen by physicians may be required to capture the full spectrum of EDS care and management. Additionally, the hEDS knowledge questionnaire was based on the 2017 International Classification criteria, which were given to physicians at the conclusion of the study. This document may not fully capture all patients suffering from hEDS, as not all hypermobility patients meet the classification. The use of this document may restrict the generalizability and interpretation of "physician knowledge" across specialties and settings.

With the locational restrictions of our study, we may have access to a regional cohort of hEDS patients that

may differ from those in other geographic locations and countries. Further studies replicated nationally and globally would provide greater insight into physician perspectives as well as the effects of regional education on management and diagnosis.

Conclusions

Physician education focused on hEDS is lacking, as evidenced by the desire of physicians in our cohort to learn more about the condition and specialty-related discrepancies in opinions on diagnosis and manifestations. This study highlights the need for further clinical research to improve physician understanding of the disease across specialties and to better elucidate differences among clinical specialties. Such education could enhance physician identification of comorbidities associated with hEDS, leading to increased identification in patients presenting to rheumatology and orthopedic subspecialties. Future studies will focus on evaluating the efficacy of the Continuing Medical Education program created to enhance physician knowledge, not just among orthopedists and rheumatologists but among all physicians.

Appendices

		Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
1	The doctor is the one who should decide what gets talked about during a visit.	O	O	O	O	O	O
2	Although health care is less personal these days, this is a small price to pay for medical advances.	O	O	O	O	O	O
3	The most important part of the standard medical visit is the physical exam.	O	O	O	O	O	O
4	It is often best for patients if they do not have a full explanation of their medical condition.	O	O	O	O	O	O
5	Patients should rely on their doctors' knowledge and not try to find out about their conditions on their own.	O	O	O	O	O	O
6	When doctors ask a lot of questions about a patient's background, they are prying too much into personal matters.	O	O	O	O	O	O
7	If doctors are truly good at diagnosis and treatment, the way they relate to patients is not that important.	O	O	O	O	O	O
8	Many patients continue asking questions even though they are not learning anything new.	O	O	O	O	O	O
9	Patients should be treated as if they were partners with the doctor, equal in power and status.	O	O	O	O	O	O
10	Patients generally want reassurance rather than information about their health.	O	O	O	O	O	O
11	If a doctor's primary tools are being open and warm, the doctor will not have a lot of success.	O	O	O	O	O	O
12	When patients disagree with their doctor, this is a sign that the doctor does not have the patient's respect and trust.	O	O	O	O	O	O
13	A treatment plan cannot succeed if it is in conflict with a patient's lifestyle or values.	O	O	O	O	O	O
14	Most patients want to get in and out of the doctor's office as quickly as possible.	O	O	O	O	O	O
15	The patient must always be aware that the doctor is in charge.	O	O	O	O	O	O
16	It is not that important to know a patient's culture and background in order to treat the person's illness.	O	O	O	O	O	O
17	Humor is a major ingredient in the doctor's treatment of the patient.	O	O	O	O	O	O
18	When patients look up medical information on their own, this usually confuses more than it helps.	O	O	O	O	O	O

TABLE 3: Patient-Practitioner Orientation Scale

Additional Information

Author Contributions

All authors have reviewed the final version to be published and agreed to be accountable for all aspects of the work.

Concept and design: Sara Strecker, Monika Kozyra

Acquisition, analysis, or interpretation of data: Sara Strecker, Monika Kozyra, Jeevan Mann

Drafting of the manuscript: Sara Strecker, Monika Kozyra, Jeevan Mann

Critical review of the manuscript for important intellectual content: Sara Strecker, Monika Kozyra, Jeevan Mann

Supervision: Sara Strecker

Disclosures

Human subjects: Informed consent for treatment and open access publication was obtained or waived by all participants in this study. Hartford Healthcare Institutional Review Board issued approval HHC-2021-0242. This research was approved by the Hartford Healthcare Institutional Review Board. **Animal subjects:** All authors have confirmed that this study did not involve animal subjects or tissue. **Conflicts of interest:** In compliance with the ICMJE uniform disclosure form, all authors declare the following: **Payment/services info:** This research was funded by the Ehlers-Danlos Society through its micro-grant initiative (#126802). **Financial relationships:** Sara Strecker declare(s) a grant from Pastore Family Foundation. **Other relationships:** All authors have declared that there are no other relationships or activities that could appear to have influenced the submitted work.

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