Kinesiophobia and Joint Hypermobility Syndrome - Why Fear of Movement Should Matter to Movement Experts

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Abstract

**Background and Purpose:** Currently there is little known regarding best practices for managing patients with musculoskeletal pain who are diagnosed with joint hypermobility syndrome(s). Kinesiophobia, a complicating comorbidity, is often present in these patients. The aim of this case report is to present an intervention protocol designed to address musculoskeletal pain in patients with joint hypermobility syndrome (JHS) that addresses the systemic nature of the condition and confounding kinesiophobia. **Case description:** The subject of this case report is a 29-year-old female who sought physical therapy for chronic neck and low back pain. The patient was diagnosed with JHS and a list of complicating comorbidities, including kinesiophobia. **Intervention:** The tri-phase intervention protocol in this study is specifically designed to address the physical impairments of the patient and provide education and coping strategies for kinesiophobia. **Outcomes:** Following successful completion of the intervention protocol, the patient demonstrated gross improvements in all areas previously contributing to her neck and low back pain. The patient verbalized understanding of her JHS diagnosis and demonstrated knowledge of how to independently implement kinesiophobia coping strategies and exercise routines with confidence. **Discussion:** Despite the suspected great prevalence of JHS in the global population, little research exists about the best intervention strategies for patients with JHS who seek treatment for chronic musculoskeletal pain. This patient population is known to have kinesiophobia, but this condition is not widely respected or acknowledged by medical professionals. More research is needed to conclude the best methods of treatment, though key aspects of this intervention style case report can aid in developing unique treatment protocols for each individual patient. (Abstract word count: 264)

**Introduction**

The aim of this case report is to consider the current lack of research of physical rehabilitation for patients with hypermobility syndromes. Currently, there is a substantial amount of research and academic consideration for the best interventional approach for patients with hypomobility. However, there is little current research focused on the other end of the spectrum, i.e. hypermobility. There is a common comorbidity that impacts individuals with joint hypermobility syndrome (JHS), kinesiophobia, and should be considered independently in the
rehabilitation process. Presented in this case report is the author’s hypothesis for the best interventions for a patient with diagnosed joint hypermobility given the complication of kinesiophobia in this patient population and its role as a barrier to implementing an effective rehabilitation protocol.

**Background and Purpose**

Joint hypermobility syndrome (JHS) is a broad clinical term that encompasses a spectrum of heritable connective tissue disorders (hCTD) including Ehlers-Danlos, Marfan Syndrome and Osteogenesis Imperfecta, and is clinically ‘characterized by hypermobility, often affecting multiple joints, and musculoskeletal pains in the absence of systemic inflammatory joint disease’. The most distinctive clinical features shared among these disorders are pain, fatigue and systemic laxity/ joint hypermobility, which is considered to be the shared ‘physical marker’ of all hCTDs which most commonly manifests as excessive range of movement in any given joint beyond normative values. Due to the systemic nature of the condition, patients with JHS often have a complex list of comorbidities that involve most organ systems of the body. The extreme variability in presentation among patients with JHS complicates current efforts to establish clinical practice guidelines and standardized diagnostics. It inhibits establishing etiology and incidence, which numerous sources suggest is the reason why JHS is likely to be grossly underdiagnosed in today’s population. At this point, the general consensus is that JHS is more prevalent in females than males, slightly greater in Asian and African American populations compared to Caucasians, and presents in childhood and tapers off in early adulthood due to the evolution of the disease over the lifespan.

There is still a lack of consensus regarding clinical diagnostic criteria or cutoff scores for the two different diagnostic tools currently used to identify patient with JHS/ED-HT. What’s more, there is a lack of agreement in academic circles as to which criteria should be adopted for standardized use internationally. At this time, ED-HT is the only subtype of the ED spectrum that lacks biological marker identified as responsible for the improper collagen production and other distinct signs and symptoms. This is especially frustrating as experts agree that ED-HT is the most prevalent of the subtypes. Thus, clinical diagnosis is currently the best means for identifying patients with JHS/ED-HT, despite the variability of assessment from clinician to clinician and clinic to clinic. However, the current knowledge base physical therapists are
equipped with varies greatly. Russek et al completed a research study in 2014 surveying US physical therapist knowledge of four widespread pain conditions: JHS, Fibromyalgia, Juvenile Rheumatoid Arthritis and Adult Rheumatoid Arthritis. Data analysis indicated that 38.8% of practicing clinicians had never learned about JHS compared to 1.4%, 8.7% and 3% for the remaining respective conditions. With approximately 40% of the study participants reporting a lack of knowledge regarding JHS,

In this interventional case report, the author utilized the Beighton Scoring System for Joint Hypermobility in assessing the degree of hypermobility during the new patient evaluation. The Beighton scoring system is a 0-9 point diagnostic tool that is used to assess hypermobility in key joints. When a patient meets the criteria then one point is awarded, and if the criteria is met bilaterally the patient is awarded two points. Clinically significant results, according to the literature, vary between $\geq 4$ points and $\geq 5$ points. Appendix A displays the diagnostic criteria assessed when administering the Beighton Scoring System.

Kinesiophobia is defined as ‘an excessive, irrational and debilitating fear of physical movement and activity resulting from a feeling of vulnerability to painful injury or reinjury’. While anxiety and depression are known to be comorbidities of JHS, the high rate of incidence of kinesiophobia in this population is still poorly recognized or understood, and more often associated with Parkinson’s Disease, TMJ and fibromyalgia. With respect to the JHS population, kinesiophobia manifests as fear avoidance behavior that results in deconditioning and maladaptive postures and movement patterns implemented by the patient as a means of avoiding perceived pain triggers in daily activities. “More specifically, pain-related fear is associated with impaired physical performance and increased self-reported disability and may predict future occupational disability”. This aversion to participating in physical activity on even the most basic levels presents a great challenge to rehabilitation professionals who are charged with implementing exercise routines intended to address the musculoskeletal deficits of JHS patients. Understanding kinesiophobia will assist in designing a plan of care and setting a patient up for success, whereas lack of acknowledgement of this condition will further impede the recovery process. Currently there is a general lack of knowledge in medical professions about the validity of kinesiophobia. As a result, patients who verbalize their fear, combined with their often lengthy list of comorbidities, are perceived by medical professionals as ‘attention-seeking’ and
‘hypochondriacs’. This lack of compassion, combined with a lack of knowledge, is a serious barrier to progress in this area of rehabilitative medicine.

The purpose of this case report is twofold. 1. Establish kinesiophobia as an impairment that translates to diminished quality of life via function limitations and activity and social participation restrictions; and the necessary call to action for physical therapists to address these issues. 2. Present a treatment model for initiating rehabilitation and progressing care for patients with joint hypermobility syndrome that considers both the universal deficits and barriers confronting patients with JHS and kinesiophobia while also providing the framework for tailoring interventions to the specific needs of each patient.

Case Description

The subject of this case report is a 29-year-old Caucasian female seeking physical therapy for neck and low back pain, both of which are insidious and chronic in nature. The patient has a complex list of comorbidities, including the following: Joint Hypermobility Syndrome (JHS) (suspected Ehlers-Danlos, hypermobility type or ED-HT), chronic bilateral shoulder subluxations, costochondritis, postural orthostatic tachycardia, asthma, depression, anxiety, Irritable Bowel Syndrome, and recent history of daily migraines of unknown source. The patient is a registered nurse, but not currently working due to her concerns regarding the physical demands of that job. Instead she is employed part time as a nanny for special needs children, and while the physical demands of caregiving cause her pain, she reports it is much more tolerable than her duties as a nurse. The patient does not exercise due to fatigue and because her joints are generally painful, both hallmark traits of JHS. She has difficulty with sustained postures and transitional movements, particularly in completion of household chores and more strenuous daily tasks due to pain in multiple joints. She also reports difficulty with upper and lower extremity use due to fatigue and complaints of neck and back pain.

The patient demonstrated deficits in joint and limb proprioception and kinesthesia, unmoderated movement and a general disregard for occurrence of a laxity deformity during movement. The reported pain in the cervical and lumbar spine lead to impairments in ROM, mobility, strength, posture and endurance. The constant and widespread experience of pain and fatigue resulted in psychosocial implications, particularly in her daily anxiety, which are common findings in persons with JHS and manifests as kinesiophobia. Following initial
evaluation, the patient expressed desire to achieve the following goals: improvements in strength, reduction in pain and to learn strategies for pain management to be used in the future.

The course of care was complicated by the patient experiencing daily migraines throughout the course of treatment. Two months after the insidious onset of said migraines, the patient was diagnosed with a spontaneous CSF leak, and was scheduled for a blood patch procedure at the end of the treatment protocol. It is worth noting that spontaneous CSF leaks are a little known but established sequela of JHS and are caused by ‘increased fragility of the meninges’ in this patient population.4

The primary clinical consideration for this patient at the initiation of therapy was the high level of complexity. The difficulty lay in designing a rehabilitation program for musculoskeletal pain caused by a systemic disorder and complicated by a unique sequela of psychological and multi-system impairments. Specific consideration for the kinesiophobia barrier was important as well. The ICF model, seen in Figure 1, was used to guide the decision-making process in designing a treatment plan and progressing interventions for the duration of therapy. Despite the complexity, the patient was determined to have good rehabilitation potential after initial evaluation.
The outcome measures administered at the initial evaluation were the Oswestry Disability Index and Neck Disability Index. These are the standard outcome measures administered to patients seeking treatment for back and neck pain respectively at the clinic site where treatment took place. At the midway point to the rehabilitative process, the Tampa Scale for Kinesiophobia was administered to the patient.

The Neck Disability Index (NDI) is a subjective questionnaire that provides insight into the impact that neck pain has on a patient’s daily activities, quality of life and pain severity. The NDI has an adequate to excellent test-retest reliability specifically with patients who have mechanical neck pain, and while that was the source of pain for this patient, the underlying cause is her JHS diagnosis and is less suited for this outcome measure.\textsuperscript{18}

The Oswestry Disability Index (ODI) is a subjective questionnaire that provides insight into the impact that back pain has on a patient in their daily life, function ability, pain severity and quality of life. It seeks to convey perceived levels of disablement regarding the back pain and any associated lower extremity symptoms. For standard low back pain, the ODI has excellent test retest reliability and the construct validity varies from adequate to excellent.\textsuperscript{19} However, as with the NDI, there is very little to suggest that the ODI is appropriate for patients with JHS seeking treatment for musculoskeletal pain.

The Tampa Scale for Kinesiophobia is a self-reporting tool used to assess fear of movement-related pain. This fear is a common complicating factor for patients with hypermobility syndromes and can be a significant barrier to progress in therapeutic rehabilitation. The original scale consists of a 17-question assessment that provides insight into a patient’s beliefs about their pain, their condition and the relationship between the two. The TSK-17 was administered twice during rehab. However, since there is little metric data for TSK-17 scoring analysis, the clinimetrics for the TSK-11 was used instead as it is more grounded in the literature. Other than the removal of six statements, the TSK-17 and TSK-11 are the same (see Appendix B). Analysis of the total scores as well as changes in the activity avoidance and somatic focus/harm subscales was completed using TSK-11. The TSK-11 has high test-retest reliability with an intraclass correlation coefficient > 0.7 and moderate to good construct validity.\textsuperscript{15,17}
Interventions

Currently there is no recognized treatment protocol for patients with JHS seeking physical therapy for musculoskeletal pain, but it is generally accepted that physical therapy should be extensive in duration in order to be most successful. What’s more, it is highly unlikely that implementation of an exercise routine will reduce ligament laxity for this patient population. Completed research considers isolated aspects of rehab protocol design i.e. type of exercise or prescription parameters, and lacks consideration of the big picture of treatment. Nonetheless, these provided essential information in creating a rehabilitation protocol specific to the deficits and needs of patients with JHS. Key aspects of treatment in these studies addressed strength and proprioception deficits, poor joint position sense throughout a range of motion and fatigue.

Strength deficits as well as fatigue in the JHS population are believed to be caused by ‘altered passive properties in the muscle-tendon unit’ that result in an abnormally long resting length which reduces the optimal length tension relationship when firing a muscle group. Additional contributing factors are constant activation of agonist and antagonist muscle groups to create stability that is normally provided by connective tissue and probable abnormality of the extracellular matrix within muscle tissue that impacts force transmission through muscle fibers. And according to Jindal et al and Wolf et al, mitigation of poor proprioception and joint position sense for this patient population is achieved through the use of isometric strengthening and closed-kinetic chain exercises, respectively. These key points of consideration guided expectations of strength gains and fatigue reduction and were factored into the decision-making process in designing the protocol.

While discrete treatment theories were pulled out of the literature and incorporated into the rehabilitation protocol in this case report, the study by Bathen et al in 2013 provided the most guidance in creating a three-part model treatment and progression over the course of therapy. The purpose of the study was to implement a multidisciplinary treatment approach for patients with ED-HT in order to improve musculoskeletal function and reduce kinesiophobia. Each of the three phases in this rehabilitation protocol include both physical and psychosocial components of treatment. Figure 2 illustrates the consideration for both aspects of care, with progression of exercise prescription represented on the y-axis and psychosocial considerations, specifically regarding kinesiophobia, represented on the x-axis. Table 1 outlines the key aspects
of exercise prescription, patient education and kinesiophobia management at each of the three phases of the program.

**Figure 2: Proposed tri-phase rehabilitation protocol**

**Table 1: Proposed Tri-phasic Exercise Protocol for JHS**
Phase one of the rehabilitation program emphasized movement education and establishing patient control over her diagnosis, her body and her kinesiophobia. The patient was prescribed isometric strengthening exercises at this time to re-establish control, invoke improvement in joint position sense and allow for improvement in muscle strength and endurance without the potential for laxity deformity. The patient was encouraged to critically reflect on what kinesiophobia meant for her and what barriers it posed to the rehabilitation process. Based upon her feedback, adjustments were made to allow for patient success in the exercise routine and promotion of confidence during therapy.

Phase two of the rehabilitation program emphasized challenge progression and implicit patient understanding. At this point, the patient was expected to be more self-reliant in monitoring posture and exercise technique as a way of continuing towards promoting patient independence. The exercises were designed to provide more potential for patient error but with the inclusion of ‘fail-safe’ mechanisms to prevent injury or laxity deformity in the event of fatigue. As the patient progressed through the exercises, she was encouraged to be more involved in the rehabilitation process in determining her own readiness for more challenging exercises. In doing so, the patient self-determined her readiness for new challenges in a way that allowed her to continue to control her kinesiophobia.

The third and final phase of the rehabilitation program emphasized physical competence and personal empowerment. At this stage, the patient demonstrated the ability to self-monitor and progress exercise difficulty as well as identify areas needing improvement. In promoting her to this high level of awareness and independence, the patient also achieved a level of personal empowerment in her ability to physically handle activities of daily living without the barrier of kinesiophobia. Her empowerment led her to independently manage her physical and mental strength at time of discharge.

**Outcomes**

As previously stated, two of the three outcome measures utilized in this case report are not appropriate for use with the JHS patient population. The NDI and ODI are well vetted for typical acute musculoskeletal injuries but have little application for the hCTD spectrum as the systemic hypermobility is a lifelong condition that does not adhere to the traditional course of
inflammatory resolution as the result of therapeutic intervention. That being said, there are currently no more suitable outcome measures available to clinicians. Given this information, it remains worth noting that the patient’s perceived disability on both the NDI and ODI reduced over the course of treatment. Though neither score met MCID criteria, the patient reported a 6% reduction in perceived disability on the NDI and an 8% reduction on the ODI. Rather, great emphasis was placed on subjective data of patient’s perception of her disability over the course of therapy as she continuously indicated improvements with regards to both her neck and low back pain. This data was heavily relied upon in guiding the patient specific components of the protocol interventions.

With regards to the TSK-11, the patient had an overall reduction in kinesiophobia as well as diminishing of kinesiophobia severity on the activity avoidance and somatic focus/ harm subscales. While the TSK-17 was used to collect data, there is currently little in the literature with regards to TSK-17 data analysis whereas the TSK-11 has been well validated. Thus, the data that was applicable to the TSK-11 was extracted and analyzed for overall kinesiophobia reduction assessment as well as changes in the activity avoidance and somatic focus/ harm subscales. TSK-11 analysis data is presented in Table 2. Graph A illustrates the quotient changes of the TSK-11 total score and both subscale scores upon completion of the therapeutic protocol.

<table>
<thead>
<tr>
<th></th>
<th>Initial Examination</th>
<th>Post-Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>TSK-11 Total Score</td>
<td>73%</td>
<td>64%</td>
</tr>
<tr>
<td>TSK-11 AA Score</td>
<td>67%</td>
<td>61%</td>
</tr>
<tr>
<td>TSK-11 SF Score</td>
<td>80%</td>
<td>67%</td>
</tr>
</tbody>
</table>

Table 2: TSK-11 score reporting Graph A

Graph A: Outcomes
The greatest area of improvement for this patient was her reduction in somatic focus or perception of harm while participating in physical activity over the course of therapy. Roelofs et al published preliminary mean and standard deviation data with regards to TSK total and subscale scoring, though not unique to the JHS population. Upon completion of therapy, the patient scored within 1 SD of the mean in all categories. Regression towards the mean for this patient is successful demonstration of kinesiophobia reduction and improved management of fear in daily activities. Improvements in function trended upward while degree of kinesiophobia impairment trended downward over the course of therapy. Both subjective reporting of the patient’s perceived functional ability and TSK-11 scoring analysis together provide a complete picture of patient outcome following participation in the tri-phase intervention protocol.

**Discussion and Future Considerations**

It is important to recognize that physical therapy, no matter how skillfully executed, will not cure a patient of joint hypermobility syndrome or abolish the existence of kinesiophobia. What is within reach is the opportunity to improve awareness and understanding of JHS with independent and equal consideration for kinesiophobia management as an aid in progress towards recovery of function. The author has identified four key starting points from which therapeutic management of this patient population can advance.

Firstly, the significant lack of knowledge and understanding of what kinesiophobia is and its relevance with the JHS population is a major barrier to successful treatment at the hands of skilled physical therapists. Better understanding will lead to better and more appropriate exercise prescription and establishing realistic expectations of the results of treatment. For example, the subject of this case report was unable to participate in therapy on several occasions due to asthma, postural tachycardia and intense migraines, resulting in interrupted treatment. For this reason, progress within the timeframe was potentially diminished or limited compared to expectations at the outset of treatment.

Secondly, patients with JHS are often viewed as attention-seeking and high-maintenance by health care providers at this point. While this may be understandable due to the extreme fear avoidance behaviors combined with chronic multi-system/ multi-complaint nature of this condition, it does not excuse the mismanagement of these patients at the hands of medical
providers. These patients are, as a group, some of the most medically complex in terms of treatment. Better understanding and awareness of this condition and the true nature of its complexity are essential in de-stigmatizing the diagnosis and connecting patients and providers on the same level. Additionally, it is imperative for physical therapists to mitigate the fear-driven behavior by providing education and promoting patient independence and self-confidence during the course of therapy. These are vital tools with which to equip the patient in order to promote continued success after discharge from therapy.

Thirdly, it is imperative that future clinicians are better educated with regards to recognition of the signs and symptoms indicative of JHS and kinesiophobia and basic/ key strategies for management. These need to be established and universally recognized within the profession and integrated into physical therapy education as well as guided comprehensive care planning for current clinicians. This is of extreme importance since severity of kinesiophobia and function are completely linked with a strong inverse relationship. In order to see an improvement in function in this patient population, there must be a concurrent decline in kinesiophobia severity. There is a great need for future research to demonstrate, via data collection, the existence of this inverse relationship.

Finally, physical therapists self-advocate for their role as movement experts. It is important for this profession to take a leading role in research and education of fellow healthcare providers in order to improve diagnosis, patient education and optimizing function in patients with JHS across the lifespan. In doing so, determination and implementation of appropriate outcome measures specific to the JHS/ED-HT population can occur, resulting in better analysis of outcomes following therapy.

Limitations

Limitations of this case report include duration of intervention and choice of kinesiophobia scale. Since JHS is a medically complex, chronic, lifelong condition, a longer duration of therapeutic intervention is necessary to allow patients to make significant changes in functional limitations, and conversely, gain autonomous control of kinesiophobia impairment in daily life. Outcome measure data collection will not reflect clinically significant changes within standard musculoskeletal rehab time frames. Also, the author’s use of the TSK-17 for data collection was not ideal as there is little clinimetric data for this outcome measure. For this
reason, the author was compelled to extract the applicable data of the TSK-11 from the TSK-17 to complete data analysis.

**Conclusion**

While there is a suspected moderate prevalence of joint hypermobility syndrome in the current global population, there is relatively minimal information in the literature regarding therapeutic rehabilitation of musculoskeletal pain complaints. There is equally little known regarding kinesiophobia, the patient-specific rehabilitation barrier common in the JHS population. Current rehab measures, interventions and treatment techniques lack the specificity in design that JHS patients require in order to make progress. Successful rehabilitation protocols should include gradual therapeutic exercise progression, patient education and kinesiophobia management. The inverse relationship between function and kinesiophobia is a vital point of understanding for rehabilitation professionals. Greater understanding of the pathophysiology, diagnosis and treatment in JHS populations will lead to well-informed management of this complex population. The profession of physical therapy is best equipped to become informed and powerful patient advocates who can provide long-term quality care to each individual across the lifespan.
Appendix A

Beighton Scoring System for Joint Hypermobility

<table>
<thead>
<tr>
<th>Joint Assessment/ Criteria</th>
<th>Points Possible</th>
</tr>
</thead>
<tbody>
<tr>
<td>Passive dorsiflexion of the 5th metacarpal beyond 90°</td>
<td>1 per hand, max 2</td>
</tr>
<tr>
<td>Opposition of the thumb to the flexor aspect of the forearm</td>
<td>1 per hand, max 2</td>
</tr>
<tr>
<td>Hyperextension of the elbows beyond + 10°</td>
<td>1 per arm, max 2</td>
</tr>
<tr>
<td>Hyperextension of the knees beyond + 10°</td>
<td>1 per leg, max 2</td>
</tr>
<tr>
<td>Forward flexion of the trunk with knees fully extended and palms resting flat on the floor</td>
<td>Max 1</td>
</tr>
</tbody>
</table>

Appendix B

Tampa Scale for Kinesiophobia - 11

<table>
<thead>
<tr>
<th>Item</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I’m afraid that I might injure myself if I exercise.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. If I were to try to overcome it, my pain would increase.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. My body is telling me I have something dangerously wrong.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. People aren’t taking my medical condition seriously enough.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. My accident has put my body at risk for the rest of my life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. Pain always means I have injured myself.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. Simply being careful that I do not make any unnecessary movements in the safest thing I can do to prevent my pain from worsening.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. I wouldn’t have this much pain if there weren’t something potentially dangerous going on in my body.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. Pain lets me know when to stop exercising so that I don’t injure myself.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. I can’t do all the things normal people do because it’s too easy for me to get injured.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. No one should have to exercise when he/she is in pain.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Note: TSK-AA: items 1, 2, 7, 9, 10, 11; TSK-SF: items 3, 4, 5, 6, 8
Bibliography


8. Marco Castori, Claudia Celletti, Isabella Sperduti. Symptom and Joint Mobility Progression in the Joint Hypermobility Syndrome (Ehlers-Danlos Syndrome, Hypermobility Type).


