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Rehabilitation and Physical Activity in Ehlers-Danlos Syndrome: A Review of Interventions and Outcomes

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Abstract

Purpose of Research:

This study aims to explore the impact of physical activity on the quality of life of individuals with Ehlers-Danlos Syndrome (EDS), a group of disorders affecting connective tissues. The focus is on understanding how tailored exercise programs can improve symptoms and overall well-being across different EDS subtypes.

Research Materials and Methods:

A PubMed review identified studies on Ehlers-Danlos syndrome, quality of life, and exercise. Relevant peer-reviewed research from the last 20 years was included, screened, and synthesized.

Basic Results:

The findings indicate that physical activity plays a crucial role in improving the quality of life for individuals with EDS. Tailored exercise programs, including proprioceptive and stabilization exercises, have been shown to reduce pain and enhance functional capacity. Additionally, interdisciplinary approaches combining physical therapy with cognitive-behavioral strategies can mitigate psychological factors such as anxiety and depression, which are prevalent among EDS patients. Studies highlight the importance of adapting exercises to individual needs to avoid exacerbating symptoms like joint instability and chronic pain.

Conclusions:

In conclusion, physical activity is a vital component of EDS management, offering benefits in pain reduction, improved joint function, and enhanced quality of life. However, further research is necessary to determine the optimal exercise strategies for different EDS subtypes and to address the limitations of current studies, which often suffer from small sample sizes and heterogeneity in interventions. Developing personalized treatment plans that integrate physical therapy with psychological support can significantly improve patient outcomes and should be a priority in future studies. Additionally, there is a need to explore the effectiveness of interventions in pediatric and adolescent populations with EDS.

Keywords

physical activity, joint hypermobility, hypermobile Ehlers-Danlos syndrome, rehabilitation, exercise

INTRODUCTION

The prevalence of Ehlers-Danlos syndrome (EDS) varies widely, estimated between 1 in 5,000 to 1 in 100,000, depending on the subtype, though these figures may be underestimated. Accurate data for individual subtypes remains limited, particularly since most epidemiological studies rely on the older 1997 classification, which did not prioritize genetic diagnosis. The hypermobility subtype (hEDS) is the most common, with an incidence of approximately 1 in 10,000 to 1 in 15,000 (1).

EDS encompass a range of 14 distinct types. The various types of EDS exhibit shared characteristics, including joint hypermobility, skin and vascular weakness, as well as general fragility of connective tissues (2) . Among these, 13 are rare monogenic disorders, with prevalence rates ranging from 1 in 20,000 to fewer than 1 in 1,000,000. It is crucial to recognize initially that various EDS types share common characteristics, and additionally that the unique clinical features and diverse genetic origins that set them apart necessitate distinct management and monitoring approaches. We distinguish:

1. Classical EDS
2. Vascular EDS
3. Kyphoscoliotic EDS
4. Arthrochalasia EDS,
5. Brittle cornea syndrome
6. Classical-like EDS type 1
7. Classical-like EDS type 2
8. Musculocontractural EDS
9. Myopathic EDS
10. Periodontal EDS
11. Spondylodysplastic EDS
12. Dermatosparaxis EDS
13. Cardiac-valvular EDS

14. Hypermobile EDS and Hypermobility spectrum disorders (3).

The majority of monogenic EDS types result from harmful gene mutations that produce proteins such as collagen I, III, V, or enzymes that play a role in the synthesis of these collagens or in the production of proteoglycans (4).

The treatment of EDS focuses on symptom management and improving patients' quality of life. Physiotherapy helps strengthen joints and reduce the risk of injuries, while occupational therapy facilitates daily activities. For chronic pain, psychotherapy and cognitive behavioral therapy can be effective. Additionally, regular diagnostic tests and genetic counseling support health monitoring and a better understanding of the condition (5).

MATERIALS AND METHODS

A comprehensive literature review was conducted using the PubMed database to identify relevant studies related to "Ehlers-Danlos syndrome", "quality of life", "exercise", "physical activity". Inclusion criteria were original research articles, systematic reviews, and meta-analyses published in peer-reviewed journals within the last 20 years. Articles not available in English and those lacking full-text access were excluded. The retrieved studies were screened based on titles and abstracts, followed by full-text evaluation to determine their relevance. The findings were synthesized to provide a comprehensive overview of the current state of knowledge on the topic.

DISCUSSION

It has long been known that psychological stress and behavioral responses, such as kinesiophobia—the fear of movement and activity (6)- can exacerbate the physical effects that persons with EDS suffer (7,8)

In a 2010 study, 32 women with EDS were compared with a control group to assess musculoskeletal disorders, physical activity, and health-related quality of life. The researchers found that people with EDS had significantly more musculoskeletal problems than the healthy population, especially joint pain, joint dislocations, tendinitis and muscle cramps. It is also worth noting that patients suffered more from fatigue and headaches. People with EDS had lower levels of physical activity than the control group, which is likely due to pain and fear of injury (9).

Patients with EDS have many treatment options for symptom control. These include drug therapy, surgery, and physical therapy. Seventy-nine patients were studied to assess the frequency and effectiveness of various treatments, of which only six did not use pharmacological medication. Almost 71% had undergone some type of surgery, and almost 52% were currently enrolled in a physical therapy program. Of the patients undergoing physical therapy, 63.4% were satisfied with the results, which may provide a perspective for improving symptom control with exercise. Nevertheless, in nearly 40% of the cases, treatment appears incapable, which is reflected by the patient as a neutral or even a negative result (10).

Regular, appropriately tailored physical activity under the supervision of specialists plays a significant role in improving the quality of life for patients with hypermobile Ehlers-Danlos syndrome (hEDS) and hypermobility spectrum disorders (HSD). Both low- and high-load exercises reduce pain and enhance patients' quality of life. Incorporating exercise programs and the use of adjunctive measures, such as kinesiotaping or compression garments, can alleviate pain, improve function, and mitigate symptoms associated with joint instability. Patients with hEDS/HSD often experience kinesiophobia, arising from concerns about exacerbating pain or fears of subluxation and injury. Well-designed exercise programs can gradually reduce fear of movement and build patients' confidence in their own bodies (11).

The 2024 study evaluates the impact of wrist-stabilizing exercises compared to hand orthosis use in individuals with hEDS. The study involved 169 adults, with the experimental group performing a 12-week progressive wrist-stabilization exercise program. After this period, no significant differences were observed between the experimental and control groups regarding pain and paraesthesia reduction, improvements in hand function and grip strength, or quality of life. Both interventions demonstrated similar effects on the analyzed outcomes. The findings suggest that both wrist-stabilizing exercises and orthotic interventions offer potential benefits; however, their efficacy in improving quality of life and symptom control in hEDS patients appears comparable. Physical activity in the form of structured stabilization exercises presents an alternative therapeutic option (12).

According to the study analyzing the impact of physical activity on patients with Postural Orthostatic Tachycardia Syndrome (POTS), with a particular focus on individuals with EDS, exercise, especially when individualized, is safe and can reduce POTS symptoms while improving quality of life. It is crucial to appropriately adapt the exercises to avoid joint overload, which may lead to subluxations or pain. In conclusion, exercise can significantly

benefit patients with Ehlers-Danlos Syndrome and coexisting POTS; however, it requires careful adjustment to meet individual patient needs, considering pain, fatigue, and the specific challenges associated with hypermobility (13).

In 2021, a systematic review was conducted, which was the first systematic review on physical therapy for patients with hypermobile type EDS. In the various databases, only six randomized clinical studies concerning non-pharmacological therapy for hypermobile type EDS could be found and were included in the systematic review to the qualitative analysis. The most common exercise strategy to enhance proprioception was muscle training. The major goal of the treatments was to restore motor control in the lower limbs and maintain adequate balance. Interdisciplinary programs involving therapeutic education sessions were suggested by two of the studies. All trials examining pain or proprioception found a significant difference between the intervention and control groups, with benefits shown solely in the intervention group. Furthermore, advantages in the intervention group were shown independent of the kind of intervention. The authors of the paper highlighted certain limitations. The most significant restriction was that the new criteria for distinguishing between hEDS, isolated, non-syndromic joint hypermobility, and hypermobility spectrum disorders were only recently established, therefore some individuals may have been included based on other criteria. Another drawback was the small number of studies and the heterogeneity of their therapies and results. The high incidence of dropout, primarily owing to patients' nonattendance at the sessions, was also a possible limiting factor (14).

Physiotherapy is a crucial component of treatment for patients with EDS particularly those with the hypermobile subtype. Exercise has been shown to reduce pain intensity, especially in milder forms of EDS. Impaired proprioception in EDS is correlated with increased pain severity; therefore, enhancing proprioception through targeted exercises may be beneficial. Joint-stabilizing exercises can help decrease the frequency of subluxations and dislocations, which are common issues among patients with EDS. Strength training should be approached with caution to minimize excessive microtrauma in weakened connective tissues. While physical activity offers significant benefits for individuals with EDS, it must be carefully tailored to their specific needs. The most effective physiotherapeutic interventions focus on improving proprioception and muscular stabilization. In contrast, strength training should be introduced with particular caution, as patients with EDS experience prolonged tissue healing times (15).

A study conducted at the University Hospital of Ghent assessed the effectiveness of two home exercise programs in treating multidirectional shoulder instability (MDI) in 21 patients with hEDS and HSD. Patients were randomly assigned to two groups to perform different exercise programs for six months. The primary outcome measure, the WOSI, showed a significant improvement of 240 points after 12 weeks and 325 points after 24 weeks. Significant improvements were also noted in the DASH, PSFS and GROC questionnaires. Only the TSK scale measuring kinesiophobia (fear of movement) did not show significant improvement. The study found no significant difference between the effectiveness of the two programs - both led to similar improvements in shoulder function. The results suggest that home exercise therapy may be an effective approach to treating shoulder instability in hEDS/HSD patients, but it may not be sufficient alone to overcome the fear of movement, indicating the potential need for a multidisciplinary, supervised treatment approach (16).

Peterson et al. conducted a systematic review of randomized controlled trials (RCTs) and quasi-RCTs evaluating physical and mechanical interventions for lower limb problems in children with hypermobility. Inclusion criteria included studies involving children aged 0–17 years with hypermobility and lower limb symptoms diagnosed with joint hypermobility syndrome (JHS) or hEDS. Of the 520 titles and abstracts reviewed, only 2 RCTs with a total of 86 participants met the inclusion criteria. These studies evaluated: differences between general and targeted physical therapy programs; and differences between performing knee extension exercises in the neutral range and the hypermobile range. No clear benefits were found for any of the physical therapies evaluated. When comparing targeted physical therapy with general physical therapy, there were no statistically significant differences at three or five months for any outcome measures. When comparing exercises performed to a neutral range of knee motion with those performed to a hypermobile range, there were no statistically significant differences in pain, function, or health status as measured by the Child Health Assessment Questionnaire. There is very limited evidence to guide the use of physical and mechanical therapies for lower limb problems in children with hypermobility spectrum disorder and hEDS. The available evidence does not show a clear benefit of performing exercises to a neutral range of knee extension compared with those performed to a hypermobile range, nor a clear benefit of a targeted physical therapy program compared with a general one (17).

A 2023 study investigates the effects of a 9-week rehabilitation program (RP) on patients with hEDS. The findings indicate that structured physical activity in a controlled environment provides multidimensional benefits in both the short- and medium-term. Functional exercise capacity, assessed using the six-minute walk test (6MWT), significantly improved following the intervention and remained elevated six months post-program. Additionally, patients exhibited reduced fear of movement (kinesiophobia) and reported a notable increase in energy levels, suggesting that a well-structured physical activity regimen may effectively mitigate chronic fatigue. In conclusion, rehabilitation programs incorporating physical activity represent an effective therapeutic strategy for individuals with hEDS, contributing to enhanced physical function, reduced pain, anxiety, and fatigue, and overall improvements in quality of life (18).

Resistance training is not only feasible but also beneficial for individuals with hEDS/HSD. Rigorous exercise regimens may provide advantages for hEDS patients, while organized exercise programs can help reduce musculoskeletal dysfunction and alleviate pain in affected joints. It is advisable to integrate exercise training with cognitive-behavioral strategies to address kinesiophobia-related tasks and exercises. The author highlights several key areas for future investigation: the need to identify and validate specific outcome measures tailored for the hEDS/HSD population to enhance comparability across research studies, and the importance of conducting additional studies involving children and adolescents with appropriate control groups. The author underscores that the primary objective of strength and resistance training for the pediatric hEDS/HSD demographic should be to manage symptoms effectively and facilitate safe participation in play, particularly in sports with a higher risk of injury (19).

CONCLUSIONS

Based on the analysis of a systematic review of studies examining the impact of exercise and rehabilitation on patients with EDS physical activity has been found to play a significant role in reducing joint stiffness, alleviating pain, and improving quality of life (18) . Studies investigating various interventions, including proprioceptive, stabilization, and strengthening exercises, as well as respiratory muscle training, have demonstrated improvements in muscle strength, proprioception, and joint function. Additionally, a reduction in pain levels, as measured by the Visual Analog Scale (VAS), and a decrease in kinesiophobia have been

observed, which may encourage greater physical activity and help prevent further musculoskeletal decompensation. However, despite these potential benefits, the findings are limited, and further research is needed to precisely determine the effectiveness of different forms of physical therapy in this patient population (20).

DISCLOSURE

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