How Can Physical Therapy Help My EDS/HSD Symptoms?

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A Checklist of potential physical therapy interventions For EDS/HSD is available on my web page:
https://webspace.clarkson.edu/~lrussek/hsd.html
Objectives

1. List complaints PT may be able to address
2. Outline a process for PT to evaluate you and determine a plan of care
3. Describe treatment approaches PT may use
4. Describe the role of PT in long-term management of EDS/HSD
5. Explain how your PT should empower YOU to manage your EDS/HSD signs and symptoms
Complaints PT may be able to address

- Pain: localized or widespread, including headaches
- Joint instability, subluxations or dislocations
- Functional limitations: gross or fine motor
- Developmental delay and clumsiness
- Fatigue, sleep disturbance
- Postural Orthostatic Tachycardia Syndrome (POTS)
- Incontinence, vaginal or pelvic pain
- (Anxiety and depression)
- (Gastrointestinal problems, gastroparesis)
- (Immune issues)
Why Physical Therapy?

• **PTs are experts in the movement system**
  - Some approaches are best provided by PT:
    - Exercise, neuromuscular re-education, body mechanics, posture, ergonomics, manual therapy, modalities, braces, assistive devices...

• Most PTs are skilled in:
  - Pain management, pain neuroscience education
  - Application of behavioral approaches to functional activities: e.g. pacing, sleep hygiene...

• You may develop a strong therapeutic relationship with your PT, discuss problems & solutions

• Some PTs have advanced training: e.g., women’s health, visceral mobilization, etc.
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Pain Management

1. Assessment of pain type, source, perpetuation
2. Education about prevention and management
3. Exercise to improve quality of movement, endurance, enhance natural pain-decreasing neural pathways
4. Manual therapy for alignment, tissue healing
5. Taping/bracing/orthotics for alignment & quality of movement
6. Modalities for pain and inflammation

(Engelbert, 2017, Chopra, 2017)
Pain Assessment

- Use a biopsychosocial approach
- Look for contributing factors as well as signs, symptoms, & involved tissues
Types of Pain

**CENTRAL SENSITIZATION:** Central nervous system becomes hyper-responsive; widespread allodynia

**NOCICEPTIVE:** ‘normal’ pain sensing in **response to threats** in the environment; sharp

**NEUROGENIC INFLAMMATION**

**INFLAMMATORY:** increased pain sensing that raises sensitivity to normal levels of pressure and activity; aching

Inflammation → nociception and SENSITIZATION

**NEUROPATHIC:** abnormal pain in response to things that normally ‘do’ and ‘don’t’ hurt; burning, zinging, tingling.

**DEEP SOMATIC NOCICEPTION:** muscle/trigger points, ligament, tendon, bursae, fascia: referred pain, other symptoms; dull cramping or aching, poorly localized.

**DEEP VISCERAL NOCICEPTION:** Many ‘silent nociceptors’.
Biopsychosocial Pain Assessment

• Identify causal, aggravating & perpetuating factors
  o Stressors affecting sensitive, stressed, or injured tissues
    • (Nociception, inflammation)
  o Referred pain from musculoskeletal or visceral tissues
    • (Nociception, inflammation, activation of silent nociceptors)
  o Sensitive nerves, neurogenic inflammation, neuroplasticity
    • (Neuropathic pain, peripheral and central sensitization, inflammation, neurogenic inflammation)
  o Emotional, psychological and environmental factors
    • (Central sensitization, neurogenic inflammation)
Physical Stresses to Tissues

1. Is there an imbalance between lax joints and tight muscles?
2. Does poor posture, alignment or gravity stress joints/muscles?
3. Are body mechanics stretching or stressing joints/muscles?
4. Is poor proprioception or motor control leading to instability?
5. What is causing muscle trigger points?
visceral and deep musculoskeletal tissues can refer pain
- pain referral can irritate tissues at the referral site through neurogenic inflammation
- this can cause nociception and tissue damage at the referral site.

visceral referral patterns

trigger point referral patterns
Referred Pain: Headaches

• Many headaches are caused by musculoskeletal problems in the neck or head
• Trigger points
• Joint problems in the neck
• Temporomandibular disorders

(picture from Travell & Simons)
Neurological Changes

Neuroplasticity
• Changes in brain structure or connections due to pain

Peripheral & central sensitization:
• Increased reactivity of neurons in peripheral or central nervous system
• Occurs due to inflammation, psychological factors (e.g. stress or anxiety), being sedentary

Neurogenic inflammation
• Sensory nerves can fire backwards and release inflammatory chemicals at their peripheral receptors.
• Can cause nociception and tissue damage in those tissues

Picture: http://www.nationalpain.com/central-sensitization/
Psychosocial Aspects of Pain

The pain experience is affected by:

- Physiologic response to actual or potential tissue damage
- Previous pain experience
- Beliefs/attitudes about pain
- Coping style
- Emotions
- Family, social, and cultural background
- Interaction between sensory input and brain processing

Figure 1: The “biopsychosocial” model of pain

Pain Management: Education

• Factors contributing to/perpetuating tissue stress
• Preventing and managing nerve sensitivity
  o Pain neuroscience education & “Explain Pain”
• Addressing psychosocial factors aggravating pain
• Self-management using exercise, TENS, heat, ice, topical rubs, relaxation, mindfulness meditation, etc.
• Use of braces, splints, orthotics, assistive technology, environmental modification
Pain Management: Exercise

- To address contributing factors: posture, muscle tightness/weakness, trigger points, coordination problems, non-muscle tissue weakness.
- Neuromuscular re-education for motor control training, muscle recruitment, balance, relaxation.
- Aerobic exercise to restore normal pain inhibitory pathways and improve endurance.
- Neuromuscular re-education and exercise to address kinesiophobia (fear of movement) (Kernan, 2007)
Pain Management: Exercise

“Exercise-induced analgesia”

• Regular exercise activates nerve pathways from the brain, stopping nerves from transmitting nociceptive information
• Improves descending pain control
• Decreases hypersensitivity of nerves
• This process does not work properly in people who are deconditioned/sedentary
  • A single bout of exercise may increase pain
  • Regular exercise restores proper function of exercise-induced analgesia

Not All Exercises Are Appropriate

• For exercise to be helpful and not harmful, it must be:
  o The correct exercise (for you, now)
  o Done correctly (proper motor control)
  o At the correct dose (intensity, time/reps)
  o Not overstressing other joints or muscles

• There is no protocol appropriate for everyone with EDS/HSD
Doing Exercises Correctly

- External feedback seems to improve accuracy, learning and retention compared to internal feedback. (Lauber, 2014; Lohse, 2014)
- Using laser targets, biofeedback, etc.
- See Jan Dommerholt’s presentation

www.amazon.com

www.optp.com/SenMoCOR-System

www.optp.com/STABILIZER-Pressure-Biofeedback?kw=stabilizer
Pain Management: Manual Therapy

• Goals:
  o Decrease spasm, trigger points, adhesions
  o Restore proper tissue alignment and mobility
  o Calm peripheral or central nervous system
  o Decrease pain

• Options: massage, trigger point release, soft tissue mobilization, myofascial release, joint mobilizations, instrument-assisted, dry needling
Pain Management: Taping

Kinesio/Rock taping

- Improve tissue alignment, position sense, stability, fluid movement in tissues

McConnell taping

- Improve tissue alignment, stability, proprioception

http://www.ktss.us/what

https://americanpostureinstitute.com/the-ultimate-guide-to-posture-taping/

Pain Management: Modalities

• Options: Heat, ice, TENS (conventional or acupuncture-like), ultrasound/phonophoresis, laser, iontophoresis, shock-wave therapy, etc.
• Can be helpful to temporarily decrease pain or inflammation, or improve tissue mobility
• Benefit is not maintained unless tissues are used during the period of benefit, through active interventions such as exercise or function
• Regular home use of heat, ice, TENS may decrease pain enough to improve function and exercise tolerance
Pain Management Patient Resources

• 5-minute video about chronic pain neuroscience: https://www.youtube.com/watch?v=RWMKucuejIs

• UC Davis pamphlet: search “U.C. Davis pain self-management plan” has multiple modules that let you pick what area might be most helpful for you now.

• American Chronic Pain Association: https://www.theacpa.org

• On-line pain self-management: https://www.liveplanbe.ca has questionnaires to customize information and suggestions for issues that you face
Complaints PT may be able to address

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Joint Instability

• Potential causes:
  o Joint laxity
  o Trauma
  o Muscle weakness, poor motor control
  o Poor position sense or body awareness
  o Excessive stress from tight muscles
  o Excessive stress from habits, postures or activities
    ◦ (but stresses may be really mild)

Cartoon from: https://darrengoossens.wordpress.com/category/comic/page/8/
Joint Instability: Education

- Address contributing factors: posture, body mechanics, ergonomics, joint protection
- Use of braces, splints, taping, assistive technology, environmental modification.
  - Generally recommended for acute flares, return to function, controversial for long-term use

(Engelbert, 2017)
Joint Instability: Neuromuscular Re-education

• Improve body awareness (Engelbert, 2017)
  o Intrinsic feedback: proprioception, body awareness, tactile feedback (compressive clothing or taping)
  o External/augmented feedback: laser, pressure biofeedback, wobble boards, virtual reality, Wii
  ◦ External focus seems to result in better retention and transfer of motor skills than internal focus
  o (Lauber, 2014; Lohse, 2014)
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Decreased Function: Manage Pain

• Assessment of pain type, source, contributing factors

• Education about:
  o Musculoskeletal, neurological, and psychosocial contributing factors
  o Self-management of pain
  o Orthotics, braces, environmental modifications

• Exercise to address contributing factors, motor control/coordination, aerobic conditioning

• Manual therapy, taping, modalities
Decreased Function: Fear of Movement

- People with EDS/HSD may be afraid of movement (kinesiophobia) due to fear of pain, injury or instability.
- Decreased activity leads to decreased muscle tone, aerobic capacity, and strength, making pain and injury more likely.
- Fear of movement is also linked to fatigue, perhaps through decreased activity and deconditioning. (Celletti, 2013)
- Fear of movement is a common reason people with EDS/HSD do not exercise. (Simmonds, 2017)
Decreased Function: Fear of Movement

- PT should address this fear through gradually progressed activity and exercise
  - Best if integrated with a behavioral approach
- PT should not aggravate this fear by increasing pain (Perrot, 2018)
- Good communication and partnership with a PT knowledgeable about EDS/HSD can help patients exercise more successfully (Simmonds, 2017)
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Developmental Delay in Children

• Education about contributing factors
• Neuromuscular re-education (as for joint instability)
• Therapeutic exercise for functional stability, especially in mid-range (but not excluding end range)
• Orthotics, braces, environmental adaptations

(Engelbert, 2017)

http://www.otforkids.co.uk/conditions/developmental-delay.php
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Fatigue and Sleep Dysfunction

• Assess reasons for fatigue
  o Sleep disturbance due to:
    ◦ Pain, anxiety, poor sleep hygiene, apnea
  o Deconditioning, sedentary lifestyle
  o Trying to do too much, not pacing, boom/bust cycles
  o Stress, not being able to relax and recharge
  o Autonomic disorder such as POTS or orthostatic tachycardia
  o Psychological factors such as depression, grief, etc.
  o Diet
  o Medications
  o Other medical conditions: MCAD, fibromyalgia, etc.
    ◦ (Hakim, 2017)
Fatigue: Managing Poor Quality Sleep

- Pain interfering with sleep
  - Positioning for decreased pain
  - General pain management
- Sleep hygiene
- Physiological quieting, relaxation training
- Regular exercise
- Good information at https://sleep.org
Fatigue: Education

- Pacing
- Body mechanics
- Assistive technology and environmental modifications
- Excellent fatigue self-management booklet at: https://www.ncl.ac.uk/medicalsciences/research/centres/fatigue/ “CRESTA Fatigue Clinic - Managing Your Energy”
Fatigue: Managing POTS

- Education about: Hakim, 2017
  - Common triggers
  - Fluids, salt, compression stockings
  - Postural changes, muscle activation
  - Exercise positioning and progression
  - Pacing
  - Adapting tasks
- Exercise:
  - Progression from horizontal to vertical
  - Graded exercise therapy
- See WWW.POTSUK.ORG for excellent info
Fatigue: Graded Exercise Therapy

• Many people try to do too much too fast: “Start low, go slow”
• Stabilize your daily routine
• Start easy, e.g., muscle stretches or relaxation exercises
• Select an activity/exercise you enjoy and will do consistently
  o Set a baseline that you can do 5d/wk, even on bad days
  o Rest after exercise, sitting, not lying down, <30 minutes
• Increase time gradually – no more than 20%/wk
• Increase intensity once you can do 30 min/day
• Plan for setbacks
• Source: “Graded Exercise Therapy: A self-help guide for those with chronic fatigue syndrome/myalgic encephalomyelitis.”
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Incontinence

- Education about voiding, fluid management, urge inhibition, nocturia control
- Pelvic floor muscle retraining, including biofeedback
- Manual therapy to low back/pelvis/hips
- TENS protocol for incontinence (Neville, 2016)
- May need an women’s/men’s health specialist
Vaginal Pain

• Education about self-management
• Pelvic floor muscle retraining, including biofeedback
• Electrical stimulation
• Dilators
  (Morin, 2017)
• May need a women’s health specialist
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Anxiety

• Education about EDS/HSD
• Assessment for POTS, education about POTS self-management
• Neuromuscular re-education & exercise
  o To decrease fear of movement (Kernan, 2007)
  o To calm the nervous system
• Exercise: stretching muscles, relaxation, aerobic
  o Encourage Tai Chi, qigung, Pilates, (yoga), etc.
• Manual therapy, massage (Pederson, 2018)
Gastroparesis/Constipation

- Education about gastroparesis in EDS/HSD
- Aerobic exercise
- Trigger point management through self-care or manual therapy?
- Abdominal propulsive massage?
  Harrington & Haskvitz, Phys Ther. 2006;86:1511-19)
- Visceral mobilization (additional training needed)
Inflammation

• Education about inflammation, neurogenic inflammation, role of stress

• Education about Mast Cell Activation Disorder

• Exercise (regular aerobic exercise stimulates immune function; Abd El-Kader, 2018)

• Modalities to decrease localized inflammation during flares: ice, non-thermal ultrasound, phonophoresis, iontophoresis
Summary

• Physical Therapy can address a range of concerns that are common in EDS/HSD
• There are a variety of treatment approaches
  o Education emphasizing self-management
  o Exercise, neuromuscular re-education
  o Orthotics/bracing/adaptive equipment
  o Manual therapy
  o Modalities
• Exercises must be the correct ones for you, done correctly, in the correct dosage
• Some approaches require specialized training
Your PT should empower YOU to manage your EDS/HSD signs and symptoms
References


