PHYSICAL THERAPY AND EHLERS-DANLOS SYNDROME

From a Structural Approach to a Process Approach

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PHYSICAL THERAPY

A lack of awareness of the condition amongst health professionals, patients and wider society


EDS-HT: A CHARACTERIZATION OF THE PATIENT’S LIVED EXPERIENCE

- Joints (99%)
- Cardiovascular system (96%)
- Gastrointestinal system (96%)
- Skin (95%)
- Neurological/psychological manifestations (88%)
- Genitourinary system (67%)

Murray B et al. EDS-HT: A characterization of the patients’ lived experience. AJOMG. 2013

SUBJECTIVE HEALTH COMPLAINTS

The complaints reported were
- Musculoskeletal (98%)
- Pseudoneurological (96%)
- Gastrointestinal (94%)
- Allergic (73%) and
- Influenza-like (58%)


 PHYSICAL THERAPY IS generally accepted as an efficient treatment for some musculoskeletal complications of EDS


Physical therapy has limits especially concerning time spent (by both the practitioner and the patient), inter-operator variability, and long-term efficacy


ONLY 10%

of physicians referring EDS-HT patients to rheumatology clinics realized that their joint hypermobility was the underlying cause of their patient’s pain

ATTITUDES, BELIEFS AND BEHAVIOURS TOWARDS EXERCISE AMONGST INDIVIDUALS WITH JOINT HYPERMOBILITY SYNDROME/ EHLERS DANLOS SYNDROME – HYPERMOBILITY TYPE
J. Simmonds, M. Cairns, N. Ninis, W. Lever, Q. Aziz, A. Hakim
- 900 females and 46 males
- 81% (755/942) had received exercise advice from a physiotherapist
- 77% (701/940) agreed or strongly agreed that exercise was important for management

Swimming 28% (261/946)
Walking 24% (233/946) and
Pilates 22% (221/496)

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PHYSICAL THERAPY
- Diagnosis and subsequent referral to physiotherapy services is often difficult and convoluted
- Referral was often for acute single joint injury, failing to recognize the long-term multi-joint nature of the condition

PHYSICAL THERAPY
- Health professionals and patients felt that if left undiagnosed, EDS was more difficult to treat because of its chronic nature
- When EDS was treated by health professionals with knowledge of the condition, patients reported satisfactory outcomes

POSTURE CORRECTION
- Perceived asymmetry, imbalances, misalignments, or postural deviations are usually normal biological variations and not pathology, even in many cases of EDS
- The cause of many common musculoskeletal and pain complaints cannot be explained solely by biomechanics, structure or posture

ONLY ABOUT 4% OF PHYSICAL THERAPISTS ADMIT LIKING THE MANAGEMENT OF PATIENTS WITH PERSISTENT (CHRONIC) PAIN
Wolff MS et al 1991 Physical Therapy 71:207-214
LACK OF VALIDITY OF MOST COMMON ORTHOPEDIC TESTS

The majority of orthopedic tests used in physical therapy and medicine lack diagnostic validity, i.e.,

- Most tests for the shoulder (gleno-humeral joint) lack sensitivity and specificity
- There are no reliable tests for the position of the sacroiliac joint

The validity of a clinical test can be defined as the extent to which the test measures the intended construct.

The anatomical findings are not associated with the level of pain

Symptoms of Pain Do Not Correlate with Rotator Cuff Tear Severity
A Cross-Sectional Study of 393 Patients with a Symptomatic Atraumatic Full-Thickness Rotator Cuff Tear Dunn et al. JBJS 2014

LACK OF VALIDITY OF SACRO-ILIAC JOINT TESTS

- Tests for sacroiliac joint (SIJ) symmetry of motion and palpation fail to achieve meaningful reliability
- Numerous studies have examined the validity of palpatory and motion symmetry tests and have consistently found it to be limited
- Asymmetrical positions are likely to be the product of local muscular forces producing strain on the pelvis, which give the illusion of SIJ positional faults

Abnormal Findings in Asymptomatic Subjects

Of 1211 asymptomatic subjects in their 20s:

- 73.3% of males
- 78.0% of females

JOINT MANIPULATION

Many of our patients with EDS-HT have received joint manipulations to “correct stiff spinal segments”

It is, however, questionable whether EDS-HT patients ever need spinal manipulations

NO HANDS-ON PHYSICAL THERAPY??

If the goal of hands-on physical therapy is to correct asymmetry, imbalances, misalignments, or postural deviations, its value is questionable

ERGONOMICS

The best ergonomic chair is only as good as the behavior of the person who sits in that chair

ERGONOMICS

Ergonomic modifications are often indicated, but they are not the silver bullet to solve all problems

RING SPLINTS
CHRONIC PAIN

Dutch study:
- 92% reported chronic pain
- 87% of those with pain were disabled


“Waiting for the pain to go before returning to physical activity is not going to work, because inactivity and abnormal movement are the two most important driving forces for the pain”


“.... the pain will ease but only when the muscles are strong and fit and are protecting the joints more fully, and when the child is functioning normally both biomechanically and generally....

.... the pain is the last thing to improve and only does so slowly.....


PHYSICAL THERAPY FOR PAIN MANAGEMENT

- In chronic pain these areas of the brain are likely to be ‘enslaved’ by pain
- Exercise or specific movements can be difficult, since the motor cortex is being utilized as part of the pain neuromatrix

PHYSICAL THERAPY FOR PAIN MANAGEMENT

- Patients have been accused of malingering, or being lazy or not motivated
- Yet from a neuroscience perspective there is a justified reason for their difficulty with these exercises


PHYSICAL THERAPY FOR PAIN MANAGEMENT

- Traditionally, clinicians have either followed a top-down (cognitive) or a bottom-up approach (such as manual therapy) to treat pain
- The two approaches are not mutually exclusive and clinicians are therefore urged to consider a combination of the two


COMBINATION

- TOP-DOWN: therapeutic neuroscience education (TNE)
- BOTTOM-UP: manual therapy and exercise

HANDS-ON PHYSICAL THERAPY??

If the goal of hands-on physical therapy is to complement "therapeutic neuroscience education", hands-on therapy can be very useful

- Manual therapy
- Soft tissue mobilizations
- Dry needling
- Exercise

HANDS-ON PHYSICAL THERAPY??

- Therapeutic neuroscience education works best if combined with movement-based therapies such as manual therapy and exercise
- Feeding the brain information ‘from both ends’

WHAT DOES THE RESEARCH SAY ABOUT PT, EDS AND EXERCISE?

Not much......
Positive outcome:

- Only 33.9% of the patients who underwent surgery
- Only 63.4% of patients in physical therapy

No convincing evidence that exercise was better than control or that joint-specific and generalized exercise differed in effectiveness
Internal Focus

vs

External Focus

COMMON PT HOME EXERCISE PROGRAM

AROM shld push-ups at wall
- Stand facing wall, about 12-18 inches away
- Place hands on wall at shoulder height
- Slowly bend elbows, bringing face to wall
- Push back to start position and repeat
Perform 1 set of 5 repetitions, twice a day
Perform 1 repetition every 4 seconds

COMMON PT HOME EXERCISE PROGRAM

AROM knee step ups
- Stand with involved leg up on step
- Shift weight over knee
- Step up slowly
- Step back down leading with involved leg
- Repeat
Special Instructions:
Do not push off with trailing foot. This can be done by keeping ball of foot of the trailing foot lifted up.
Perform 1 set of 5 repetitions, twice a day
Perform 1 repetition every 4 seconds

COMPLIANCE

- Of 364 patients, 73% were referred to exercise rehabilitation following cardiac surgery, 42% did not complete the program and 28% never showed up


COMPLIANCE

- Up to 70% of patients do not engage in prescribed home exercise

An apparent conflict existed between

- offering a ‘specific’ exercise program based on physical impairments and pain patterns derived from assessment, and
- empowering patients to take control by undertaking an exercise program they found fun or enjoyed

Physiotherapy (2015)

**INTERNAL VS EXTERNAL**

**Internal focus:**
- “Exert force with outer foot”

**External focus:**
- “Exert force on the outer part of the plate”

**Control:**
- No focus instructions


Examples of supra-postural tasks
The focus of attention clearly has significant effects on the **accuracy** with which subjects can **generate force** and significant effects of **motor planning in force production**

Human Movement Science 31 (2012) 12–25

Training with an external focus of attention leads to improved performance when no attentional focus instructions are given

Human Movement Science 31 (2012) 12–25

An external focus of attention increases the automaticity of control

Human Movement Science 31 (2012) 12–25

- Competitive cyclists performed significantly faster during a 16.1-km competitive trial than when performing maximally, without a competitor
- The improvement in performance was elicited due to a greater external distraction, deterring perceived exertion

Journal of Science and Medicine in Sport 18 (2015) 486–491

The advantages of an external focus of attention may not be immediate, but often emerge only later in practice (but the research is not consistent....)

Human Movement Science 33 (2014) 120–134

An external focus of attention does not only improve performance, but could improve learning as well

Human Movement Science 33 (2014) 120–134
An internal focus of attention can hinder learning relative to an external focus.

Human Movement Science 33 (2014) 120–134

APPLIES TO

Sports performance:
- Golf
- Basketball
- Volleyball
- Soccer
- Dart throwing
- American Football
- Jumping

MULTIPLE SCLEROSIS

MS patients with balance problems
1. conventional balance training (control),
2. exergame training (playing exergames on an unstable platform)
3. single-task (ST) exercises on the unstable platform

Playing exergames on an unstable surface had superior outcomes in balance and adherence

DOES IT WORK?

From a Structural Approach to a Process Approach

- Ehlers Danlos Syndrome??
- POTS??

There is no research yet, that demonstrates superior outcomes

Eileen - Ehlers Danlos Syndrome
DOES IT WORK?

Molly - Postural Orthostatic Tachycardia Syndrome

DOES IT WORK?

Molly - Postural Orthostatic Tachycardia Syndrome

DOES IT WORK?

Cassidy - Ehlers Danlos Syndrome and Postural Orthostatic Tachycardia Syndrome

THANKS TO

EILEEN
MOLLY
CASSIDY
DR. MARIA ARINI, PT, DPT
EDNF
OUR OTHER PATIENTS

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