Ehlers-Danlos, Exercise & Rehabilitation

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Disclosures

- No conflicts of interests
- All patients have given permission for their images/stories to be used in this talk.
Not Weightlifting Injuries
Not Football Injuries

THAT'S GOTTA HURT ...
Pittsburgh Steelers running back Destry Wight lies injured on the field Sunday night after he dislocated his right ankle and broke his right leg.
Not all hyperflexible athletes have a connective tissue disorder!

Not all patients with connective tissue disorders are pathological flexible!!
Do EDS Patients Exercise?

- 1440 questionnaires
- 205 responses
- Response rate 13.8%
- 196 questionnaires were included
- Respondants:
  - 160 female
  - 38 male

Type of Respondents

- 22 (11.6%) Unknown
- 14 (7.1%) Vascular
- 50 (25.5%) Classical
- 103 (52.6%) Hypermobile

How Active are EDS patients?

- **Age Range:** 5-75y.o.
- **17% (34/196) Swam in:**
  - HS, College, or Recreatationally
- **26.5% (48/181) Exercised Daily**
- **43.7% (79/181) Exercised 2-4x/wk**
- **16.6% (30/181) Did no exercise**

What factors determine flexibility?

- Genetics
- Stretching
- Muscular Mass
- Age
- COLLAGEN!!

USAW Pan Am Team July 2015, Toronto, CAN
USOTC Colorado Springs, CO -- 130 kg (286 lbs) deadlift
**Strength Training**

- **DO**
  - Core strength
  - Daily exercise
  - Body weight
  - Resistance Bands
  - Dumbbells/Barbells
  - Machines

- **DON’T**
  - Cross-fit
  - Olympic Lifts

Kendrick Farris at 2011 Pan Am Games before 2012 Summer Olympic (London)

Kendrick at 2015 Pan Am Games, GOLD Medal

Bronze Medalist: Chad Vaughn
2011 77kg BW 176 C&J
Cardio Training

◆ DO
  - Walk (10,000)
  - Swimming
  - Elliptical/Stepper
  - Treadmill-incline
  - Stationary bike
  - Ergometer

◆ DON’T
  - Distance running

4.4 mile Chesapeake Swim
Core strength/ Flexibility/Balance

◆ **DO**
  - Thera-Ball
  - Yoga
  - Tai Chi
  - FMS
  - Ballroom Dance
  - TRX

◆ **DON’T**
  - Competitive Cheer / Gymnastic

2014 World University Team USA in Chang Mai with 1st and 2nd place team trophies!
Just Do it!

- Do not feel sorry for yourself!!
  - Or I will introduce you to
    - US Veteran
    - Baby with Retinolastoma

- GET OFF YOUR NARCOTICS!!
Just Do it!

- Exercise EVERY day!! UNLESS
  - Temp > 101
  - Having surgery that day
- Laugh EVERY Day
- Help someone less fortunate than you weekly
Just Read this Book!

- You will learn to appreciate:
  - Your pain
  - What generations before us had to endure!

- Set GOALS:
  - Short-term (1-3 months)
  - Long-term (1-3 years)
Case #1: Hong Kong Phooey

- 34yo Martial Artist
  - World Champion
- Presents with:
  - Multiple joint complaints
  - Joint Pain
  - Multiple joint laxity/dislocations
  - “loose skin”
History

- **Family History**
  - Mom some “loose joints”
  - Maternal Aunt “loose jointed”

- **Athletic History (currently, retired)**
  - 7 State Titles
  - 3 National Titles
  - 1 World Championship, Gold Medal
  - Martial Arts Hall-of-Fame inductee

  - 2000 Competitor of the Year
Case 2: Stretch Armstrong

- 15y.o HS Wrestler
- Presented w/
  - R shoulder dislocation (x5)
  - L shoulder pain
- Exam:
  - Muscular, strong
  - Notable laxity when relaxed
Exam

- **Face Skin:**
  - No scars
  - Hyperextensible

- **Hands:**
  - Hypermobile at:
    - MCP
    - Thumb

- **Shoulders:**
  - Auto-Sublux

- **Meet 9/9 Carter-Wilkerson Criteria**
Case 3: Champion Swimmer

- 17y.o. HS varsity swimmer
  - Freestyle/Butterfly
  - Swims 15,000m/day
  - Gone to State championship last 2 years.
  - c/o b/l shoulder pain
  - Skin: hyperextensible, soft
**Exam**

**GEN:**  Ht 6’1” Wt 185  
Ht:Armspan <1:1.05

**Wrist:**  
Hyper flexion to 125°  
Thumb to forearm

**Shoulder:**  
Painless auto-dislocate  
Abduct to 230°

**Hips:** hyperflexible  
“Palm on floor”
Case 4: Recreational Cyclist

- 28 y.o. cyclist who fell & struck his left chest and abdomen.
- He sustained:
  - Large left flank hematoma
  - Left A/C separation
  - Left Chest wall contusion
- Initial eval. was in ER
Tests

- **CXR:**
  - Aortic Aneursym?

- **ECHO:**
  - Large aortic arch dilation
  - nl EF
  - min MVP
  - no MR

- **Biopsy:** (+) **COL3A1 gene**

- **Diagnosis:** **EDS**
  - Vascular type
In Conclusion
Recommendations

- Consider Physical Therapy:
  - Strengthening the kinetic chain
  - Proprioceptive re-training
  - FMS training

- Prevent injury:
  - Avoid contact, collision sports
  - Avoid high dynamic sports
Recommendations

- **Encourage activity:**
  - Low *static*, Low to Mild *dynamic*
  - May recommend sports like biking, swimming, weight-training, golf.
  - Patients often excel at certain sports due to "genetic" advantage b/c of flexibility.
  - Mild Strength training has show benefits in joint stabilization
Recommendations

- Cardiovascular Screening
  - ALL patients should get an initial ECHOCARDIOGRAM & AORTIC ULTRASOUND
  - Every 3-5 years for average patient
  - Every year for those with:
    - Aortic Dilatation
    - Severe valvular disease
    - Severe HTN
    - Highly Dynamic sports
Recommendations

- **Wound closure issues**
  - Dermabond / steristrips better than sutures

- **Reproductive concerns**
  - Pregnancy
  - Autosomal Dominant

- **Provide psychological support**

- **Surgery as last resort.**
Final thoughts

- Keep EDS in differential diagnosis of the Hyperflexible Athlete.
- Still as of 2014, diagnosis made by history and a thorough exam.
- Be wary of sports where flexibility is important!
  - Gymnastics, wrestling, swimming, figure-skating, cheerleading, dancers
Sometimes athletes, despite less than optimal genetics, still can succeed if they work hard enough.
Thank You!

2013 US World Weightlifting Team, Wroclaw, Poland
References

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