Do people with joint hypermobility represent a subgroup of ME/CFS?

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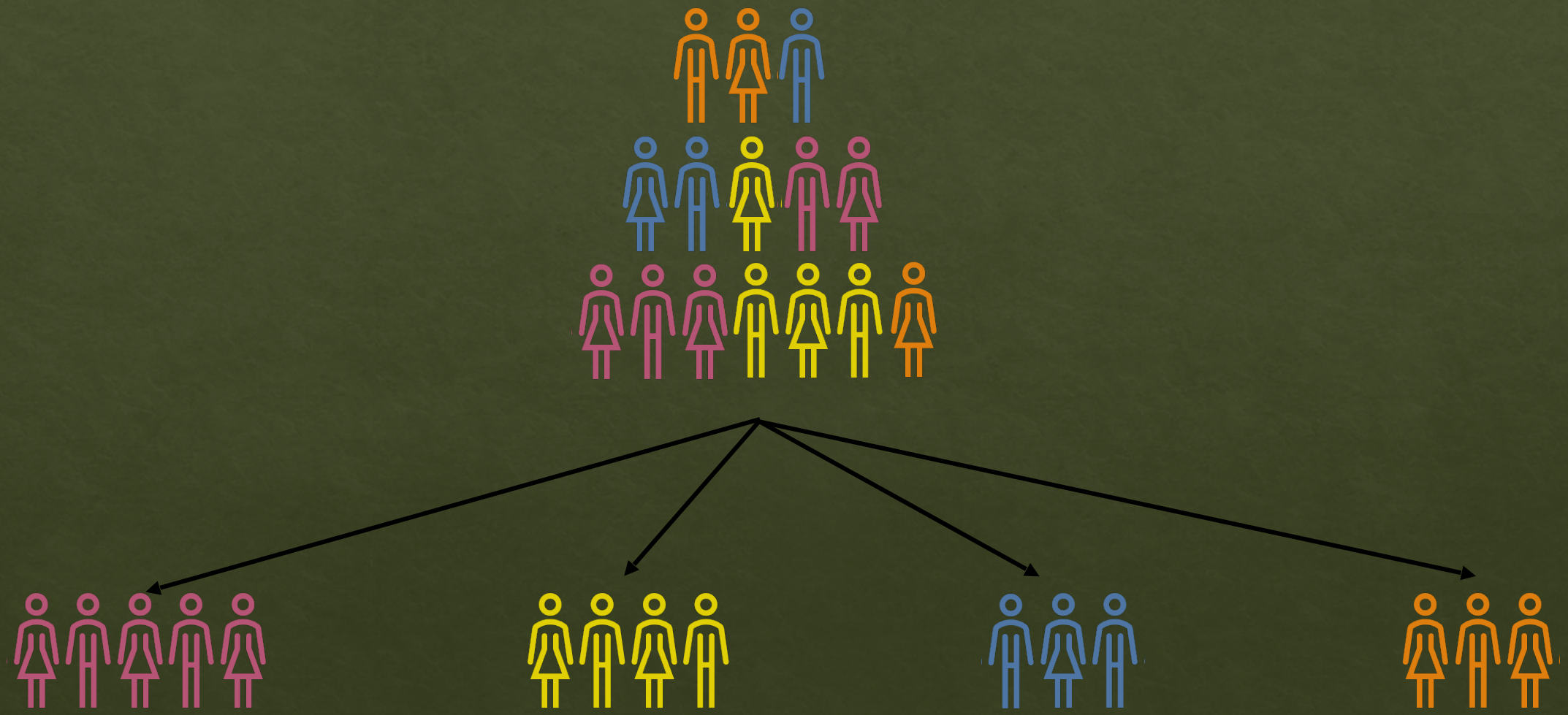
Subgroups of ME/CFS



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Joint Hypermobility (JH+)

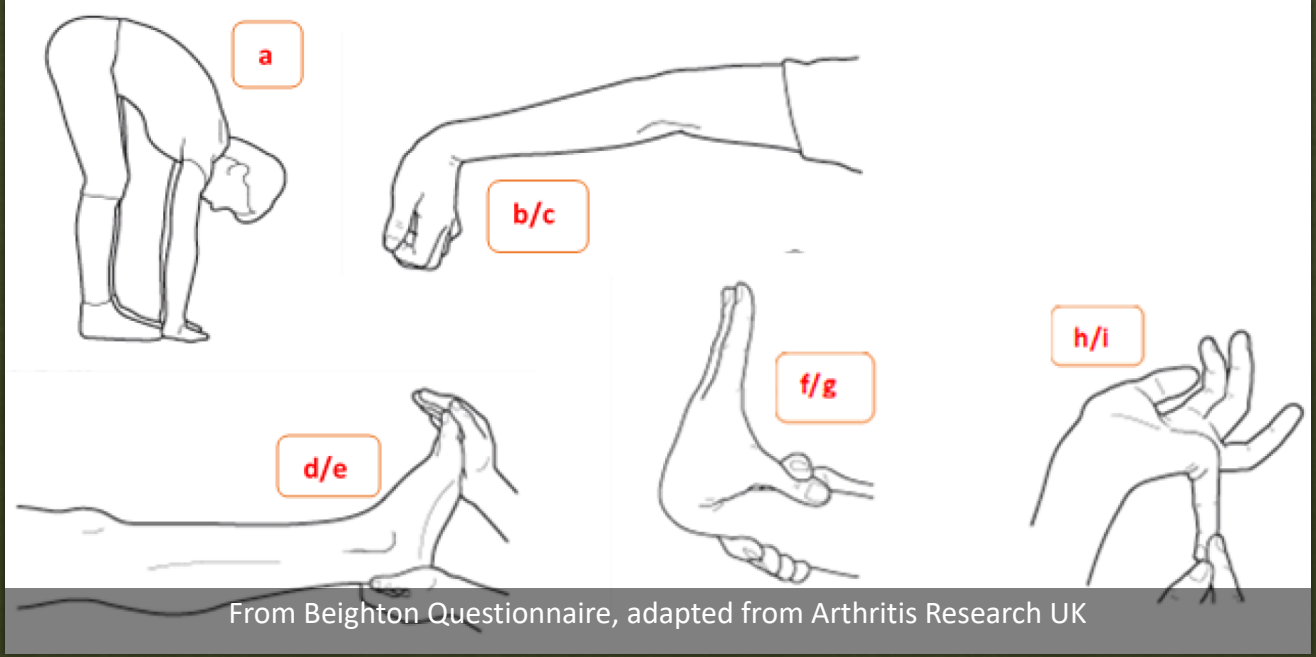
'Double-jointedness'

Advantage or Disadvantage?

- Joints = more mobile than usual
- Exact cause(s) = unknown
- Feature of genetic connective tissue disorders, e.g. Ehlers-Danlos Syndrome (EDS)

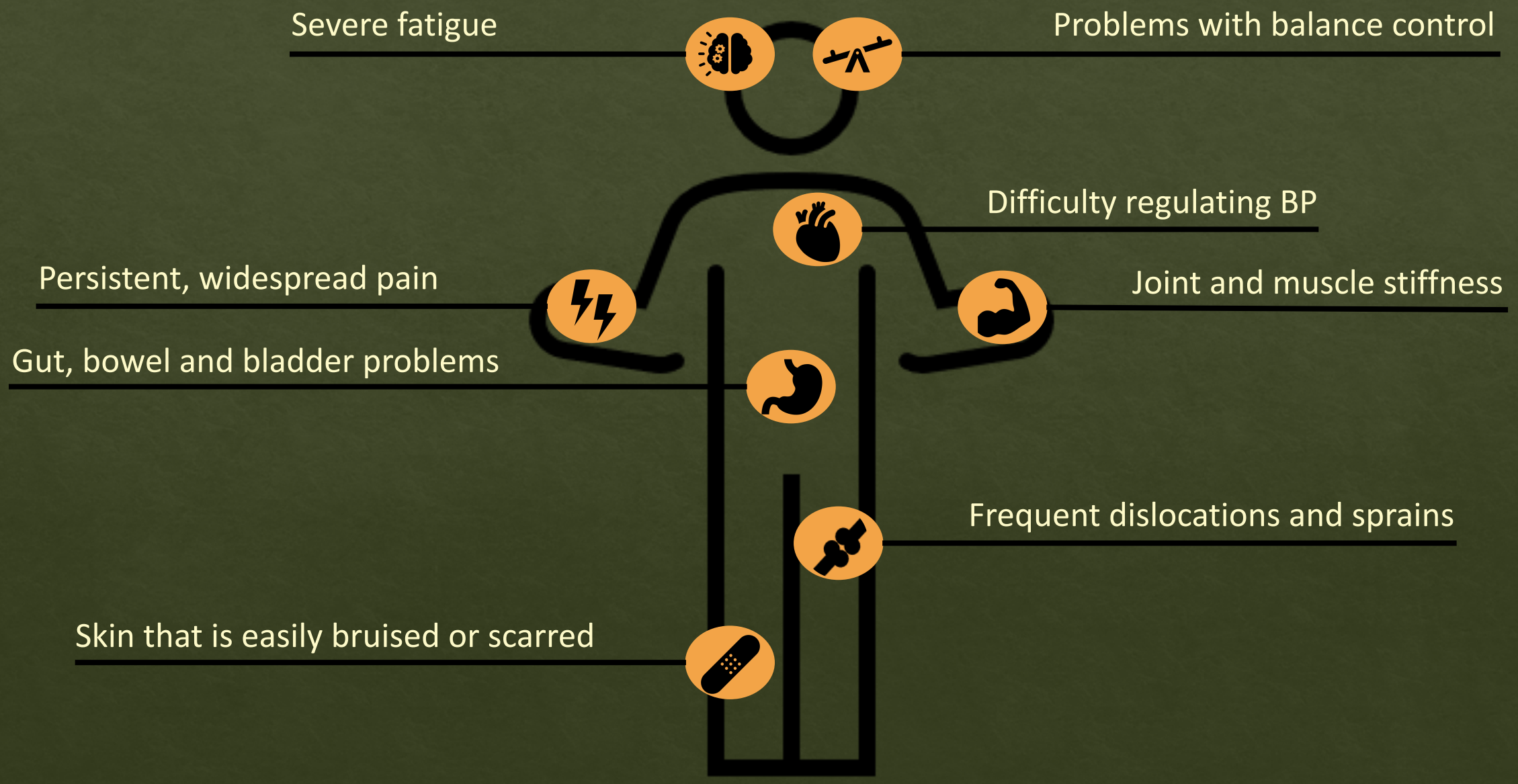
Generalized JH+ using Beighton Score

- Only examines limited # of joints
- Will miss internal disease
- May not act as predictor for disease severity



From Beighton Questionnaire, adapted from Arthritis Research UK

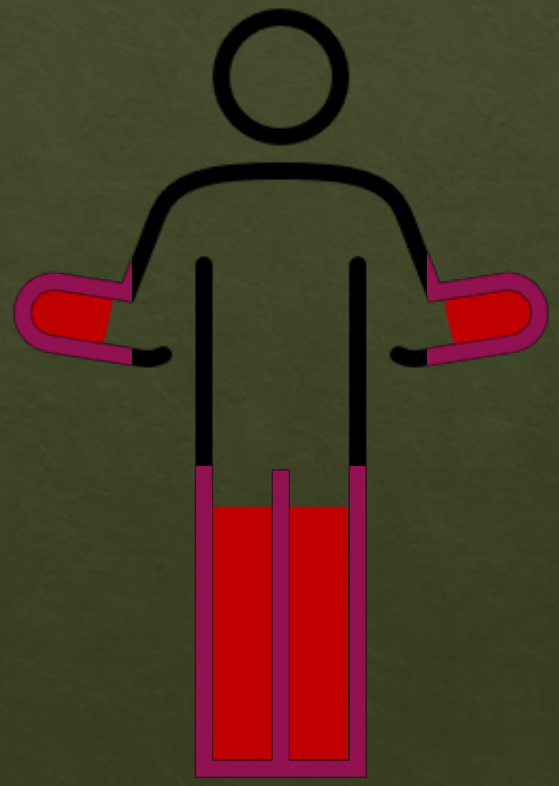
JH+ = Multi-Systemic



Is JH+ Associated with ME/CFS?

1. Connective tissue looseness in the circulatory system

upright posture leads to excessive pooling of blood in extremities and to many of the symptoms seen in ME/CFS, like POTS



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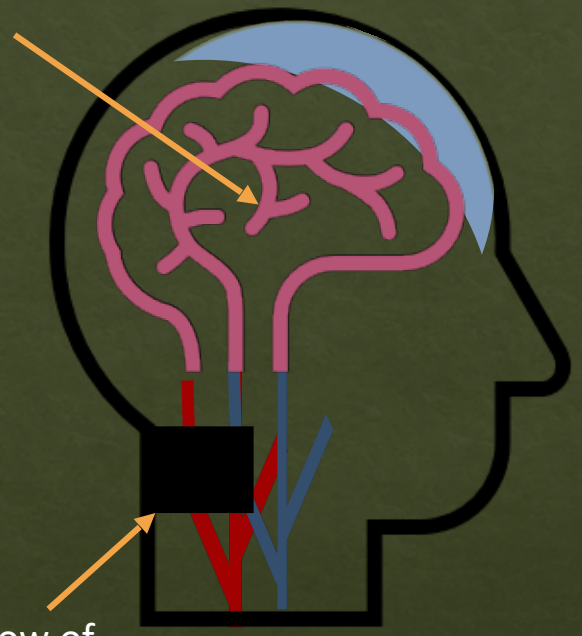


2. Craniocervical obstructions

obstruction of arteries and veins result in fluid build-up in parts of the brain, which can cause symptoms like brain fog

Impact of JH+ on ME/CFS

age of onset

type of onset (abrupt vs gradual)

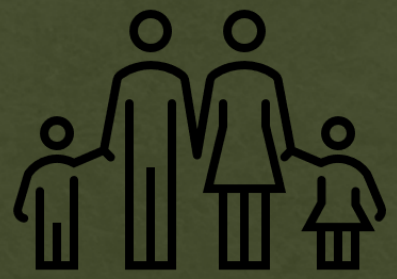
types of symptoms

co-existing conditions

health-related quality of life (HRQoL)

overall severity

Do JH+ ME/CFS represent a subgroup?



- 55 ME/CFS (CDC-94)
- aged 10-30 years
- JH+ = Beighton score ≥ 4 (51%)

PREVIOUS RESEARCH:
Vogel et al 2022 publication with Dr Rowe

- **Hypothesis**: JH+ ME/CFS = earlier onset of symptoms, increased severity, more co-existing conditions, lower HRQoL
- **Found:** joint hypermobility was not associated with clinical characteristics of the illness

"This paradox requires further exploration"

https://doi.org/10.1016/j.jpeds.2021.09.014

The You + ME Registry

3,487

ME/CFS

Do JH+ ME/CFS represent a subgroup?

- 687 ME/CFS (CDC-94/CCC)
- aged >18 years

CURRENT RESEARCH:
You + ME/CFS Registry

- **Hypothesis**: JH+ ME/CFS and JH- ME/CFS = sub-groups -> could lead to targeted treatment for a beneficial impact on HRQoL
- JH+ = Beighton score >= 5 if under 50 & >= 4 if over 50 (12%)

Findings: No Significant Differences

Biological sex
Age
BMI
# of co-existing conditions
Onset of ME/CFS
Age at symptom onset
SF36 scores (HRQoL)
Multi-dimensional Fatigue Inventory scores

Headache or migraine symptoms
Light headedness
Brain fog
Tingling or numbness in arms / legs
Dizziness or faintness while standing
Intolerance to standing
Gut, bowel, or bladder problems
Anxiety

Findings: Differences

Significant differences:

- Self-reported EDS
- Family history of EDS
- Self-reported POTS
- Loss of balance, unsteadiness on feet when standing or inability to focus vision

Some differences:

- Mild/Moderate Impairment vs Severe/Very Severe Impairment
- Dizziness or faintness while standing up
- # of autonomic symptoms
- Intolerance to standing
- Joint pains moving to different joints without redness or swelling

Indicates whether increased/decreased in JH+ ME/CFS compared with JH- ME/CFS

Limitations

Low Beighton score DOES NOT rule out JH+: 4% of ME/CFS self-reporting EDS did not meet JH+ according to Beighton Score

Self-reported data

Selection bias

Future Research

- To accurately diagnose JH+:
  - In-depth and thorough physical exam + family history
  - Appropriate genetic testing
  - Skin biopsy
  - Indication of severity
- To accurately investigate hypotheses of association:
  - POTS testing
  - Heart rate variability & blood pressure
  - Loss of blood flow to brain

Thank you!

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