II INTERNATIONAL CONGRESS ON HYPERMOBILITY, EHLERS-DANLOS SYNDROME AND PAIN

21 to 23 August, 2015
São José do Rio Preto – SP – Brazil

"Is hypermobility healthy?"

Joint limitations of lower limbs are also a sign of Ehlers-Danlos syndrome (EDS). Results with 252 patients

Claude. Hamonet* ** MD, PhD,* Isabelle Brock* MD, MD, David Cypel*, Carolina Baeza-Velasco*** PhD
*Ehlers-Danlos Clinic, Hospital-Hotel-Dieu, 1 place du Parvis Notre-Dame, 75181 Paris, Cedex 04, France.
**Department of Medicine, University Paris-East-Creteil (UPEC), 8 rue general Sarrail, 94000, Creteil, France.
***Psychology Institute, University Paris-Descartes, Sorbonne, Paris City, Boulogne-Billancourt, France

INTRODUCTION

Hypermobility in Ehlers-Danlos syndrome was the first historical finding (Tschenogobow, 1892, Ehlers 1900) and is still deemed by many to be a requirement for diagnosis. The discovery of muscle and tendon retractions in lower limbs as a part of this syndrome sheds new light on the diagnostic.

GOALS

To assess the incidence of lower limbs retractions and mobility limitations in Ehlers-Danlos syndrome.

METHODOLOGY

Our study included 232 patients (84% women) from 2 to 70 years of age. Diagnosis Type III/joint hypermobility was made in accordance with the Villefranche classification and Brighton criteria (Grahame & Beighton).The patients enrolled in the study are of the hypermobile type. We looked for muscle, tendon, and aponeurosis retraction in the knees, ankles, and the soles of feet.

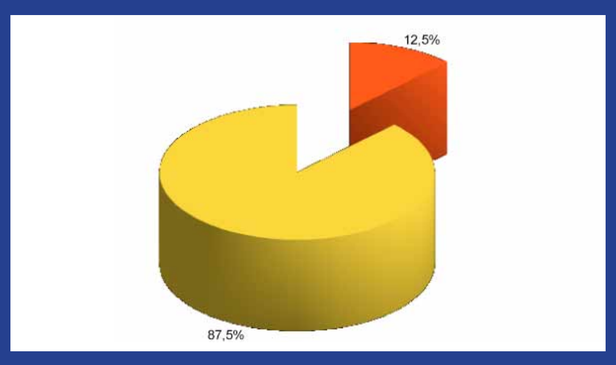
Retraction of hamstrings and sural triceps

Test hill- buttock, contrasting with hamstring retraction

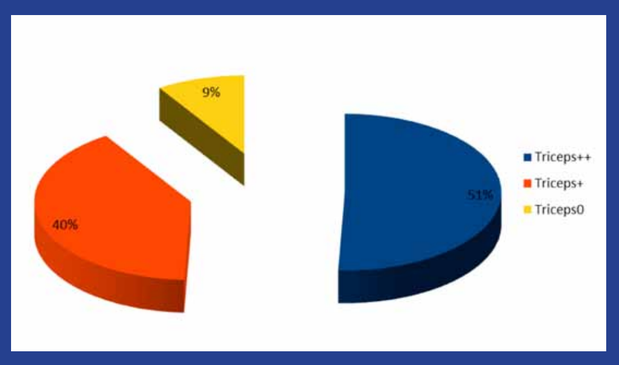
Impossible to touch the ground with hands (hamstrings contracture)

RESULTS

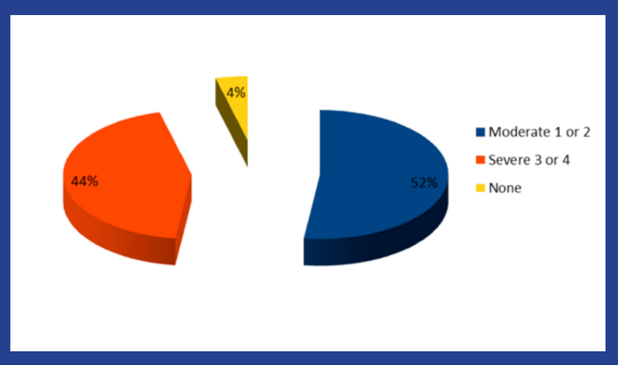
In our population of patients, we found a retraction of the hamstrings in 203 individuals (87.5%). Retractions of the sural triceps were found in 90.9% of patients, and retractions of the soles of feet were observed in 95.9% of patients. **In children aged 10 and under (32/38 patients): 84.2%.**



Prevalence (87, 5%) of hamstrings contractures inside a population of 232 patients.

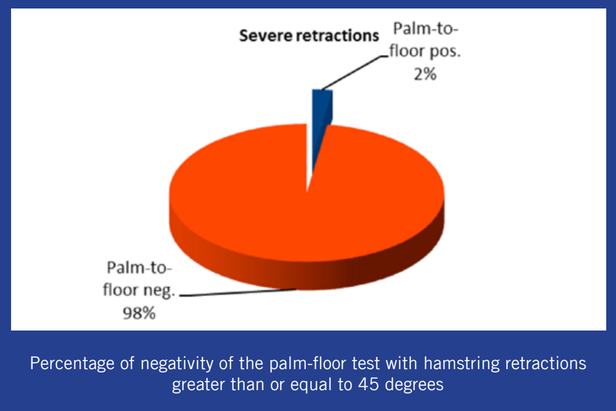


Retractions of the sural triceps

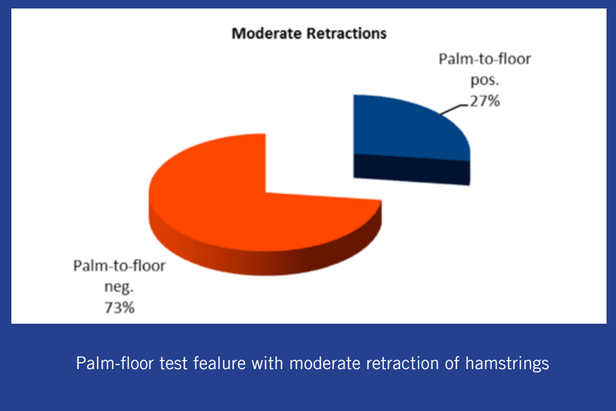


Plantar retractions

The impact of retraction on the Beighton palms-on-the-floor test is very great indeed: 97.8% of patients who present a retraction of the hamstrings of over 45° cannot perform this maneuver.



Percentage of negativity of the palm-floor test with hamstring retractions greater than or equal to 45 degrees



Palm-floor test fealure with moderate retraction of hamstrings

Hamstring retraction does not, however, affect the test of knee recurvatum.

CONCLUSION

The presence of muscle and tendon retractions in the posterior muscle compartments of the lower limbs and the soles of the feet constitute clinical features of Ehlers-Danlos syndrome. This finding moderates the results of Beighton score. They should be addressed with a view to prevention and treatment, through physical therapy (stretching) but not by surgery.

KEY-WORDS Ehlers-Danlos Syndrome, hypermobility, Beighton score, Brighton score, contractures, physical medicine.

BIBLIOGRAPHY 1- Hamonet Cl., Vlamynck E., Serre N., "*Ehlers-Danlos syndrome, retractions of muscles flexor of Knees and Beighton test*", Poster, First international Symposium on the Ehlers-Danlos syndrome, Ghent (Belgium), September 8th-11th 2012
2-C. Hamonet, I Brock (2015) Joint mobility and Ehlers-Danlos syndrome, (EDS) new data based on 232 cases. J Arthritis 2015, 4: 148 doi: 10.4172/2167-7921.1000148

II INTERNATIONAL CONGRESS ON HYPERMOBILITY, EHLERS-DANLOS SYNDROME AND PAIN

21 to 23 August, 2015
São José do Rio Preto – SP – Brazil

"Is hypermobility healthy?"

Ehlers-Danlos Syndrome (EDS). Contributions of therapeutic compression garments and oxygen therapy.

Claude Hamonet* ** MD, PhD, Elodie Vlamynck***, Monique Vienne****, Franck Leroux*****, Gilles Mazaltarine******, Roland Jaussaud*******, Carolina. Baeza-Velasco PhD********
*Ehlers-Danlos Clinic, Hospital-Hotel-Dieu, 1 place du Parvis Notre-Dame, 75181 Paris, Cedex 04, France.
**Department of Medicine, University Paris-East-Creteil (UPEC), 8 rue general Sarrail, 94000, Creteil, France.
***Orthopédie Vlamynck, 34 Rue de l'Orangerie, 78000 Versailles, France.
**** IMAP 06800 Cagnes sur mer.
*****ASV Santé, 93240 Stains, France
******Service de Rééducation neuro-orthopédique, CHU Henri Mondor, Créteil, France
*******Service de Médecine Iinterne CHU de Nancy, France.
********Psychology Institute, University Paris-Descartes, Sorbonne, Paris City, Boulogne-Billancourt, France

INTRODUCTION

The mechanical consequences of the achievement of collagen in the connective tissue on SED are twofold: their least resistance and loss of elasticity. The tissues are more brittle (bleeding) and less reactive: sensors implanted in these tissues do not transmit or badly (sometimes too much) information to the control systems, creating an imbalance of what is also called the **sixth meaning**: that of his **own body**.

GOALS

Our therapeutic goal is to improve the responsiveness of tissues to the whole of the body casing and the respiratory tract.

METHODOLOGY

For body shell, compression garments, custom, are used for the trunk and limbs. They apply the principle of clothes for burned but with another pressures (13.5 mmHg, for a cross section of 24 cm and between 6 and 10 mm Hg, for a radius of 55 cm). They are associated with other orthotics systems (insoles, lomboscapulaire belt, hand braces) with which they combine their effects. Other types of orthotics (dental, palate, prism glasses) can also enhance proprioceptive control.
For the respiratory system, the first application was the use of Percussionnaire of Forrest Morton Bird to solicit respiratory proprioception and fight against «blockages» and frequent (76%) dyspnea in the SED. Observing that ventilation by the Percussionnaire decreases fatigue, we coupled this treatment with oxygen 2 or 3 times a day, 3/5 liters per minute for an adult or oxygen alone.

RESULTS

1,800 patients were fitted with compressive garments. Proprioception is significantly improved by the clothes («*I feel my body*» say some patients) with better control of walking and upper extremities (shoulders and hands). The pains decrease.
Over 2000 patients have received ventilatory treatment. The percussionnaire improves dramatically blockages, bronchitis, pathological manifestations of the upper airways. Oxygen therapy has an effect on fatigue in 73% and 93% in episodic. On headaches, efficiency was 67% and 53% on the subjective quality of life.

Proprioceptive garments

Gloves with a special adhesive system

Socks with external couture (skin hyperesthesia)

CONCLUSIONS

In a very difficult to treat disease, the compressive garments and oxygen therapy appear to be a particularly interesting contribution .

KEY-WORDS Ehlers-Danlos syndrome, oxygen therapy, compressive garments, orhesis.

CONTACT

Report of the first International colloquium «treatments of Ehlers-Danlos syndrome», Paris-Creteil 7 mars 2015 - claude.hamonet.free.fr/fr/home.htm

II INTERNATIONAL CONGRESS ON HYPERMOBILITY, EHLERS-DANLOS SYNDROME AND PAIN
21 to 23 August, 2015
São José do Rio Preto – SP – Brazil

"Is hypermobility healthy?"

Specialized certificate on Ehlers-Danlos syndrome (SED), a new medical cursus (continuing education) in a French University since 2014

Claude Hamonet* ** MD, PhD, Carolina. Baeza-Velasco PhD***
*Ehlers-Danlos Clinic, Hospital-Hotel-Dieu, 1 place du Parvis Notre-Dame, 75181 Paris, Cedex 04, France.
**Department of Medicine, University Paris-East-Creteil (UPEC), 8 rue general Sarrail, 94000, Creteil, France.
***Psychology Institute, University Paris-Descartes, Sorbonne, Paris City, Boulogne-Billancourt, France

INTRODUCTION

The main problem faced by individuals with Ehlers-Danlos syndrome is the absence and inadequacy of knowledges from physicians about their disease and its treatments. To fill this gap, the Paris-Est-Creteil University, decided to put in place, a specialized degree *Ehhers-Danlos syndrome*.

GOALS

Train physicians for clinical diagnosis and treatments of the SED. Psychologists, health professionals are also allowed.

METHODOLOGY

Teachers are both competent in their field and in the Ehlers-Danlos syndrome. Geneticists, Rehabilitation, (included scoliosis and bladder reeducation), rheumatologists, gastro-enterologist, orthopaedic and visceral surgeons, gynecologist, odontologist, cardiologist, sleep therapist, psychologists, neuro-imagist, orthesists, physical therapist. They came From France, Quebec (Gail Ouelette) and Great-Britain (Rodney Grahame). The volume of lessons is 110 hours of theoretical instruction and 30 hours of practical lessons. Six two-day sessions over six months for theoretical teaching. Realization of an applied research work about EDS.
A French international colloquium with the participation of EDS specialists was organised in the middle of the teachings with the participation of Rodney Grahame, (London), president, Marco Castori (Roma), Jaime Bravo (Denver & Santiago), Daniel Manicourt (Brussells).

RESULTS

15 medical students will graduate in September 2015 (8 generalists practioners:, 3 Rehabilitation medicine, 1 orthopedist surgeon,1 gynecologist:, 1 pain therapist) and a psychologist. Thea are from different places in France and for three of them to Geneva, Germany and Rabah.

CONCLUSIONS

This type of training has shown that trained physicians are able to diagnosis and treatment of people with SED. This model is reproducible.

KEY-WORDS Ehlers-Danlos syndrome, continuing education, education and Ehlers-Danlos syndrome.

CONTACT

pr. hamonet@wanadoo.fr and claude.hamonet.free.fr/fr/home.htm