

Shoulder function, pain and health related quality of life in adults with Joint Hypermobility Syndrome/Ehlers-Danlos Syndrome, Hypermobility Type

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Introduction. The shoulder is a frequently reported pain area and associated with shoulder instability in patients with Joint Hypermobility Syndrome (JHS) and Ehlers Danlos-hypermobility type (EDS-HT). No studies have reported the nature of shoulder function in this group.

Aims. To investigate characteristics of shoulder function, pain and health related quality of life (HRQoL) in adults with JHS/EDS-HT, compared with the general population (controls).

Materials and methods. Through postal survey 110 patients diagnosed with JHS/EDS-HT from two Norwegian specialized hospitals, and 140 gender- and age-matched healthy controls from Statistics Norway were invited. Shoulder function (Western Ontario Shoulder Instability Index, WOSI), pain (Numerical Pain Rating Scale, NPRS, and pain drawing chart), and HRQoL (36-item Short Form, SF-36), were registered.

Results. Totally, 81 individuals responded (overall response rate: 34%; JHS/EDS-HT: 53%; controls: 21%). JHS/EDS-HT had significantly lower shoulder function (WOSI total: 49.9 vs. 83.3; $p < 0.001$), general physical function (SF-36, Physical Component scale: 28.1 vs 49.9; $p < 0.001$), higher pain intensity (NRS: 6.4 vs. 2.7; $p < 0.001$), than controls, and JHS/EDS-HT often reported generalized pain. Neck and shoulder joints were the most frequently rated painful areas, with higher frequency in JHS/EDS-HT (neck: 90% vs 27%; shoulder: 80.% vs 37%) than controls.

Conclusions. Adults with JHS/EDS-HT have impaired shoulder function, increased pain intensity, more often generalized pain, as well as reduced physical HRQoL, compared with the general population. Neck and shoulder joints were the most often painful areas in both groups, however, with significantly higher frequency for JHS/EDS-HT.