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EXERCISE BELIEFS AND BEHAVIOURS AMONGST INDIVIDUALS WITH JOINT HYPERMOBILITY SYNDROME/ EHLERS DANLOS SYNDROME – HYPERMOBILITY TYPE

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Background: Joint hypermobility syndrome is a complex multisystem hereditary disorder of connective tissue (HDCT). Many authorities now consider JHS to be indistinguishable from Ehlers-Danlos Syndrome - Hypermobility Type (EDS-HT). The term JHS/EDS-HT is used here to describe these inseparable entities. The reported prevalence of JHS/EDS-HT in musculoskeletal rheumatology and physiotherapy outpatient settings in the UK ranges between 30% and 60%. Physiotherapy plays a central role. Exercise and pain management is considered the treatment of choice, however there is limited research evidence about optimal exercise prescription. Greater understanding of individual preferences, perceptions of exercise and patients' experience of physiotherapy is needed to optimise treatment approaches.

Purpose: To explore the beliefs and behaviours about exercise amongst individuals with JHS/ EDS-HT. A secondary objective was to explore experiences of physiotherapy.

Methods: A survey design collected quantitative and qualitative data via a self – administered questionnaire. Expert opinion was sought from physiotherapists, rheumatology consultants and patients to ensure face validity of the questionnaire. The questionnaire was distributed to members of the Hypermobility Syndrome Association (HMSA) and Ehlers Danlos Syndrome Support UK (EDSUK) aged 18 years and older. 948 questionnaires were returned. Data was scrutinised and 2 duplicate questionnaires were removed. Descriptive statistics and Chi squared tests using SPSS v23 were used to analyse the data. 12 incomplete questionnaires were included in this data analysis. Qualitative data were analysed thematically.

Results: Nine hundred females and 46 males completed the questionnaire. 90% (897/946) of respondents suffered 'constant' or 'frequent' joint pain while 87% (819/946) suffered 'constant' or 'frequent' fatigue. Spinal pain was the most commonly reported site of pain (668/946). Mental health disorders 44% (411/946), cardiovascular dysautonomia 41% (385/946), gastrointestinal dysfunction 27% (251/946) were the most frequently reported comorbidities. 81% of respondents (755/942) had received exercise advice from a physiotherapist. 90% (860/946) 'agreed' or 'strongly agreed' that exercise was important for fitness, while 78% (741/946)/) 'agreed' or 'strongly agreed' that exercise was important for their well-being. These beliefs were also associated with the amount of weekly exercise undertaken ($P < 0.001$). 41% (380/946) 'agreed' or strongly believed' exercise helped their pain, while 59% (566/946) were 'undecided' or 'disagreed'. Swimming 28%(261/946), walking 24% (233/946) and Pilates 22% (n=221/496) were reported as the most helpful modes of exercises. 87% of respondents (821/946) reported pain to be a barrier to exercise, while fatigue 79% (745/946) and fear of injury 50% (453/938) were also reported. Three themes emerged regarding experience of physiotherapy, 'physiotherapist as a partner', 'communication' and 'knowledge and experience'.

Conclusion: JHS/EDS-HT is a complex HDCT and comorbidities may coexist. The majority of individuals surveyed had been given exercise advice by a physiotherapist and believed exercise to be important for fitness and wellbeing. Swimming, walking and Pilates were reported to be the most helpful modes of exercises. Pain, fatigue and fear of injury were reported barriers to exercise. Physiotherapists working in partnership with individuals, who communicated clearly and who were knowledgeable about JHS/ EDS-HT provided a positive patient experience.

Implications: Physiotherapists need to be mindful of the presence of possible complex comorbidities. Beliefs, barriers and fears regarding exercise may influence adherence. Swimming, walking and Pilates may be helpful forms of exercise for individuals with JHS/ EDS-HT.

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