

THE PSYCHOSOCIAL IMPACT OF JOINT HYPERMOBILITY SYNDROME AND EHLERS-DANLOS SYNDROME (HYPERMOBILITY TYPE): A QUALITATIVE INTERVIEW STUDY

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Background: Existing research examining those with Joint Hypermobility Syndrome (JHS) and Ehlers-Danlos Syndrome (Hypermobility Type) (EDS-HT) has predominately focused on factors such as pain, range of movement and physical function. However psychosocial factors have received much less attention.

Objectives: This study sought to 1. Identify the psychosocial impact of JHS/EDSHT by examining participants' lived experiences, and; 2. Identify characteristics of effective coping with JHS/EDS-HT, using qualitative methods.

Methods: Adults with JHS/EDS-HT took part in semi-structured telephone interviews to discuss their own lived experiences and the impact of the condition on their lives. All met the Hakim and Grahame (2003) five-item criteria for clinically significant joint hypermobility, and had a self-confirmed diagnosis of JHS/EDSHT. The transcripts were coded using NVivo 10 and analysed using inductive thematic analysis.

Results: 17 participants (14 women, 3 men) took part (age range 22–70, mean 38 years). The sample was purposively selected from across the UK to broadly represent different genders, ages and ethnicities. Inductive thematic analysis indicated five main themes:

Healthcare limitations: All participants reported a lack of awareness of JHS/EDSHT among healthcare professionals, and diagnosis typically took several years. Examples were given where local anaesthetics had either partly or completely failed, leaving patients aware of severe pain during surgical or dental procedures.

A restricted life: Participants experienced a range of symptoms including joint pain and instability, fatigue, gastrointestinal issues, frequent dislocations and subluxations. Due to difficulty completing daily activities, some relied on their partners or family for support, but this led to feelings of guilt and shame.

Social stigma: The invisible nature of their condition led to participants facing criticism and confrontations with others as they 'looked fine'. Fears of being judged led some to hide their symptoms. Many felt frustrated and angry that due to fatigue or injury they could not keep up with friends, family or colleagues.

Fear of the unknown: Not knowing when the next injury was going to occur, and how JHS/EDS-HT would affect them over time made participants especially fearful of declines in their physical ability. Many cited a lack of reliable information about their condition, other than in published books or research journals. Psychological support to better cope with the enduring impact of JHS/EDS-HT on their lives was lacking.

Ways of coping: Several coping approaches were identified by participants, including acceptance of their condition, building social networks, finding out more about JHS/EDS-HT and adapting their activities. Physiotherapists were instrumental in supporting participants to exercise regularly.

Conclusions: The results of this qualitative study highlight the significant psychosocial impact of JHS/EDS-HT on participants' lives. Further research should consider potential interventions to

improve information provision, address psychological support and increase awareness of JHS/EDS-HT among healthcare professionals.

REFERENCE: [1] Hakim A, Grahame R. A simple questionnaire to detect hypermobility: An adjunct to the assessment of patients with diffuse musculoskeletal pain. *International Journal of Clinical Practice* 2003;57(3):163–166.

Disclosure of Interest: None declared