



THE PSYCHOSOCIAL IMPACT OF HYPERMOBILITY SPECTRUM DISORDERS (HSD) AND HYPERMOBILE EHLERS-DANLOS SYNDROME (HEDS): A QUALITATIVE STUDY

S.E. Bennett, N. Walsh, T Moss, S. Palmer

Faculty of Health and Applied Sciences, The University of the West of England, Bristol, UK

BACKGROUND

Existing research examining those with Hypermobility Spectrum Disorders (HSD) and Hypermobile Ehlers-Danlos Syndrome (hEDS) has focused on factors such as pain, range of movement and physical function. However psychosocial factors have received much less consideration.

Using qualitative methods, this study sought to:

1. Identify the psychosocial impact of HSD/hEDS by examining participants' lived experiences; and
2. Identify characteristics of effective coping with HSD/hEDS.

METHODS

Adults with HSD/hEDS were recruited from the Hypermobility Syndromes Association (HMSA) and Ehlers-Danlos Support UK (EDS-UK).

Participants were invited to take 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 (1) five-item criteria for clinically significant joint hypermobility, and, had a self-confirmed diagnosis of HSD/hEDS.

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:

- 1) Healthcare limitations: Lack of awareness of HSD/hEDS among healthcare professionals. Issues with local anaesthetics.
- 2) A restricted life: Wide range of symptoms. Difficulty completing daily activities. Some relied on their partners or family for support, but this led to feelings of guilt.
- 3) Social stigma: Issues with the invisible nature of their condition. Some hid their symptoms from others. Participants could struggle to keep up with friends and family.

- 4) Fear of the unknown: Participants were fearful of declines in physical ability. They cited a lack of reliable information about their condition. Psychological support was lacking.
- 5) Ways of coping: Several coping approaches were identified by participants, including acceptance, building social networks, finding out more about HSD/hEDS and adapting activities. Physiotherapists were instrumental in supporting participants to exercise regularly.

CONCLUSIONS

The results of this qualitative study highlight the significant psychosocial impact of HSD/hEDS on participants' lives. Further research should consider potential interventions to improve information provision, address psychological support, and, increase awareness of HSD/hEDS among healthcare professionals.

REFERENCES

Hakim AJ, Grahame R. A simple questionnaire to detect hypermobility: an adjunct to the assessment of patients with diffuse musculoskeletal pain. *Int J Clin Pract.* 2003;57:163–166.

DECLARATIONS OF INTEREST

None