

DEVELOPING A SELF-MANAGEMENT INTERVENTION TO MANAGE HYPERMOBILITY SPECTRUM DISORDERS (HSD) AND HYPERMOBILE EHLERS-DANLOS SYNDROME (hEDS): AN ANALYSIS INFORMED BY BEHAVIOUR CHANGE THEORY

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BACKGROUND

Hypermobility Spectrum Disorders (HSD) and Hypermobility Ehlers-Danlos Syndrome (hEDS) are disorders of connective tissue that can cause joint instability and pain, and are associated with increased anxiety and depression. There is currently little UK guidance for supporting patients with HSD/hEDS. The analysis presented here used the Behaviour Change Wheel made up of the Theoretical Domains Framework (TDF) and Capability, Opportunity, Motivation and Behaviour (COM-B) model (1) to identify possible intervention options to improve self-management for people with HSD/ hEDS. The aim was to determine recommendations for the components of a behaviour change intervention for people with HSD/hEDS.

METHODS

Data from: i. a systematic review and thematic synthesis of the literature examining adults' lived experiences of HSD/hEDS (2) and, ii. a thematic analysis of interview data where UK adults with HSD/ hEDS (n=17, 14 women, 3 men) discussed the psychosocial impact of the condition on their lives (3) (EDS ECHO SUMMIT Abstract 016), were mapped onto the TDF and COM-B in a behavioural analysis.

A modified Nominal Group Technique focus group (n=9, all women) explored which interventions identified by the TDF/COM-B mapping exercise were most important to them.

RESULTS

Participants prioritised a range of potential self-management interventions, including:

1. Education: To improve their knowledge of HSD/hEDS, including self-help strategies for coping with injury, fatigue and overexertion, and how to evaluate information about their condition.
2. Training: In activity pacing, assertiveness and communication skills, and what to expect during pregnancy, when symptoms of HSD/hEDS can worsen.
3. Environmental restructuring and enablement: Support from occupational therapists to maintain independence at home.
4. Modelled behaviour: Positive first-person narratives that address how other patients with HSD/hEDS have coped with anxiety, depression, distress, fear, frustration and feelings of loss.

CONCLUSION

This study is the first to apply theoretically informed approaches to the management of HSD/hEDS. Through a modified nominal group technique, potential behaviour change interventions for addressing barriers to self-management have been prioritised.

Discussion with participants indicated poor access to psychological support and occupational therapy and a lack of knowledge of HSD/ hEDS. Future research with healthcare professionals and patient stakeholder groups will further evaluate which intervention options would be most acceptable and feasible for the management of HSD/ hEDS.

REFERENCES

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DECLARATIONS OF INTEREST

None