Reasons for Participating in the EDS-HEART Program: Holistic and Performative Within a Supportive Community: a supplementary report

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Background : Hypermobile Ehlers-Danlos Syndrome (hEDS) results in multiple, complex health-related risks and associated fear of movement (kinesiophobia). Therefore, the purpose of this research study was to examine how a holistic, embodied, and performative movement program (EDS-HEART) can affect body schema, physical and mental health, and lifestyle, which contribute to the joy of movement and physical activity participation among adult women with hEDS. Methods : This was a hermeneutic, phenomenological, quasi-experimental, and community-based research study among six women with hEDS, who participated in the EDS-HEART movement program at a local physical therapy clinic. The seven-week program incorporated stretching and strength training activities as well as performative-thematic movement sequences. Results : Based on the qualitative analysis, three themes emerged regarding reasons for the joy of the EDS-HEART program: (a) improved body schema: body awareness, confidence, posture, and proprioception ; (b) highly motivating program: holistic, embodied, performative, pleasant, and safe ; and (c) psychosocial reasons: supportive setting, sense of pleasure and euphoria, and freed from social comparisons and the fear of movement . Conclusions: Based on the study results, public health experts should develop and implement easily accessible and holistic movement programs among people with hEDS and similar conditions to improve physical health, psychosocial health, and the joy of movement.

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