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Project Title:
Exploring the Psychosocial Components of Exercise Adherence in Women with Hypermobile Ehlers-Danlos Syndrome and Hypermobility Spectrum Disorders

ABOUT NOAH

Noah Martin is an MSc student in Community Health Sciences at the University of Calgary, with interests in disability health, women's health, and patient-oriented research. Noah is co-supervised by Dr. Ranita Manocha and Dr. Cheryl Barnabe within the Cumming School of Medicine. Their research background spans qualitative methodologies, knowledge synthesis, and community-engaged approaches to healthcare improvement. Guided by their lived experience of navigating healthcare systems since early childhood with a physical disability and chronic pain, Noah is committed to advancing equitable, accessible, and patient-informed health systems. Noah has served in research roles across several faculties and departments, including Obstetrics and Gynecology, Kinesiology, and Rehabilitation Medicine where he had the opportunity to explore health behaviours (exercise, care-seeking, social participation, etc,) across many different populations. Noah is dedicated to translating research into practice to improve long-term health outcomes and accessibility for the hypermobility and disability communities.

PROJECT SUMMARY

Hypermobile Ehlers-Danlos syndrome (hEDS) and hypermobility spectrum disorders (HSD) are connective tissue disorders characterized by joint instability, chronic pain, and multisystemic dysfunction. These conditions predominantly affect women, often resulting in significant functional

disability and reduced health-related quality of life. While exercise is recognized as a useful tool for managing these chronic conditions, long-term participation is complex and difficult to sustain. Patient adherence is frequently undermined by a traumatic "diagnostic odyssey" and dismissive clinical encounters where physical symptoms are labeled psychosomatic. Physical barriers like chronic fatigue and psychological barriers like kinesiophobia (fear of movement) further complicate exercise behaviours. Additionally many women turn to unregulated online spaces and peer networks for guidance, which can expose them to medical misinformation. This study uses a qualitative psychosocial lens to understand how exercise adherence is constructed, supported, or undermined in this population. Through semi-structured interviews, this research explores women's lived experiences across three environments: clinical care encounters, specialized structured exercise contexts, and daily informational or social spaces. By capturing patients' emotional, cognitive, and physical responses, the project aims to identify the feedback loops that either sustain movement or discourage participation.

Centered on participatory patient-oriented research principles, this project embeds a dedicated committee of patient partners (women living with hEDS or HSD) at all stages of the research, from refining interview guides to interpreting findings and co-designing dissemination materials. Anticipated outcomes include evidence-based frameworks to improve clinical exercise counseling, design safer psychological environments in specialized programming, and help patients safely navigate online information networks. Ultimately, this work seeks to empower both patients and healthcare providers with practical strategies to foster sustainable exercise behaviours and improve long-term health outcomes.