ATTITUDES, BELIEFS AND BEHAVIOURS TOWARDS EXERCISE AMONGST INDIVIDUALS WITH JOINT HYPERMOBILITY SYNDROME/ EHLERS DANLOS SYNDROME – HYPERMOBILITY TYPE

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Introduction

Joint hypermobility syndrome (JHS) is a complex multisystem hereditary disorder of connective tissue (HDCT). Authorities consider JHS to be indistinguishable from Ehlers Danlos Syndrome - Hypermobility Type (EDS-HT)[1].

Prevalence of JHS/EDS-HT in adult NHS musculoskeletal outpatient settings in the UK ranges between 30% and 60%. Physiotherapy plays a central role in the management. Exercise, pain management and drug therapy are considered the treatments of choice by Arthritis UK[2]. Reports of physiotherapy however have not always been positive and there is limited research evidence about optimal type of exercise. Greater understanding of individual preferences, perceptions of exercise and experience of physiotherapy is needed to help optimise treatment.

Purpose

The primary aim was explore the beliefs, attitudes and behaviours of individuals suffering with JHS/ EDS-HT towards exercises. A second aim was to explore experiences of physiotherapy.

Methods

A self administered questionnaire was distributed to members of the Hypermobility Syndrome Association (HMSA) and Ehlers Danlos Syndrome Support UK (EDSUK) who were age 18 years and older. 948 questionnaires were returned. Data were transferred to Microsoft Excel and scrutinised by 2 researchers. 2 duplicate questionnaires were removed. 12 incomplete questionnaires were included in this analysis. Descriptive statistics were used to analyse the data. Agreement regarding categories for comorbidity data was obtained from specialist physicians. Qualitative data were coded and analysed thematically[3].

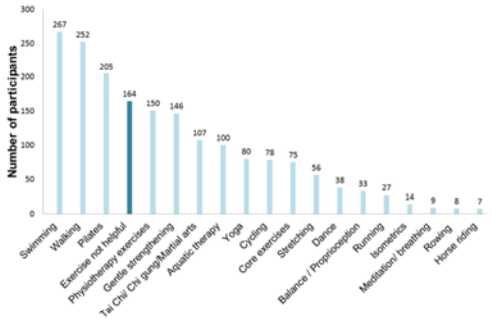
Results

900 females and 46 males completed the questionnaire. Comorbidities were commonly reported by participants. See Table 1.

81% (755/942) of respondents reported that they had received exercise advice from a physiotherapist. 77% (701/940) participants agreed that exercise was an important for management. Swimming, walking and Pilates were reported to be amongst the most helpful forms of exercise. Interestingly some respondents did not find exercise helpful. See graph 1 for more detailed information.

Table 1. Reported comorbidities (n=946)

Categories of Medical Conditions	Number	%
Mental health	412	44
Musculoskeletal	406	43
Cardiorespiratory and cardiovascular dysautonomia	386	41
Allergy and autoimmune	243	26
Gastrointestinal	235	25
Metabolic and nutritional	120	13
Fatigue and sleep related	99	10
Urogenital/ women's health	97	10
Neurological/neurodevelopment	42	4
Undifferentiated skin conditions and atopic phenomena	24	3



Graph 1. Types of exercise reported to be most helpful (n=946)

87% of respondents reported pain to be a barrier to exercise while fatigue (79%) and fear of injury (50%) were also commonly reported as barriers.

Three themes emerged relating to experiences of physiotherapy:

'Physiotherapist as a partner'

'Only recently have I managed to find a physiotherapist who listens and is willing to work with me and help me to plan and manage my condition. It has made all the difference' P 32

'Communication'

'It's really helpful when the physio explains, puts their hands on and shows you how to do the exercises when they give them to you, because you can't always tell if you're doing it right just from a line of text/static picture.' P 767

'Knowledge and experience'

'The specialist physio I am receiving is brilliant. Physio is useless though if you have a therapist who is inexperienced and knows nothing about hypermobility syndrome because they can prescribe exercises that can make you feel WORSE.' P 622

Conclusions and Implications

JHS/EDS-HT is a complex HDCT and complex comorbidities may coexist. The majority of individuals surveyed believed exercise to be important in management of JHS/EDS-HT. Swimming, walking and Pilates were reported to be the most helpful modes of exercises. Pain, fatigue and fear of injury were reported barriers to exercise. Physiotherapists working in partnership with individuals, who communicated clearly and who were knowledgeable about JHS/ EDS-HT provided a positive patient experience. Physiotherapists need to be mindful of the presence of possible comorbidities and the barriers to exercise when advising individuals with JHS/EDS-HT about exercise.

Ethics

Ethical approval was obtained from the University of Hertfordshire Health and Emergency Professions Ethics Committee

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