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Physiotherapy management of joint hypermobility syndrome – a focus group study of patient and health professional perspectives

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Abstract

Objective To develop an understanding of patient and health professional views and experiences of physiotherapy to manage joint hypermobility syndrome (JHS).

Design An explorative qualitative design. Seven focus groups were convened, audio recorded, fully transcribed and analysed using a constant comparative method to inductively derive a thematic account of the data.

Setting Four geographical areas of the UK.

Participants 25 people with JHS and 16 health professionals (14 physiotherapists and two podiatrists).

Results Both patients and health professionals recognised the chronic heterogeneous nature of JHS and reported a lack of awareness of the condition amongst health professionals, patients and wider society. Diagnosis and subsequent referral to physiotherapy services for JHS was often difficult and convoluted. Referral was often for acute single joint injury, failing to recognise the long-term multi-joint nature of the condition. Health professionals and patients felt that if left undiagnosed, JHS was more difficult to treat because of its chronic nature. When JHS was treated by health professionals with knowledge of the condition patients reported satisfactory outcomes. There was considerable agreement between health professionals and patients regarding an 'ideal' physiotherapy service. Education was reported as an overarching requirement for patients and health care professionals.

Conclusions Physiotherapy should be applied holistically to manage JHS as a long-term condition and should address injury prevention and symptom amelioration rather than cure. Education for health professionals and patients is needed to optimise physiotherapy provision. Further research is required to explore the specific therapeutic actions of physiotherapy for managing JHS.

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Keywords: Benign hypermobility syndrome; Ehlers–Danlos syndrome hypermobility type; Physiotherapy; Focus groups; Life experiences

Introduction

Musculoskeletal problems represent some of the most common reasons for seeking primary health care [1]. Joint hypermobility syndrome (JHS) is a heritable connective tissue disorder, characterised by excessive joint range of motion and symptoms of pain, fatigue, proprioception difficulties, soft tissue injury and joint instability [2]. Many experts now consider JHS to be indistinguishable from Ehlers Danlos Syndrome-Hypermobility Type (EDS-HT) [3]. This paper uses the term JHS. Physiotherapy is generally the preferred management option, however, if patients are referred for an acute injury rather than for JHS, it is possible that physiotherapy could exacerbate symptoms [4].

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Generalised joint laxity (often described as being 'double jointed') is very common and generally asymptomatic, occurring in 10 to 20% of Western populations, with higher prevalence in Indian, Chinese, Middle Eastern and African populations [5–7]. JHS is thought to be under-recognised [8], although there is a lack of high quality epidemiological data on its true prevalence, complicated by the historical use of different diagnostic criteria. The revised Brighton 1998 criteria are now recommended for diagnosis [9]. A key component of the Brighton criteria is the Beighton score, a nine-point score of joint mobility in clinical usage for many years [6]. One point is awarded for being able to place the hands flat on the floor whilst keeping the knees straight. One point is also awarded for left and right joints as follows: 10° knee hyperextension; 10° elbow hyperextension; 90° extension of the 5th finger metacarpophalangeal joint; and opposition of the thumb to touch the forearm. The Brighton criteria incorporate other clinical features to exclude other differential diagnoses. However, diagnosing JHS is often challenging, as symptoms may easily be attributed to other causes. Patients report a wide range of fluctuating symptoms in addition to pain, and it has been suggested that many patients presenting in primary care with everyday musculoskeletal conditions may have unrecognised JHS [10]. Indeed use of the Brighton criteria has revealed that a very high prevalence of JHS in musculoskeletal clinics, with rates of 46% of women and 31% of men referred to one rheumatology service [11]; 30% of those referred to a Musculoskeletal Triage Clinic in the UK [12]; and 55% of women referred to physiotherapy services in Oman [13].

Physiotherapy, particularly exercise, is the mainstay of treatment for JHS [13]. However, there is little empirical evidence supporting its efficacy. Two recent systematic reviews included only a handful of eligible trials of physiotherapy and occupational therapy interventions for JHS and found limited evidence for their clinical and cost-effectiveness [14,15]. The current lack of evidence on the most effective management options for JHS may contribute to anecdotally reported negative experiences of management [16,17]. Higher quality multi-centre trials are clearly required to investigate the clinical and cost effectiveness of physiotherapy for JHS. However, before such trials take place, there is a need to develop a clearer understanding of patients' and health professionals' attitudes towards, and experiences of, physiotherapy to manage JHS. Such information could help to inform the development of effective intervention packages. The study reported here therefore aimed to qualitatively explore patients' and health professionals' views on physiotherapy management of JHS.

Method

Participants

Seven focus groups were conducted between January and February 2013 in four UK locations. The purposive sampling strategy aimed for diversity with regard to professional discipline (for health professionals); socio-economic situation (for patients); and age, gender, and geographical location (for both groups). All participants were recruited via mailed invitations. Potential patient participants were identified as follows: (1) from clinical records at two NHS Trusts; (2) people with JHS who previously expressed interest in assisting with research at two Universities; (3) members of the Hypermobility Syndromes Association (HMSA) who lived locally to the same two Universities (identified by the HMSA). Eligible patients were aged 18 or over, had previously received a diagnosis of JHS, had attended physiotherapy within the preceding 12 months and were able to speak English. Other known musculoskeletal pathology causing pain was an exclusion criterion. Potential health professional participants were identified by lead physiotherapists within the two NHS Trusts and by lead academic researchers from two Universities (including previous attendees on courses relevant to JHS management). Eligible health professionals were post-qualification health professionals who had some interest or involvement in treating people with JHS. There were no specific exclusion criteria. Ethical approval was obtained from the North East NHS Research Ethics Committee (12/NE/0307) and all participants gave written consent.

Procedure

Focus groups were conducted in meeting rooms distant from clinical physiotherapy departments (to preserve confidentiality and facilitate open and honest discussion). The focus groups were facilitated by two researchers. One researcher (SP) led the discussion using open-ended questioning techniques to elicit participants' own experiences and views and to ensure all participants had an opportunity to take part. Another researcher (JH) summarised the discussion, audio-recorded the session and noted down who was speaking to aid transcription. Each focus group lasted between 71 and 100 minutes. Topic guides, developed and refined by the research team (including patient research partners), were used to facilitate discussions and, in line with an inductive approach, were revised in light of emerging findings. A further researcher (KR) attended the first patient focus group as an observer and contributed to subsequent refinement of the topic guides. Topic guides explored experiences of physiotherapy and views regarding education, advice, exercises and support. Separate focus groups were conducted with patients and health professionals.

Data analysis

All focus groups were audio-recorded, transcribed, anonymized, checked for accuracy and then imported into a qualitative software package (NVivo 10) to aid data analysis. Thematic analysis [18], using the constant comparison technique [19] was used to identify and analyse patterns across the dataset. Transcripts were examined on a line-by-line basis

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