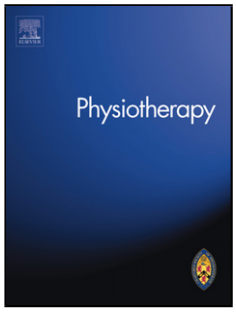

Title: Physiotherapy management of joint hypermobility syndrome–a focus group study of patient and health professional perspectives

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TITLE PAGE

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TITLE

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

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 2 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.

Key Words: 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].

Generalised joint laxity (often described as being 'double jointed') is very common and generally asymptomatic, occurring in 10-20% of Western populations, with higher prevalence in Indian, Chinese, Middle Eastern and African populations [5, 6, 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^{o} knee hyperextension; 10^{o} elbow hyperextension; 90^{o} extension of the 5^{th} 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 with codes being assigned to segments of the data and an initial coding frame developed. An inductive approach was used to identify participants' perceptions of their experiences. To enhance analysis and enable team discussion and interpretation, team members (RT and JH) independently coded transcripts; any discrepancies were discussed to achieve a coding consensus and maximise rigour. Scrutiny of the data showed that data saturation had been reached at the end of analysis, such that no new themes were arising from the data [20]. All participants were assigned a letter as a pseudonym.

RESULTS

In total 4 focus groups were conducted with 25 patients (3 men and 22 women; aged 19-60 years) and 3 focus groups with 16 health professionals (3 men and 13 women; 0-30 years post qualification; 14 physiotherapists and 2 podiatrists) (Table 1). Three themes, developed from the analysis, related to: 'JHS as a difficult to diagnose, chronic condition' 'Physiotherapy to treat JHS' and 'Optimising physiotherapy as an intervention for JHS'.

JHS as a difficult to diagnose, chronic condition

The chronic, heterogeneous nature of JHS

Both patients and health professionals described the chronicity of JHS and its symptoms. Patients recognised that they were *"going to have it forever" [Female patient E, age 19, FG6]* and that *"you won't be fine, not completely" [Female patient C, age 40, FG1]*. Similarly, one health professional described having JHS as *"almost like a recovering alcoholic, you are always a recovering hypermobility person" [Female health professional B, 28 years post-qualification, FG4]*. The diverse nature of the symptoms was also noted by patients, that *"everyone with hypermobility has different symptoms" [Female patient F, age 44, FG1]* and by health professionals, who explained *"it's the heterogeneous group that makes it very interesting" [Female health professional D, 22 years post-qualification, FG4].*

Scepticism and lack of understanding amongst health professionals

As joint laxity is sometimes perceived as an asset, and JHS symptoms fluctuate and vary, patients' reports of problematic symptoms to health professionals were often met with scepticism.

"… there's still quite a prevalent view that it's all in the mind, that […] "I don't believe in hypermobility" […] it's a kind of … there are people who don't feel it's a genuine diagnosis, that it's something psychological and you, you know, just need to be a bit braver." [Female patient A, age 60, FG2].

Both patients and health professionals therefore felt that JHS is not a widely understood or recognised condition amongst health professionals.

"when I went back to physio for strengthening exercises to help my joints after the hypermobility diagnosis, there was … I got that a little bit, 'I'm not sure about this hypermobility …'" [Female patient B, age 34, FG2].

"I work in a rheumatology department who don't recognise joint hypermobility as an entity and in fact, probably a lot of people tend to get diagnosed with things like fibromyalgia more than normal" [Female health professional E, 30 years post qualification, FG3].

Consequentially, health professionals perceived "*a lot of mismanagement"* of JHS by health professionals *[Female health professional E, >20 years post qualification, FG4]* and that patients may be given erroneous information by some health professionals. One patient described a rheumatologist who said*, "in his opinion, his professional opinion, that hypermobility doesn't cause pain" [Female patient C, age 53, FG2].* JHS trained health professionals felt that they were required to *"undo misconceptions, other health professionals' understanding and what they have taught or implied to the patient about their condition. So for us we sort of have to unravel an onion so to speak, and it's quite hard, yeah challenging I think" [Female health professional E, >20 years post qualification, FG4].*

Patients felt that JHS does not generally fit with health professionals' models of acute injury and recovery and that this may be a source of frustration for health professionals.

"[physiotherapists] get frustrated because their model of physiotherapy and what they're taught and how joints move and how they get better, hypermobility is totally the opposite of what they're expecting and they can't understand that. I've had physios before say 'well stop the shoulder dislocating'" [Female patient B, age 32, FG1].

Diagnosis of JHS and subsequent referral

The heterogeneous nature of JHS symptoms, lack of recognition of the syndrome and subjective diagnostic criteria were seen to contribute to often slow and convoluted diagnostic trajectories. Patients commonly remarked that "*it takes so many years to get diagnosed" [Male patient E, age 36, FG5]*. Health professionals highlighted the difficulties in diagnosing JHS using the criteria available.

"I think it's the diagnostic criteria for hypermobility syndrome that's actually part of the problem […] So it's almost going right back to the start, finding a slightly more sensitive diagnostic criteria that can help us to then manage it" [Female health professional, 11 years post-qualification, FG7].

For patients, receiving a diagnosis was considered essential in order to access appropriate treatment: *"the sooner you get the treatment the less likely it is that it is going to have such a great impact on your life" [Male patient E, age 36, FG5]*. However, health professionals felt that care pathways for JHS were not well defined and, as a result, patients may develop more complex problems or chronic pain issues.

"I see the other end. I think we don't have a structured pathway of care for hypermobiles, which is what I'm interested in developing, but we don't have it. So there's no rheumatologist in the trust that has a special interest in hypermobility, and my God I've tried to find one […] So there isn't a defined pathway of care for someone with generalised - with hypermobility syndrome, so" [Female health professional C, 25 years post qualification, FG4] .

"So for me I feel that's a key problem because I think we end up getting them too late, and if ((name)) had the support I feel to get these pathways better earlier" [Female health professional E, >20 years post qualification, FG4].

Physiotherapy to manage JHS

Physiotherapy for acute individual joint problems is unhelpful

Physiotherapy is the mainstay treatment for JHS symptoms. However, both patients and health professionals emphasised that physiotherapy would not be effective if individual joints were treated in isolation and described difficulties in treating JHS within some National Health Service (NHS) constraints:

"Because of, I think, the way – at least in my experience – that the NHS seems to approach things, they have a sort of, 'you're here for one joint' approach, which is quite difficult, because you go: 'Well, I'm floopy all over,'. And then you have to have the conversation about 'Well, which is the most difficult?' You're like 'Well, it's kind of all related', so if, like, if my knee is stronger and I'm doing less weird things with my knee, then my hip will feel better because - and I can say that, and to me it's obvious, that if you fix - just because it's your hip that hurts it doesn't mean

that it is actually the problem. It could well be that your knee is the issue, making you do weird things with your hip, but there's this, 'This is the joint, and we will deal with this joint,' when that isn't really …" [Female patient C, age 53, FG2].

Patients and health professionals reported that in the NHS, 'usual care' was normally up to six physiotherapy sessions to treat a specific joint. However, it was felt that this was not necessarily appropriate for JHS.

"They've got us as their clinical leads telling them to look at people globally, pick up this diagnosis, but then they've got their managers telling them you have to do six sessions [….] I should really be saying "I know you've got hypermobility, I know it's all related, but actually I need six sessions with your back, I need six sessions with your shoulder and I need six sessions with your knee, and we need to negotiate that with your PCT because otherwise ((place name)) is not going to get paid" [Female health professional E, 30 years post qualification, FG4].

In all focus groups, the need for continuous, ongoing access to physiotherapy was highlighted. One patient felt: *"the difficulty is, it's a chronic condition and the only time you are actually able to access any care in the NHS is when you have an acute incident from it" [Female patient G, age 48, FG2].* Health professionals, unless practicing privately, were equally frustrated by the lack of flexibility in the number of treatment sessions that could be offered.

"And I think the limitations of, like, if you were receiving NHS treatment, then you're only going to get so many sessions" [Female health professional D, newly qualified, FG3].

In addition to the perceived limited number of sessions, physiotherapy may also be unsuitable and exacerbate symptoms if it ignores the complexity of JHS symptoms:

"*Then, as you say, being given some more exercises that weren't helpful because they did seem to cause more pain which then sets you back even more and then you seem to get into the cycle of never sort of making any progress and then the treatment's over because you only get a few sessions" [Female patient G, age 48, FG2].*

Although most patients described negative experiences of physiotherapy, for example when being referred without a diagnosis of JHS, once patients had been diagnosed and referred to JHS trained physiotherapists, many participants reported beneficial treatment.

"*I was originally seen by a physio who hadn't diagnosed with the hypermobility and then went back to a musculoskeletal specialist who then put me forward to specialist hypermobility physiotherapist and since then it's been amazing I feel like it's been worthwhile and it felt like the right thing to do and I've been really enjoying it" [Female patient B, age 27, FG 5].*

Physiotherapy is less effective if diagnosis is delayed

Both physiotherapists and patients recognised that if JHS remained undiagnosed, chronic pain may develop which may be less responsive to physiotherapy. The biopsychosocial impact of living with untreated or inappropriately treated symptomatic hypermobility may lead to a more multidisciplinary approach being required.

"And you see by the time - for me they come with quite a lot of psychological baggage, and you know, they are difficult patients. And then you're trying to unravel what's the primary and secondary issue here, is it that your mental health is actually what's driving your hypermobility, or is it the fact you have such debilitating joints is making you mentally unwell. But by the time they get to us that's so hard to deal with, [….] and they almost then, it's a cry for help. So they're desperate to get help so the psychological side comes out because the physical manifestation of what they're suffering with is just so severe" [Female health professional E, >20 years post qualification, FG4].

"actually, there's some that do quite well [with physiotherapy] as well in terms of …. especially I think if you catch them early, really the key is, before they develop a lot of the chronic pain" [Male health professional B, 8 years post qualification, FG 7].

Patients also recognised that delays in diagnosis may result in maladaptive responses to JHS, for example, compensatory postures, which are then difficult to rectify.

"I was 15 when I was diagnosed and that was even too late really for me because the way I stand, the way I move, everything, my Pilates teacher - her grandson was 3 when he was diagnosed and he has Pilates, and physiotherapy now so he will get into habits of a life time" [Female patient G, age 30, FG 1].

Optimising physiotherapy to manage JHS

All focus groups were able to provide descriptions of an 'ideal' physiotherapy intervention or suggested improvements based upon their own experiences of giving or receiving treatment. Health professionals' and patients' descriptions of ideal physiotherapy were notably similar (Table 2). Both felt it was important to have continuity of therapist, who was trained in JHS and who provided reassurance. Both patients and health professionals described the importance of flexible treatment delivery; patient led treatment that meets and manages goals and expectations; taking a holistic, long term approach; and treating JHS rather than its acute manifestations. The importance of ongoing, 'maintenance' physiotherapy was also highlighted.

Central role of education in managing JHS

Both patients and health professionals considered education to be key to optimising physiotherapy for JHS.

Education for health professionals: many patients felt that education was required for health professionals.

"*I think actually it's the health professionals that need education […] I mean there's lots of things I still need to know about hypermobility but on the flip side I do think it's the health professionals that need to know more" [Female patient G, age 42, FG 5].*

Because of the lack of understanding that patients perceived to be common amongst health professionals, some felt that they were providing education for the health professionals, and that this was not necessarily beneficial for them.

"So there's this odd situation where I'm explaining how it works to them and I think that it isn't ideal and I think there does need to be better education for the physios because I think that is quite important that they tell you how and why things are happening to you, rather than vice versa because that's unhelpful" [Female patient E, age 21, FG2].

Health professionals also highlighted the need for better education and suggested a variety of educational sources, including websites, special interest and support groups and further professional training. One health professional highlighted the value of evidence based guidelines: *"because if you get a patient in front of you, you need to be able to think, okay, what can I look at? What is the most effective? So guidelines that you were talking about, or maybe you can do, would be very helpful" [Female health professional E, 30 years post qualification, FG3].*

Education for patients: Health professionals felt that patient education was necessary to facilitate a greater understanding of the condition.

"I think a large part of it, as well, is to the education. To think that the patients don't necessarily understand the condition. [….] Sometimes they don't actually, nobody has never actually sat down and explained to them what that is and the implications. And what can actually be done to help them. So I think that's a large part of it" [Female health professional D, newly qualified, FG3].

Health professionals felt that education is necessary for patients to develop realistic expectations of treatment and a better understanding of the rationale for particular treatment plans.

"A lot of … I think what is … is education, "this is why I'm doing it", and making sure they understand why I'm getting them to do these exercises […] … even if it doesn't work and goes horrendously wrong, that's fine, we can change that, but they've got to have an understanding of what we're asking them to do and why we're asking them to do it" [Male health professional B, 8 years post qualification, FG7].

Patients similarly recognised that education helped them to fully engage with treatment.

"because I kind of understand and have an interest in it, I think it makes it really easy and go really quick so I suppose it's where someone who doesn't really know about it, they've got to learn about it first because you can't tell someone to do it if they don't understand it" [Female patient D, age 21, FG1].

Measuring success, and managing expectations, of physiotherapy

All participants recognised the aim of physiotherapy was to manage, rather than cure, the symptoms of JHS; that 'successful' therapy did not mean being pain free; rather, the aim was for the patient to be able to manage their pain.

"I think measuring success should be more about reaching a point of continuity where you know you might not be great all the time or you might not be really bad all the time but you're manageable" [Female patient G, age 30, FG1].

"… you may not be expecting to get them pain free, but if they're happy and if they're managing the problem better, you know what to do to manage it, then you're there" [Female health professional C, 19 years post qualification, FG3].

However, some health professionals raised concerns about patient expectations; that patients were expecting to gain more than they could realistically offer. For example, one health professional felt that patients often wanted, and expected, a 'cure'.

"I don't want them to go away and think, well, she's done nothing, when they expected me to fix it. So I have to say from the beginning, well, I can't fix it, but this is what I can do. And to a point, that's all you can do, isn't it, really?" [Female health professional E, 19 years post qualification, FG7].

Some patients considered that physiotherapy would be successful if it resulted in some reduction in pain intensity, in some parts of their body. But contrary to some health professionals' perceptions, patients did not appear to hold unrealistic expectations about treatment:

"*You can measure it [*i.e. the success of physiotherapy*] by parts of body I guess because I, although I don't feel remotely better in many parts I still say that my last physiotherapy was a success because it significantly helped me with my shoulders so that I, I like suffer a lot less pain in that area of the body now, so I call it a success but when you get to my knees and ankles and neck and back it did do that much, the neck surgery was a success because that significantly reduced the neck pain although I still get probably more muscular now than any joints but that's still again one part of it, so there's lots of other areas that are still very bad, so erm I guess that in order to say that I'm better every bit would have to have improved significantly to say that they didn't affect my day to day life, but to have individual parts improve is still a success" [Female patient F, age 19, FG5].*

DISCUSSION

This is the first in-depth qualitative exploration of patients' and health professionals' perspectives on physiotherapy for JHS. As such, it provides invaluable information to help reflect upon and enhance management of this complex long term musculoskeletal condition.

Both patients and health professionals described JHS as a painful, chronic condition with heterogeneous and evolving symptoms, in line with other empirical research [21]. Patients and health professionals reported a lack of recognition and understanding about JHS and even some scepticism. Patients reported difficulties in being diagnosed and how they had encountered health professionals who they felt didn't believe or understand their descriptions or experiences of JHS [22]. Both patients and health professionals recognised that a diagnosis was essential in order to facilitate effective treatment. Previous research has similarly referred to the significance and the sense of relief for patients when a diagnosis is received following many years of frustration and searching for a reason for their symptoms [23]. Recent surveys have also highlighted the need for further education to improve recognition, diagnosis and management [24, 25].

Although physiotherapy is the mainstay treatment for JHS, there is a lack of empirical evidence to indicate the optimum type, frequency or means of delivering physiotherapy interventions [26]. In the current study, participants indicated that the success of physiotherapy appears to be dependent upon having a prior diagnosis of JHS and receiving physiotherapy from a therapist trained in JHS. Recent surveys of physiotherapists treating adults with JHS identified that between 68% and 51% reported receiving no training in JHS [24, 25]. Only 9.8% received undergraduate training in hypermobility [24]. Development of appropriate learning opportunities and resources for health professionals would seem warranted. Health professionals and patients also highlighted the importance of early diagnosis and intervention to prevent the establishment of maladaptive postural habits or movements. It is possible that many symptoms of JHS could be prevented or ameliorated by

addressing issues such as joint control (posture, motor control, muscle strengthening, and proprioception), education, physical activity and physical fitness [27]. On the other hand, our focus group data suggest that once chronic pain had developed, JHS management may become much more complex due to its substantial psychological impact [15]. Moreover, as previous research has implicated acute pain episodes in the subsequent development of chronic pain [10], further research is required to investigate the extent to which repeated acute pain episodes influence chronic pain development. The extent to which other variables influence the efficacy of physiotherapy also requires further exploration (for example age; severity and duration of pain symptoms; the degree of joint hypermobility and instability; psychological dysfunction [15]; and concurrent conditions such as postural tachycardia syndrome [28], dysautonomia [29] and gastro-intestinal dysfunction [30]). Further research is required to assess the value of physiotherapy and a feasibility trial is underway to investigate the acceptability of a tailored physiotherapy programme for JHS (ISRCTN29874209).

There were many similarities between patients' and physiotherapists' descriptions of an 'ideal' physiotherapy service (Table 2). Their descriptions also reflected 'best practice' in some physiotherapy services specialising in JHS. Whilst some health professionals felt that patients may hold unrealistic expectations of the extent to which physiotherapy could help, in fact, patients in our focus groups recognised that their condition would never be cured, and that amelioration of their symptoms was the most that they could hope for.

There was a consensus from participants that patients would benefit from health professionals who understood JHS and its complexities. A central aim of physiotherapy should be to equip the patient to manage JHS over the life course and education was seen as the most salient factor to facilitate a correct and timely diagnosis, to raise awareness within society and to enable those with the condition to maximise their function.

Limitations and strengths

A particular strength of the research is the fact that data were gathered from both patients and health professionals, allowing a clearer understanding of views regarding physiotherapy for JHS. Employing focus group methodology allowed consensus to be gained regarding physiotherapy treatment, although it is recognised that focus groups do not permit as much in-depth exploration of issues as other forms of data collection such as interviews. Greater diversity in health professional perspectives would have been welcome. Unfortunately an occupational therapist, osteopath and rheumatologist who expressed an interest in taking part were subsequently unable to attend the focus groups.

The congruence between patients' and health professionals' descriptions and perceptions of JHS was notable. Whilst this is encouraging, it should be noted that the health professionals in these focus groups were experts in the field, providing specialist care for JHS. Further research is required to understand the perceptions and experiences of other health professionals and to develop an understanding of any potential barriers to providing appropriate care.

Conclusion and future directions

Physiotherapy is likely to be helpful for JHS, but may be more beneficial if used to manage JHS holistically rather than to treat acute injuries in isolation. Physiotherapy services need to recognise the chronic nature of JHS, and the aim of physiotherapy should be long term injury prevention and symptom amelioration. It appears that physiotherapy may be particularly beneficial for JHS patients who have not developed chronic pain syndromes. For JHS patients with chronic pain, physiotherapy may also be valuable, but treatment is more complex and may require input from a multidisciplinary pain service. Education for health professionals and patients and raising awareness of the condition is essential to optimise physiotherapy provision for JHS. Research is required to explore the specific therapeutic action of physiotherapy and its role within the wider multidisciplinary team.

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647 **Table 1. Participants' demographic characteristics.**

Patients (total n=25)		**N (%)**
Age	18−29 30−39 40−49 50−59 >60 mean, (median)	8 (32) 7 (28) 6 (24) 2 (8) 3 (12) 33 years, (36)
Gender	Female Male	22 (88) 3 (12)
Ethnicity	'White' 'Other'	23 (92) 2 (8) (both self-reported as 'British White and Chinese')
Socio-Economic Status (SES)*	1 (affluent) 2 3 4 5 (most deprived)	8 (32) 8 (32) 4 (16) 3 (12) 1 (4)
Education	Schooling to 16 yrs College diploma/equivalent University degree/equivalent Post graduate degree	3 (12) 6 (24) 10 (40) 6 (24)
Employment	Employed full time Employed part time Student full time No paid job Retired	7 (28) 8 (32) 4 (16) 5 (20) 1 (4)
Staff (total n=16)		**N (%)**
Gender	Female Male	13 (81) 3 (19)
Role	Physiotherapists Podiatrists	14 (88) 2 (13)
Years since qualifying	Newly qualified ≤5 years 6-20 years >20 years	1 (6) 1 (6) 7 (44) 7 (44)

648 * Measured as Index of Multiple Deprivation (IMD) quintile from home post code
649 (*Source: Office for National Statistics)*

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651 **Table 2. Suggestions for an 'ideal' physiotherapy service.**

Suggested improvements	Illustrative excerpt from patient	Illustrative excerpt from health professional
Regarding therapist		
Continuity of therapist to improve patient-therapist interaction/relationship	*"They get to know you as well, don't they, and they know your lifestyle and they know what you do day in day out and therefore they can start to understand any triggers, ... they get to know you as a person" [Female patient G, age 30, FG1].*	*"For everybody, all patients, is continuity. But it's especially difficult [for JHS patients] because they have so many different problems" [Male health professional A, 6 years post qualification, FG3].*
Therapist should be JHS expert	*"… the two physiotherapists I've had who've known about [erm] hypermobility have been a lot better than ones I've had in the past where they obviously haven't had a clue" [Female patient C, age 60, FG 6].*	*"... if they see somebody who hasn't had an interest in that then they're learning along with the patient at the same time. … So that's quite difficult. It's much better, isn't it, to be seen by a specialist straight away who has got a broader knowledge base to be able to tap into their tools and skills" [Female health professional E, 30 years post qualification, FG 3].*
Therapists should provide reassurance and encouragement	*"quite often I'll come out of the next physio feeling much happier because they've reassured me that it's not the end of the world and you know sometimes you have a bad week but it doesn't mean that you won't then have a good week" [Female patient F, age 44, FG1].*	*"I think you've got to set achievable goals, then you've got to give a lot of reassurance and positive feedback" [Female health professional B, 28 years post qualification, FG 4].*
REGARDING Physiotherapy		
Flexibility in treatment, (e.g. number of sessions, content, specific techniques, mode of delivery, structure and focus)	*"… Or consider the person's life style, … and that sort of flexibility, not just on what they're asking the patient to do, even being flexible on the times of day or you know when these things can happen, you know make it*	*"Ideally, you'd want to have a service offer where they could tap into the service where they wanted to. If they suddenly got a flare up of something, say their hands started to give way or become more of a*

	interesting, you know we can't all get in at 11 o'clock in the morning or 2 o'clock in the afternoon, we do need the half past 7's the 8 o'clock in the morning, and the evening appointments" [Female patient C, age 40, FG1].	*problem, then they could come back to you" [Female health professional E, 30 years post qualification, FG3].*
Patient led treatment, whilst managing and understanding patient expectations.	*"I think being patient led, … what it is that they want to achieve out of it and how the best way they can do that, and you know with a bit of guidance, like..." [Female patient B, age 32, FG 1].*	*"You try and tease out, you know, what are your expectations? No idea. So your hopes? No idea. I don't know what I'm supposed to be doing … Forget that, what would you like to be doing? …. Then you start to offer things and start to treat or start to address …" [Male health professional D, 5 years post qualification, FG 7].*
Meeting individual goals, to manage rather than cure	*"Or consider the person's life style, you know consider what is going to be feasible, what they need to be able to get to in terms of achievement and you know and that sort of flexibility not just on what they're asking the patient to do …" [Female patient C, age 40, FG1].*	*"Because we're very good at having goals, but you know, it's making sure that the patients, they are the patients' as well" [Female health professional G, 23 years post qualification, FG4].*
Holistic, long term approach	*"It's not just your joints, it is all the other bits around it and that sort of slightly bigger picture, you're probably going to be like this always, you need to think of different ways to manage different things" [Female patient E, age 34, FG2].*	*"… obviously if there's a mechanical element to it we'd have to go into that, but as I say, the hypermobility is something that needs to be addressed more holistically" [Female health professional E, 19 years post-qualification, FG7].*
Recognition of the need to treat multiple joints for JHS rather than individual problematic joints	*"I think they need to take notice that it is a full body condition rather than just individual, rather than just like one area, it is individual parts but they often concentrate on one area and then forget that the rest of the body hurts as well and that the pain can be*	*"If it was classified as a condition, [unclear 31:00] spondylitis or all those other rheumatological conditions which are, extend beyond one section, it's treated differently isn't it, so it's got to do with its recognition presumably. It's*

	interlinked" [Male patient E, age 36, FG5].	*multi systemic, therefore you can treat multiple sites and therefore it may take longer in the end" [Female health professional D, 22 years post qualification, FG 4].*
Focus on core strengthening and 'correct' movement	*"basically you've really got to give them a comprehensive set of useful exercises that will cover a whole range of joints, you know because most of our joints are affected, but particular core stability" [Female patient E, age 44, FG1].*	*"but really just concentrating on … on kind of core, and … good posture .. concentrate on how they're exercising, what they're doing, technique rather than just exercising. Because a lot of them just … they find the most bizarre ways of doing things that I could never do in a million years" [Male health professional B, 8 years post qualification, FG7].*
Maintenance physiotherapy for a chronic condition rather than acute problems arising from JHS	*"If it's like say the diabetic clinic, where you get called every year to see them. … So could they not do a package where you actually went back every six months to see somebody regardless of how you were feeling" [Female patient A, age 60, FG2].*	*"So what we've tried to do is …a sort of self-referral back into the service, so they're not having to go round the houses, and we pick them up quickly when they're starting to get a flare up or a deterioration" [Female health professional E, >20 years post-qualification, FG4].*

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