ARTICLE

Knowledge, Assessment, and Management of Adults With Joint Hypermobility Syndrome/ Ehlers–Danlos Syndrome Hypermobility Type Among Flemish Physiotherapists

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Physiotherapy plays a fundamental role in managing adults with the joint hypermobility syndrome/Ehlers–Danlos syndrome hypermobility type (JHS/EDS-HT). However, it is a challenge for both the patient and the physiotherapist as the condition is poorly understood and treatment for JHS/EDS-HT is currently undefined. Insight into current practice is, therefore, necessary in order to establish baseline knowledge in this area and in the long term to improve the standard of patient care. Therefore, the purpose of this study was to evaluate current physiotherapists' knowledge of JHS/EDS-HT and to gain insight into current physiotherapy practice with emphasis on assessment, management, and treatment efficacy. Three hundred twenty-five Flemish physiotherapists participated in the study by filling out electronically a modified version of the "Hypermobility and Hypermobility Syndrome Questionnaire" (HHQ), which covered theoretical constructs such as general knowledge, assessment, management, and learning in relation to generalized joint hypermobility and JHS/EDS-HT. The results show that physiotherapists report a low level of confidence with regard to assessment and management of JHS/EDS-HT. Knowledge of hypermobility and JHS/EDS-HT is weak, especially regarding the features associated with JHS/EDS-HT. Many treatment approaches are used by physiotherapists with the majority showing preference for education, reassurance, muscle strengthening, proprioceptive and core stability training. Almost all approaches were perceived as being clinically effective by the physiotherapists, highlighting a lack of consensus. In conclusion, this study in Flemish physiotherapists confirms that JHS/EDS-HT is under-recognized, not well known and deemed difficult to treat. Further education is required and sought by the physiotherapists surveyed, and future research is needed. © 2015 Wiley Periodicals, Inc.

KEY WORDS: assessment; Ehlers–Danlos syndrome hypermobility type; generalized joint hypermobility; joint hypermobility syndrome; management; physiotherapy; treatment

How to cite this article: Rombaut L, Deane J, Simmonds J, De Wandele I, De Paepe A, Malfait F, Calders P. 2015. Knowledge, assessment, and management of adults with joint hypermobility syndrome/ Ehlers–Danlos syndrome hypermobility type among flemish physiotherapists. Am J Med Genet Part C 169C:76–83.

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DOI 10.1002/ajmg.c.31434

Article first published online in Wiley Online Library (wileyonlinelibrary.com).

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INTRODUCTION

Joint hypermobility syndrome (JHS) and Ehlers–Danlos syndrome hypermobility type (EDS-HT) are two often underdiagnosed or misdiagnosed heritable connective tissue disorders (HCTDs) characterized by generalized joint hypermobility (gJHM), complications of joint instability, musculoskeletal pain, and mild skin involvement [Castori et al., 2014]. Besides these diagnostic clinical features, patients with JHS/EDS-HT also suffer from a wide range of other debilitating symptoms, including neuromuscular problems [Voermans et al., 2009; Rombaut et al., 2010a, 2011a, 2012a,b], fatigue [Voermans et al., 2010a], and dysautonomia [De Wandele et al., 2013, 2014a, b]. These various complaints impair daily life activities and have a significant impact on quality of life (QOL) [Berglund and Nordström, 2001; Rombaut et al., 2011b].

Many clinicians and researchers are now interpreting JHS and EDS-HT as the variable expression of the same disorder (i.e., JHS/EDS-HT) [Tinkle et al., 2009; Remvig et al., 2011]. However, whether such a clinical overlap reflects or not in etiological identity remains to be confirmed at the molecular level [De Paepe and Malfait, 2012].

Currently, the JHS/EDS-HT patient experience is blighted by a general lack of recognition and among healthcare professionals [Berglund et al., 2000; Grahame, 2001, 2008]. Consequently, patients often report not being taken seriously, and being labeled as "lazy," "psychosomatic," or a "malingerer' [Berglund et al., 2000; Berglund et al., 2010]. Furthermore, patients experience many problems with JHS/EDS-HT management among medical practitioners, e.g., little enthusiasm for treatment, inability to provide appropriate and effective treatment, receipt of conflicting or insufficient advice, and lack of understanding the complexity of JHS/EDS-HT and the impact of JHS/EDS-HT on daily life [Grahame, 2001; Gurley-Green, 2001; Rombaut et al., 2011c].

As JHS/EDS-HT is clearly multifaceted [Castori et al., 2011, 2014; De Wandele et al., 2013], multidisciplinary management is proposed [Rombaut et al., 2010b; Keer and Simmonds, 2011; Castori et al., 2012a]. Hereby, physiotherapy has a key role to play. A recent survey of our research group showed that half of the EDS-HT patients were enrolled in a physical therapy program, 63.4% of whom reported a positive effect of the physiotherapeutic treatment they received [Rombaut et al., 2011c]. Nonetheless, physiotherapists have frequently frankly admitted that they were at loss to know how best to help their EDS patients [Hakim and Grahame, 2003]. Therefore, we receive many questions of physiotherapists about the condition and consequences and requests regarding specific management suggestions.

Very little has been reported about the physiotherapy management of JHS/EDS-HT and the lack of evidence-based treatment approaches for JHS/EDS-HT is a recognized concern. In children with JHS/EDS-HT, enhancing physical fitness, by improving joint control and physical activity seems effective, based on the two available interventional studies [Scheper et al., 2013]. In adults with JHS/EDS-HT, three interventional studies could be traced, two of them describing a positive effect of physiotherapy approaches focusing on amelioration of knee joint proprioception [Ferrell et al., 2004; Sahin et al., 2008] and one evaluating a combination of physical and cognitive-behavioral therapy [Bathen et al., 2013]. Consequently, until now treatment is generally based on "trial and error," intuition and personal clinical experience of the physiotherapists [Rombaut et al., 2011c]. Nevertheless, this might be valuable to serve as a starting point, but needs to be formally researched.

Therefore, a survey study in a cohort of physiotherapists was performed. The objective of the present study was to evaluate current physiotherapists' knowledge and perception of adults with JHS/EDS-HT and to gain insight into current physiotherapy practice with particular emphasis on assessment and management and management effectiveness.

This study will hopefully give an impetus to develop more specific information and education for physiotherapists about JHS/EDS-HT and its consequences, and to work on widely available or universally acknowledged guidelines for effective physiotherapy treatment for patients with JHS/EDS-HT.

MATERIALS AND METHODS

Subjects

The sample for this survey study included male and female physiotherapists, who are active in a private physiotherapy practice and/or a hospital and/or a rehabilitation center in Flanders (Flemish part of Belgium). One thousand physiotherapists were invited to participate in the study, of which 325 (32,5%), 201 men and 124 women, consented and participated. The respondents had a mean age of 46.7 years (SD 10.7), were mainly employed in a private physiotherapy practice (83.1%) and worked usually more than 40 hr a week (66.8%). The majority of physiotherapists treated mainly adults with musculoskeletal conditions (79.7%). In terms of experience, 73.2% had been qualified for over 15 years, and all graduated within Belgium. Only 7.3% of the respondents reported that they received undergraduate training in the area of gJHM and JHS/EDS-HT, and 2.2% received a post-qualification training concerning this issue. Of all physiotherapists employed in a hospital or a rehabilitation center (16.3%), only 4.6% had specific resources, facilities or treatment strategies for patients with gJHM.

Procedure

This study was approved by the local Ethics Committee of the Ghent University Hospital and was conducted in March 2014. Physiotherapists were invited by e-mail to participate in the study by filling out an electronic questionnaire, generated in Google Docs.

Participation was anonymous. By completing the electronic questionnaire, physiotherapists gave their voluntary consent to participate in this study. Once the questionnaire was completed, which took approximately 10 min, data were automatically collected in an Excel file. All questionnaires were complete (only when a question was filled out a subject could go to the following question). All invitations were sent at once and after 10 days one reminder was sent to all physiotherapists.

Questionnaire

A Dutch translation of the "Hypermobility and Hypermobility Syndrome Questionnaire" (HHQ) was used [Deane et al., 2008]. This questionnaire has been found to be valid and reliable (test–retest reliability of $P < 0.1$ and content and discrimination validity of $P < 0.01$) [Deane et al., 2008]. Some minor changes and additions were made to make this survey useable among Flemish physiotherapists. The modified questionnaire consisted of 50 multiple choice questions, some with open fields for specification. Seven sections were surveyed, including section 1: "Demographic data and professional profiles" (10 questions), section 2: "General knowledge of hypermobility and JHS/EDS-HT" (12 questions), section 3: "Knowledge of JHS/EDS-HT features" (16 questions), section 4: "Assessment of patients with JHS/EDS-HT" (4 questions), section 5: "Management of patients with JHS/EDS-HT" (5 questions), section 6: "Impact of JHS/EDS-HT on quality of life" (1 question), and section 7: "Future learning about gJHM and JHS/EDS-HT" (2 questions).

Statistical Analysis

Data were statistically analyzed using Statistical Package for Social Sciences (SPSS), version 22. Descriptive statistics are presented as mean ± SD for continuous data and percentages or absolute frequencies for categorical data. A "general knowledge of hypermobility and JHS/EDS-HT" score (score/12) and a "knowledge of JHS/EDS-HT features" score (score/16) was established. A correct answer was assigned a score of one and incorrect responses scored zero.

χ^2 analyses were performed to evaluate the association between on the one hand years of experience (categorized into 0–4, 5–9, and ≥ 10 years) and undergraduate/postgraduate training ("yes" or 'no") and on the other hand general knowledge of hypermobility and JHS/EDS-HT ("score 0–5/12" or "score 6–12/12"), knowledge of JHS/EDS-HT features ("score 0–8/16" or "score 8–16/16"), confidence in assessment of JHS/EDS-HT ("yes" or "no"), and confidence in management of gJHM and JHS/EDS-HT ("yes" or "no"). Statistical significance was set at the level of $P \leq 0.05$.

RESULTS

General Knowledge of Hypermobility and JHS/EDS-HT

Nearly half of the physiotherapists (44.9%) believed that hypermobility had a *prevalence* of 10–30% (correct answer); however, 18.2% of the respondents had no idea. When asked whether hypermobility could be *inherited* or *acquired*, the majority believed it could: 81.8 and 54.5%, respectively, responded affirmatively (both answers are correct). A resounding 80.0% of respondents believed that hypermobility was more *prevalent in females* (correct answer). More than half of the physiotherapists (57.5%) had no idea within which *ethnic group* hypermobility is more prevalent. 21.8% believed it to be more prevalent within the Asian community (correct answer). Approximately one out of four physiotherapists, correctly, believed that there is a *difference between gJHM and JHS/ EDS-HT*, while 69.2% had no idea. Differences were motivated on the basis of non-pathological versus pathological, non-heritable versus heritable, localization and extent of the complaints.

When asked regarding the association of JHS/EDS-HT with *HCTD*, 56.0% responded affirmatively (correct answer). Furthermore, half of the respondents had no idea whether or not JHS/EDS-HT is related to developmental coordination disorder (*DCD*) (58.2%) (related), osteoarthritis (*OA*) (55.7%) (related), rheumatoid arthritis (*RA*) (55.7%) (unrelated), fibromyalgia (*FM*) (49.8%) (related), and *implications in pregnancy* (50.2%: unrelated; 49.8%: related; no consensus).

The mean "general knowledge score" was 4.1 out of 12 (range 0–10). χ^2 analysis revealed that "general knowledge of hypermobility and JHS/EDS-HT" is significantly related to training (undergraduate and postgraduate) ($\chi^2 = 12.84$; df = 2; $P = 0.002$), but not to years of experience ($\chi^2 = 2.12$; df = 2; $P = 0.346$).

Knowledge of Features Associated With JHS/EDS-HT

The most common musculoskeletal features associated with JHS/EDS-HT, all of which were correctly, acknowledged by the physiotherapists are *laxity* (69.2%) and *dislocation/(sub) luxation* (55.7%), followed by *proprioceptive deficit* (45.8%), *muscle weakness* (43.1%), and *chronic pain* (40.6%). *Muscle-tendon problems* and *parasthesia* were acknowledged by only 17.8 and 13.2%, respectively. Nevertheless, about 40% of the respondents had no idea whether proprioceptive deficit, muscle weakness, chronic pain, muscle-tendon problems, nor parasthesia are characteristic for JHS/EDS-HT or not. Regarding the non-musculoskeletal features, the majority of respondents (51.1–71.1% depending on the symptom) had no idea of their association with JHS/EDS-HT. *Fatigue*, *striae*, and *delayed wound healing* (all of which are correct) were acknowledged by 37.2, 27.7, and 27.4% of the physiotherapist, respectively, and *autonomic dysfunction*, *prolapse*, *anxiety*, and *depression* (all of which are correct) were reported to be significantly associated with JHS/EDS-HT in less than 20% of the respondents.

The mean "knowledge of JHS/EDS-HT features" score was 4.8 out of 16 (range 0–15). Scores were found to be significantly related to undergraduate and postgraduate training ($\chi^2 = 4.17$;

df = 2; $P = 0.041$), but not to years of experience ($\chi^2 = 1.25$; df = 2; $P = 0.535$).

Assessment of Patients With JHS/EDS-HT

96.0% of the respondents reported a lack of confidence with regard to assessment and clinical evaluation of patients with JHS/EDS-HT. However, it should be noted that three quarters of respondents (74.6%) reported that they had never evaluated an JHS/EDS-HT patient, and were thereby unable to comment on assessment tools and management for those patients (see below). Of the physiotherapists who had already performed an assessment, the majority had not used specific assessment tools. Less than 3% mentioned having used assessment tools to assist diagnosis, such as the Beighton score, Brighton criteria, Villefranche criteria, or the five part-questionnaire for identifying gJHM. In addition, 71.4% correctly thought that JHS/EDS-HT cannot be diagnosed based on laboratory findings.

Assessment confidence was found to be significantly related to undergraduate and postgraduate training ($\chi^2 = 24.92$; df = 2; $P < 0.001$), but not to years of clinical experience ($\chi^2 = 2.12$; df = 2; $P = 0.346$).

Management of Patients With JHS/EDS-HT

Seventy physiotherapists (21.5%) had treated at least one JHS/EDS-HT patient. Within this group, 74.3% (53/70) indicated that diagnosis of JHS/EDS-HT affect their choice of management approach. Patient management was mainly adopted by careful handling, the application of exercises at lower intensity and with slower progression, the focus on proprioception, core stability training, and closed kinetic chain exercises, and the avoidance of end range mobilizations and manipulations.

Notwithstanding, confidence with regard to management of JHS/EDS-HT was low, with 60% of the physiotherapists (42/70) reporting an apparent lack of clinical confidence in this area. Management confidence was not significantly related to years of clinical experience ($\chi^2 = 0.492$; df = 2; $P = 0.782$) nor to undergraduate and postgraduate training ($\chi^2 = 2.685$; df = 2; $P = 0.261$).

Figure 1 provides an overview of the treatment modalities used and their efficacies perceived by the physiotherapists. The most commonly used treatment modality was core stability training (87.1%), followed by proprioceptive exercises (81.4%), muscle strength exercises (80.0%), education (71.4%), reassurance (65.7%), and cardiovascular training (58.6%). Almost half of physiotherapists applied modalities such as, manual therapy (45.7%),

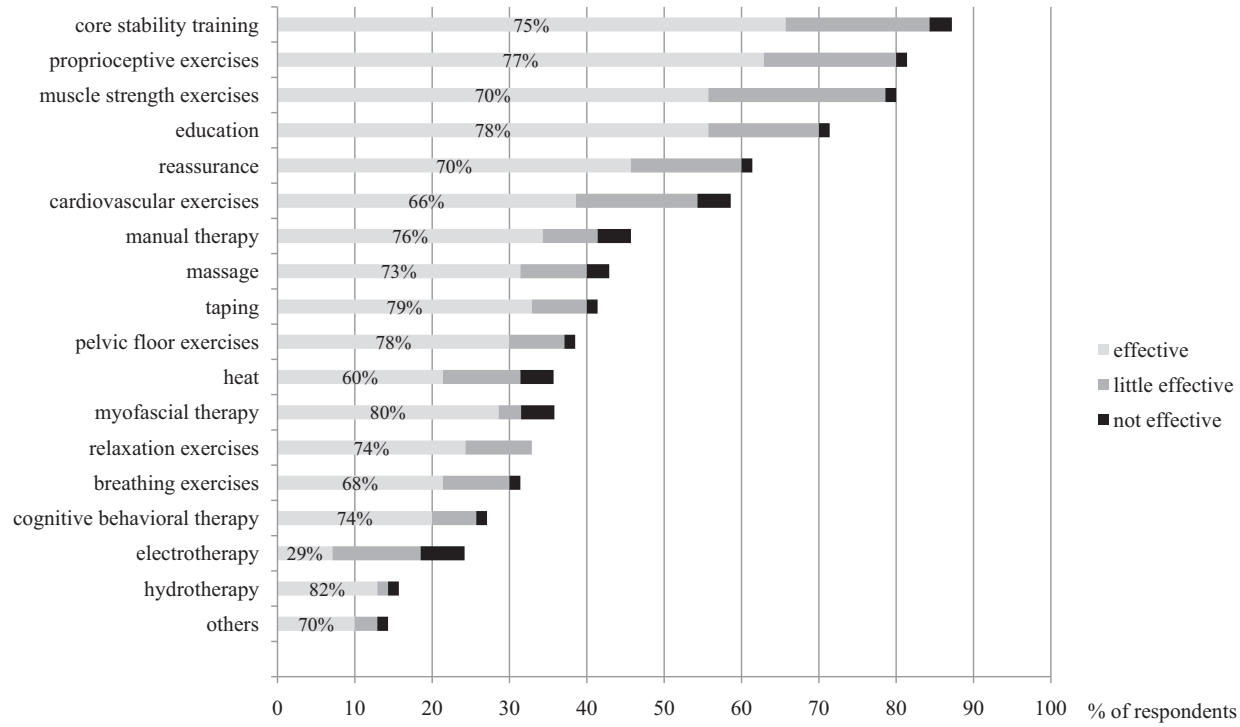

Figure 1. Treatment approaches and perceived treatment efficacy. The total bars represent the percentage of physiotherapists who used this treatment approach in the management of patients with EDS-HT. The light grey, dark grey, and black parts within the bar show the percentage of physiotherapists who found this treatment approach to be effective, little effective, or not effective, respectively, in the management of patients with EDS-HT. The numerals within the light grey bars represent the relative percentage of efficacy.

massage (42.9%), and taping (41.3%), while others were less utilized. Manual therapy mainly concerned gently mobilizations and distraction techniques. Concerning perceived efficacy, all treatment modalities except electrotherapy and heat were perceived as effective by 70% to 82% of physiotherapists using that approach (see relative percentages of efficacy, Fig. 1). Although not frequently used, hydrotherapy and myofascial therapy rated the highest perceived treatment efficacy (≥80%), followed by taping, education, pelvic floor exercises, proprioceptive exercises, manual therapy, and core stability training (≥75%).

The majority of the physiotherapists (74.3%) preferred an individual (1:1) approach for JHS/EDS-HT patients.

Impact of JHS/EDS on QOL

Nearly half of all respondents (48.0%) presumed that JHS/EDS-HT has a high impact on the QOL. A third (33.5%) had no idea concerning the impact of the disorder (see Fig. 2).

Future Learning

The majority of all respondents (79.4%) reported that they were keen to learn more about gJHM and JHS/EDS-HT in terms of assessment and management. When given the options of modes of learning, preferences were to learn through seminars (41.5%), workshops (35.2%), and books/journals (31.8%).

DISCUSSION

The results of this survey show that physiotherapists' confidence in assessment and management of adults with JHS/EDS-HT is low. There is a relatively poor general knowledge of hypermobility and JHS/EDS-HT among Flemish physiotherapists, especially regarding the features associated with JHS/EDS-HT. Also the impact of JHS/EDS-HT on QOL is under-recognized. Further, a large variety of treatment approaches are used for JHS/EDS-HT patients, albeit mostly with a moderate treatment efficacy, as perceived by the physiotherapists. Nevertheless, treatment remains difficult.

Our results confirm to a large extent previous research undertaken in this field [Deane et al., 2008; Lyell et al., 2014]. In agreement, in the UK physiotherapists' knowledge of clinical features and assessment tools for JHS/EDS-HT is poor, which may impact on patient management. Also education, reassurance and advice, in combination with hands-off exercise therapy are the general management trends, but still, management confidence is lacking.

The current study highlighted that, although one cannot comment on whether or not this is sufficient, general knowledge regarding hypermobility and JHS/EDS-HT appears poor amongst the physiotherapists surveyed, with a mean general knowledge score of 34% and a mean features knowledge score of 30%. In addition, the results indicated that about half of physiotherapists surveyed are aware that EDS-HT has a substantial impact on life, which is confirmed by several studies [Berglund and Nordström, 2001; Rombaut et al., 2010b; Rombaut et al., 2011b]. However, as many as 33.5% of the physiotherapists could not estimate the impact on QOL and 0.9% dismissed the effect on QOL as minimal, which may lead to inappropriate assessment and treatment.

Disinterest and skepticism toward JHS/EDS-HT, in combination with little attention in clinical practice, the complexity of the disorder, the still relatively limited knowledge and published literature about JHS/EDS-HT (although scientific research in this area has accumulated in the last decade), and the fact that JHS/EDS-HT is a rare disorder, all may contribute to the lack of knowledge of the syndrome.

Although we do not know how this level of knowledge impacts upon clinical outcome, the knowledge scores appear to be significantly related to undergraduate and postgraduate training. This implies that education and training are valuable for increasing the knowledge and awareness regarding JHS/EDS-HT, although learning through experience can also contribute to knowledge base in this subject area.

The most obvious musculoskeletal complaints, i.e., laxity and dislocation/subluxation, were correctly associated with JHS/EDS-HT by more than half of the participants, whereas other important musculoskeletal features, like chronic pain, muscle weakness, and proprioceptive deficit were acknowledged by only 40–46% of the physiotherapists surveyed. In addition, the majority of the participating physiotherapists were unaware of the fact that non-musculoskeletal characteristics, such as dysautonomia, fatigue, delayed would healing, etc. are associated with JHS/EDS-HT as well, suggesting limitations in respondents' perception and knowledge of the condition. A possible explanation for the non-recognition of non-musculoskeletal features of JHS/EDS-HT could be that these symptoms are not clearly visible at first glance, contrary to the more prominent

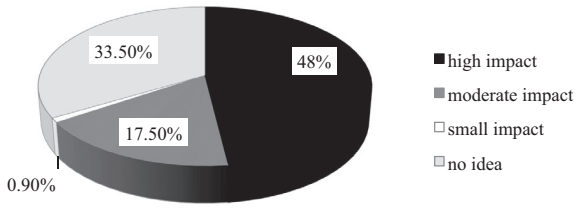

Figure 2. Perceived impact of JHS/EDS-HT on quality of life.

musculoskeletal complaints. In addition, non-musculoskeletal features of JHS/EDS-HT are not part of the diagnostic criteria nor part of usual screening questions used by musculoskelatal therapists.

In the current study, 56.0% of all participants related JHS/EDS-HT to HCTDs, of which EDS, Marfan syndrome and osteogenesis imperfecta are most common and all show clinical similarities [Malfait et al., 2006]. Furthermore, since JHS/EDS-HT patients often also meet the criteria for fibromyalgia (FM) and the fact that FM is better known among health care professionals, JHS/EDS-HT patients often get misdiagnosed with FM. A survey study demonstrated that EDS(-HT) has the longest delay (mean 14 years) among rare diseases to obtain the correct diagnosis [Kole and Faurrison, 2009]. In addition, concerning pregnancy we would like to remark that the resulting thought is that pregnancy and delivery appear relatively safe in JHS/EDS-HT. However, special care should be posed in strategies for preventing symptom worsening during pregnancy and in planning delivery and anesthesia [Castori et al., 2012b].

This study further reveals a remarkable lack of confidence with regard to assessment. In addition, very few physiotherapists (less than 3%) who performed an assessment of an JHS/EDS-HT patient reported to use (a) tool(s) to assist their assessment. When such tools were used, however, this was mainly the Beighton scale for evaluation of gJHM, which is representative of the current evidence base available [Beighton et al., 1973]. However, it has to be mentioned that the scale neglects articular involvement outside of the lumbar spine, knees, elbows, and digits of the hand and therefore gives no true indication of the degree of gJHM [Juul-Kristensen et al., 2007]. Therefore, it also seems appropriate to infer from these results that our current knowledge of the available tools that underpins our practice is perhaps inadequate.

Furthermore, assessment confidence was found to be significantly related to undergraduate and postgraduate training. Therefore, the opportunity to learn through training, theoretically as well as practically/clinically, is warranted.

Another aspect of the research was related to the management and management efficacy of JHS/EDS-HT. Three quarters of physiotherapists surveyed reported that an established diagnosis of JHS/EDS-HT has a profound effect on their treatment approach and choice of modalities. Patients with JHS/EDS-HT differ from other people in that their connective tissue defect makes them very vulnerable to trauma and overuse lesions. As such, physiotherapists have to be aware of the need for careful handling of fragile tissues, and prudence and patience is recommended.

The survey indicated that the majority of physiotherapists use the following treatment approaches and at the same time perceived them as being clinically effective: core stability training, proprioceptive exercises, muscle strength exercises, education, and reassurance. So far, there are nearly no evidence-based physiotherapy interventions for JHS/EDS-HT patients. Nonetheless, joint stability, proprioception, muscle strength, and endurance have been shown to be impaired in patients with JHS/EDS-HT [Voermans et al., 2009; Rombaut et al., 2010a,b].

Furthermore, aquatic therapy strikingly rated the highest perceived efficacy, but was barely used. This mode of therapy should be encouraged as the combination of buoyancy, support, and warmth makes it a suitable environment to treat JHS/EDS-HT patients with the possibility to enable them to exercise "safer" and longer without exacerbating symptoms [Simmonds 2003; Simmonds and Keer, 2007]. However, the accommodation needed (i.e., a heated swimming pool) obviously limits many physiotherapists, certainly those in private practice, to do so. In addition, although also perceived as clinically effective, manual therapy and myofascial therapy were applied by less than 50% of physiotherapists surveyed. This might reflect a reticence and potential fear to use hands-on therapeutic techniques. Therefore, there is a possibility, borne through a lack of understanding and much needed training, that physiotherapists adopt what they perceive to be a clinically "safer" approach, which from this study appears to include exercises, education, and reassurance.

Overall, it is striking to note that, of all approaches suggested, most interventions were favoured, highlighting a lack of consensus.

In our opinion, based on the gathered data and our clinical experience, physical therapy in adults with JHS/EDS-HT should focus on the one hand on symptomatic treatment of acute complaints, i.e., pain relief. Manual techniques can be a valuable tool in treating pain and neuromuscular dysfunction. For articular problems, gentle midrange cyclical mobilizations and distractions are generally experienced as beneficial. Manipulation techniques can be performed as well in case of acute articular restrictions, but with care. Prior to performing such end-range techniques with a high velocity thrust, the load capacity of the connective tissue should be thoroughly investigated, as well as the presence of contraindications. For muscle dysfunction, manual soft tissue techniques, massage techniques, trigger point release, and fascia techniques are perceived as useful to relieve pain symptoms. In addition, manual neurodynamic techniques are helpful in case of neurogenic irritation. Finally, electrotherapy (mainly TENS) might be useful in some cases to reduce the pain temporarily. Taping and bracing techniques can provide additional symptom relief.

On the other hand, functional exercise therapy with a focus on core and joint stability training (neuromotor control) is highly necessary for JHS/EDS-HT patients. In core stability training, a good refined motor control of the deep abdominal muscles and deep back muscles while adopting a good physiological curvature in different postures and positions should be taught, and progressed with functional movements. When core stability has been improved, joint stability of the extremities (e.g., shoulder, knee, and ankle) should be trained. Exercises are

progressed starting from closed-chain to open-chain limb movements. Once motor control is improved, muscle strength exercises and reconditioning can be added, starting at low intensity with a very gradual build-up (graded exercise). Prudence and patience is recommended, particularly with reference to increasing the number of repetitions and resistance, as patients generally progress more slowly than healthy individuals. Also sufficient spacing of the exercises and implementing adequate rest during and in between the training sessions is important (pacing). An appropriate form for patients with JHS/EDS-HT to increase strength and the activity level is aquatic training.

Furthermore, education about activity management, chronic pain (in case of central sensitization), and joint protection can be very useful.

Also an apparent lack of confidence with regard to management of JHS/EDS-HT was demonstrated among the physiotherapists (60%) and was not found to be significantly related to years of experience nor to training. The lack of knowledge and experience with JHS/EDS-HT, the complexity of the disease, and the huge variability in type, intensity and frequency of symptoms within an JHS/EDS-HT patient makes it a very difficult condition to treat. In addition, the very slow progress hampered by setbacks and flare-ups of pain and other complaints, the reduced load capacity, and the delayed recovery from exercise all can be recurrent impediments for treatment. All this can make the physiotherapist feels somehow powerless or incapable.

Consequently, it was not suprising to notice the enthusiasm with which the respondents generally embrace the opportunity to learn. 79.4% of the physiotherapists surveyed were interested to learn more about gJHM and JHS/EDS-HT, reflecting the gaps in current knowledge, assessment, and management as outlined in this study. Conversely, the level of response rate (32.5%) might reflect a general low level of interest in gJHM and hypermobility related syndromes.

In the current study, aquatic therapy, hands-on therapy, and some exercise approaches like core-stability training were perceived to be most effective. In light of these findings, further research is needed to evaluate the effectiveness of these physiotherapeutic treatment modalities, by powerful clinical randomized controlled trials. In addition, several intervention modes should be compared to try to discover the most optimal form regarding type, intensity, and frequency of exercises for patients with JHS/EDS-HT. Furthermore, there is a need for evidence-based multidisciplinary intervention studies that target the multifaceted complaints that patients with JHS/EDS-HT have. As JHS/EDS-HT patients present with various symptoms of variable severity and setbacks and flare-ups are not uncommon, interventional studies and evaluation of their effectiveness are very challenging.

The present results must be viewed within the limitations of the study. 325 physiotherapists completed the questionnaire of which merely 70 had treated a patient with JHS/EDS-HT. Consequently, the findings cannot be generalized to all physiotherapists in Flanders. However, it should be noted that it might be that some physiotherapists have been encountering JHS/EDS-HT patients but just did not realize it due to lack of knowledge and diagnosis. Furthermore, it can be suspected that many physiotherapists who never heard about JHS/EDS-HT declined the invitation. However, it was explicitly stated in the covering email that even though JHS/EDS-HT was unknown, participation was desirable.

Despite these limitations, this study has established an insight into current physiotherapy practice in this area by shedding a light on the current knowledge, assessment, and management approach of Flemish physiotherapist regarding JHS/EDS-HT. Further education is required and sought by the physiotherapists surveyed, and further research is needed to develop international management guidelines for this complex condition.

ACKNOWLEDGMENTS

The authors would like to express their gratitude to the physiotherapists who participated in this study. They also thank V. Blommaert and L. Van Hoecke for assistance in collecting and analyzing the data.

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