Conclusions: SSc-patients have markedly reduced muscle endurance and muscle function compared with reference values and patients with moderate-end-stage lung disease have reduced lower extremity muscle function compared to patients with no-mild lung disease. SSc-patients have slightly less AROM than controls and dcSSc-patients are more restricted than lcSSc. This study highlights the importance of identifying patients with an enhanced risk of developing severe muscle impairments. We suggest that physiotherapists regularly assess muscle function using standardised tests and when needed initiate exercise to improve function

Disclosure of Interest: None declared

DOI: 10.1136/annrheumdis-2018-eular.2575

THU0718-HPR THE PSYCHOSOCIAL IMPACT OF JOINT HYPERMOBILITY SYNDROME AND EHLERS-DANLOS SYNDROME (HYPERMOBILITY TYPE): A QUALITATIVE INTERVIEW STUDY

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Background: Existing research examining those with Joint Hypermobility Syndrome (JHS) and Ehlers-Danlos Syndrome (Hypermobility Type) (EDS-HT) has predominately focused on factors such as pain, range of movement and physical function. However psychosocial factors have received much less attention.

Objectives: This study sought to 1. Identify the psychosocial impact of JHS/EDS-HT by examining participants' lived experiences, and; 2. Identify characteristics of effective coping with JHS/EDS-HT, using qualitative methods.

Methods: Adults with JHS/EDS-HT took part in semi-structured telephone interviews to discuss their own lived experiences and the impact of the condition on their lives. All met the Hakim and Grahame (2003) five-item criteria for clinically significant joint hypermobility, and had a self-confirmed diagnosis of JHS/EDS-HT. The transcripts were coded using NVivo 10 and analysed using inductive thematic analysis.

Results: 17 participants (14 women, 3 men) took part (age range 22–70, mean 38 years). The sample was purposively selected from across the UK to broadly represent different genders, ages and ethnicities. Inductive thematic analysis indicated five main themes:

Healthcare limitations: All participants reported a lack of awareness of JHS/EDS-HT among healthcare professionals, and diagnosis typically took several years. Examples were given where local anaesthetics had either partly or completely failed, leaving patients aware of severe pain during surgical or dental procedures.

A restricted life: Participants experienced a range of symptoms including joint pain and instability, fatigue, gastrointestinal issues, frequent dislocations and subluxations. Due to difficulty completing daily activities, some relied on their partners or family for support, but this led to feelings of guilt and shame.

Social stigma: The invisible nature of their condition led to participants facing criticism and confrontations with others as they 'looked fine'. Fears of being judged led some to hide their symptoms. Many felt frustrated and angry that due to fatigue or injury they could not keep up with friends, family or colleagues.

Fear of the unknown: Not knowing when the next injury was going to occur, and how JHS/EDS-HT would affect them over time made participants especially fearful of declines in their physical ability. Many cited a lack of reliable information about their condition, other than in published books or research journals. Psychological support to better cope with the enduring impact of JHS/EDS-HT on their lives was lacking.

Ways of coping: Several coping approaches were identified by participants, including acceptance of their condition, building social networks, finding out more about JHS/EDS-HT and adapting their activities. Physiotherapists were instrumental in supporting participants to exercise regularly.

Conclusions: The results of this qualitative study highlight the significant psychosocial impact of JHS/EDS-HT on participants' lives. Further research should consider potential interventions to improve information provision, address psychological support and increase awareness of JHS/EDS-HT among healthcare professionals.

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Disclosure of Interest: None declared

DOI: 10.1136/annrheumdis-2018-eular.2107

THU0719-HPR NON-PHARMACOLOGICAL CARE IN SYSTEMIC SCLEROSIS: ROOM FOR IMPROVEMENT?

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Background: Although health professional (HP) treatment is considered to be a corner stone in the management of systemic sclerosis (SSc), little is known about the referral process to and the content of non-pharmacological care in SSc.

Objectives: To describe the contribution of HP to SSc care from the perspective of SSc patients, including the referral process, use of care provided by HP, treatment targets and outcome satisfaction.

Methods: Dutch SSc patients from different hospitals were invited through their rheumatologists (RT) to complete an still ongoing online survey provided by the ARCH (Arthritis Research and Collaboration Hub) working group, containing questions on a wide range of issues within SSc care. Items concerning access to care (referral versus direct access), use of HP services, and quality of care perceived by patients assessed by the CQ Index were extracted to answer the research question. Reasons for referral/direct access and treatment targets were examined by means of open questions.

Results: On January 10th, 2018, 433 SSc patients, 73% women (n=317), with a median age of 61 (SD=10,81) completed the survey. 38% of the patients had limited and 23% diffuse cutaneous SSc. The mean time since diagnosis was 4,1 years.

In total, 10 different HP disciplines were reported and 76% (n=331) of the patients ever had contact with one or more HP; 50% (n=215) had contact with a HP in the past year. Compared to the other 9 disciplines named, physiotherapists (PT) were the most often referred to; 57% (n=245) had PT treatment since SSc onset, 41% (n=177) in 2017, whereas only 35 were referred to occupational therapists and 9 to hand therapists (figure 1).

Rheumatologists (RT) were the main referrers to HP care with 49% (n=106); 27% (n=59) sought care by one or more HP through direct access in the past year. A total of 52% (n=111) of the 215 patients that received HP treatment in 2017 perceived the collaboration between their RT and the treating HP as insufficient and 68% (n=146) reported that RT and HP did not make good agreements with each other. Further, 45% (n=97) of the patients felt that there was no coordination between the referrers and the HP about advices issued.

76% (n=164) of respondents found their HP sufficiently competent for SSc treatment. 73% (n=156) could cope better with their complaints after the treatment and reported improvement in their daily activities. Qualitative analysis of the data on the PT as main HP treatment provider in 2017 yielded 36 different referral reasons and 42 treatment targets, of which the most frequently mentioned (>4) are shown below.

Referral reasons: pain, joint problems, shoulder problems, decreased mobility, back problems, muscle weakness/stiffness/ pain and general stiffness.

Treatment targets: improvement of general mobility, joint mobility, condition, muscle function, skin flexibility and hand function, pain relief, stiffness avoidance and fatigue reduction.

Abstract THU0719HPR – Figure 1. Frequency of referrals to health professionals

Conclusions: HP treatment is a meaningful part of SSc care, as reflected in the satisfaction of SSc patients. The results describe a suboptimal communication

between RT and HP. In view of other published studies on hand problems in SSc, a surprisingly small amount of referrals to occupational- and hand therapists. Further research should focus on the optimisation of professional communication.

Disclosure of Interest: None declared

DOI: 10.1136/annrheumdis-2018-eular.4428

THURSDAY, 14 JUNE 2018

HPR Interventions (educational, physical, social and psychological)

THU0720-HPR FACTORS ASSOCIATED WITH POOR SLEEP QUALITY IN PATIENTS WITH CHRONIC WIDESPREAD PAIN: RESULTS FROM THE AMSTERDAM PAIN COHORT

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Background: Reduced sleep quality is a major concern in patients with chronic widespread pain (CWP).^{1,2} Poor sleep quality in CWP has received relatively little attention in both multidisciplinary treatment and clinical research in multidisciplinary treatment.^{3,4}

Objectives: (i) To investigate the prevalence of poor sleep quality and (ii) to explore the associations between clinical, cognitive and emotional factors and quality of sleep in patients with CWP indicated for multidisciplinary treatment.

Methods: Baseline data were used from 163 CWP patients referred for multidisciplinary treatment. Linear regression models, adjusted for age and gender, were used to assess the relationship of clinical (pain, fatigue, pain interference and disability), emotional (anxiety, depression and psychological distress) and cognitive factors (catastrophizing, acceptance, self-efficacy, kinesiophobia and illness beliefs) with sleep quality, as measured with the Pittsburgh Sleep Quality Index (PSQI).

Results: Poor sleep quality was found in 92% of the patients. The multivariate model showed that a higher level of fatigue, psychological distress and more concerns about the illness were independently associated with poorer quality of sleep. The model explained 27.9% of the variance of sleep quality.

Conclusions: The high prevalence of poor sleep quality in patients with CWP referred for multidisciplinary treatment emphasises the need to target sleep during the treatment program. Poorer quality of sleep is related to a higher level of fatigue, psychological distress and more concerns about the illness. Attention to these factors during multidisciplinary treatment could contribute to improvement in quality of sleep.

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Disclosure of Interest: None declared

DOI: 10.1136/annrheumdis-2018-eular.7369

THU0721-HPR THE EFFECTS OF UPPER AND LOWER LIMB EXERCISE ON THE MICROVASCULAR REACTIVITY IN SYSTEMIC SCLEROSIS PATIENTS

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Background: Vascular endothelial injury is one of the early hallmarks in systemic sclerosis (SSc). High intensity interval training (HIIT) is known to improve vascular function in a range of clinical conditions. Ramos et al., 2015 HIIT in particular has demonstrated improvements in clinical outcomes, in conditions that have a strong macroangiopathic component. Nevertheless, the effect of HIIT on microcirculation in SSc patients is yet to be investigated.

Objectives: Therefore, the purpose of the study was to compare the effects of two HIIT protocols (cycle and arm cranking) on the microcirculation of the digital area in SSc patients.

Methods: Thirty four SSc patients (65.3±11.6 years old) were randomly allocated in three groups (cycling n=11, arm cranking n=11 and control group n=12). The exercise groups underwent a twelve-week exercise program twice per week. All patients performed the baseline and post-exercise intervention measurements where the physical fitness, functional ability, transcutaneous oxygen tension (ΔtcpO_2), body composition and quality of life were assessed. Endothelial-dependent as well as -independent vasodilation were assessed in the middle and index fingers using LDF and incremental doses of acetylcholine (ACh) and sodium nitroprusside (SNP). Cutaneous flux data were expressed as cutaneous vascular conductance (CVC).

Results: Peak oxygen uptake increased in both exercise groups ($p<0.01$, $d=1.36$). ΔtcpO_2 demonstrated an increase in the arm cranking group only, with a large effect, but found not statistically significant ($p=0.59$, $d=0.93$). Endothelial-dependent vasodilation improvement was greater in the arm cranking ($p<0.05$, $d=1.07$) in comparison to other groups. Both exercise groups improved life satisfaction ($p<0.001$) as well as reduced discomfort and pain due to Raynaud's phenomenon ($p<0.05$). Digital ulcers and hospitalizations reported in four patients (36%) of the control group and one of them proceeded for amputation. Arm cranking seems to be the preferred mode of exercise for study participants as compared to cycling ($p<0.05$). No changes were observed in the body composition or the functional ability in both exercise groups compared to the control group.

Conclusions: Our results suggest that the arm cranking has the potential to improve the microvascular endothelial function in SSc patients and to prevent digital ulcers and further related complications. Also notably, our recommended training dose (e.g., a 12 week HIIT program, twice per week), appeared to be sufficient and tolerable for this population. Future research should focus on exploring the feasibility of a combined exercise such as aerobic and resistance training by assessing individual's experience and the quality of life in SSc patients.

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Acknowledgements: This research was supported by Sheffield Hallam University. We would also like to thank the patients who took part in our research study.

Disclosure of Interest: None declared

DOI: 10.1136/annrheumdis-2018-eular.1979

THU0722-HPR PHYSICAL THERAPY IS EFFECTIVE IN PATIENTS WITH ANKYLOSING SPONDYLITIS: A RANDOMISED CONTROLLED TRIAL

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Background: Ankylosing spondylitis (AS) is a chronic inflammatory disease that predominantly affects the spine and may cause serious functional impairment. The prevalence of AS is approximately 0.1% of the Caucasoid population. Treatment of AS includes use of antiinflammatory drugs to reduce pain and stiffness. In addition, patients are advised to exercise daily and to engage in weekly group physical therapy to maintain mobility of the spine and peripheral joints.

Objectives: To evaluate the effects of physical therapy on pain, disease activity, functional and emotional status and quality of life in patients with AS.

Methods: Thirty one patients diagnosed with AS and followed up in outpatient clinic were conducted into the study. Routine physical examination of musculoskeletal and neurological system of all patients has been performed. Patients divided into two groups (physical therapy group and control group) as random. 15 seance physical therapy (hotpack, ultrasound, TENS and hydrotherapy) exercise and medical treatment performed for the physical therapy group and only home exercise programme and medical treatment for control group. All patients received medical therapy which was not changed during the study. We evaluated all patients with visual analogue scale (VAS) at night and rest for pain, Bath Ankylosing Spondylitis Functional Index (BASFI) for functional status, Bath Ankylosing Spondylitis Disease Activity Index (BASDAI) for disease activity and modified Schober, finger floor distance (FFD), lateral flexion of the lumbar spine, cervical rotation, intermaleolar distance, tragus wall distance, chest expansion, cheek manubrium distance and Bath Ankylosing Spondylitis Metrology Index (BASMI) for spinal mobility measurements at the beginning, 2nd and 6th weeks. Also Beck Depression Inventory (BDI) and short form 36 (SF-36) were fulfilled by all patients at the beginning and 6th week.