POS1473-HPR SELF- AND SHARED-MANAGEMENT INTERVENTIONS FOR CHILDREN, YOUNG PEOPLE, AND FAMILIES LIVING WITH RHEUMATIC AND MUSCULOSKELETAL DISEASES: AN INTEGRATIVE REVIEW

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Background: Self-management refers to the manner in which individuals manage the symptoms, treatment, physical and psychosocial impact of long-term conditions (LTCs). The importance of equipping children and young people living with LTCs, like rheumatic and musculoskeletal diseases (RMDs) with the capacity to self-manage is increasingly recognised in the literature, and in conversation. In addition, there is a strong case to support families who assume a shared-management role for their child. However, there is a limited understanding of interventions designed to improve self- and shared-management capacity in this population, prompting for a review of the literature, across multiple study designs.

Objectives: The aim of this integrative review was to identify and describe interventions promoting self-management of RMDs by children and young people, and shared-management of RMDs by families.

Methods: The integrative review followed a six-stage process [1]. Studies published since 2010 were identified through a search of eight bibliographic databases. Studies reporting on any paediatric-onset RMD were included, as were those in multiple condition areas where RMDs were included in the analysis. Twenty-six articles met the inclusion criteria: 24 research articles reporting on 17 interventions, and two review articles containing a further four research articles. The methodological quality of included articles was assessed using the Mixed Methods Appraisal Tool, and a thematic synthesis was undertaken.

Results: Most study participants were CYP and families living with JIA. A minority of studies included CYP and families living with other RMDs, as well as chronic pain, type 1 diabetes mellitus, epilepsy, sleeping disorder, and cancer. Around half of the articles reported a specific theory and/or model or framework guiding the intervention. Interventions tended to be focussed at either CYP or families, with few designed to span the lifecourse from birth to young adulthood, while supporting all members of the family unit. Intervention types included: decisional aids; comic educational book; family retreat weekend; internet- and group-based cognitive behavioural programme; internet-based peer mentoring intervention; internet-based self-guided self-management intervention with weekly social support; internet-based electronic patient-reported outcome platform; smartphone applications; telenursing intervention; therapeutic recreational camp; therapeutic family nursing conversations; transition programme/clinic; and video games-based task-orientated activity training.

Conclusion: This integrative review identified a range of interventions that have been evaluated to promote self- and shared management of RMDs by CYP and their families. There is a noticeable lack of emphasis on targeting the whole lifecourse for CYP, as well as supporting both CYP and families as they manage their RMD. Further work is needed to explore the underlying mechanisms which dictate how self- and shared-management interventions influence outcomes for CYP and families, under differing contexts, since this was overlooked by the majority of included studies.

REFERENCES:

- [1] De Souza et al. Integrative review: What is it? How to do it? *Einstein (São Paulo)* 2010; 8(1): 102-106.

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HPR Patients' perspectives, functioning and health (descriptive: qualitative or quantitative)

POS1474-HPR PERSONAL EXPERIENCES WITH DIAGNOSTIC DELAY AMONG AXIAL SPONDYLOARTHRITIS PATIENTS – A QUALITATIVE STUDY

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Background: The estimated prevalence of axial Spondyloarthritis (axSpA) in the U.S. is 0.4 to 1.3 percent. Undiagnosed axSpA patients suffer from symptoms on average 7 to 10 years, which can also contribute to psychological suffering and healthcare burden due to the prolonged search for diagnosis and treatment.

Objectives: To explore the experiences of diagnostic delay of axSpA patients as part of the SpondyloArthritis Screening and Early Detection (SpA-SED) Study.

Methods: We conducted exploratory semi-structured patient focus groups. English-speaking participants ≥18 years of age with a rheumatologist-verified clinical diagnosis of axSpA were recruited from three rheumatology practices in Massachusetts, Colorado, and Pennsylvania. Six focus groups were conducted with 26 total participants (16 men, 10 women, age range 21-76 years). Discussions ranged from 1.33 to 2.13 hours. Verbatim transcripts were deidentified, cleaned and coded using NVivo qualitative software. A coding list was generated and summary themes were constructed.

Results: Participants described meandering and frustrating journeys in search of a diagnosis. When doctors gave up, it was experienced by patients as profoundly negative. Intermittent axSpA symptoms confused some physicians and caused some patients to either delay seeking medical care (e.g., sporadic flare-up) or use dramatic language to convey the magnitude of the impact on their symptoms. Patients explained their experiences where physicians presumed that patients were trying to obtain narcotics or were "imagining/exaggerating" symptoms. Early symptom stories fell into five areas of importance for patients: pain, stiffness and lack of mobility, impact on sleep, impact on daily life, and changes with weather. Tenacity on the part of the patient and/or their family, patient research and confidence to challenge their physicians were important. Self-advocacy was challenging but necessary and particularly difficult when patients were sick. During the typically lengthy time that participants waited to be diagnosed, they experienced frustration and mental suffering due to lack of answers and/or not being heard, believed, or taken seriously. Some participants described the fatigue they experienced after trying without success to obtain a diagnosis or receive treatment. Early administration of a definitive diagnostic test or screening tools for axSpA would have alleviated both physical and emotional suffering for these participants.

Conclusion: Overall, participants expressed satisfaction with physicians who sought to understand them and believed them, took them seriously, and did not give up even with long delays. Patients with axSpA described significant suffering prior to diagnosis which could have been prevented and treated. Further research is needed with axSpA patients who are early in their diagnostic journey to determine best practices to support patients and reduce diagnostic delay.

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POS1475-HPR EFFECT OF ARGENTINE TANGO PRACTICE ON TOTAL PHYSICAL ACTIVITY TIME IN PATIENTS WITH CHRONIC INFLAMMATORY RHEUMATISM: A PILOT STUDY

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Background: Most patients with chronic inflammatory rheumatism (CIR) have a physical activity (PA) level below recommendations [1,2]. Currently, adapted structures offer a range of activities supervised by adapted physical activity educators. To the best of our knowledge, Argentinean tango is not yet offered in these structures.

Objectives: The objective of this pilot study was to study the effect of 24 consecutive sessions of Argentinean tango on the total PA level in patients with CIR, including rheumatoid arthritis (RA) and spondyloarthritis (AS).

Methods: In this controlled, randomized, open-label, clinical trial with two parallel arms, patients were required to attend two tango sessions per week,

48 sessions from 0 (M0) to 6 months (M6) for the intervention group (IG) and 24 sessions from 3 months (M3) to M6 for the control group (CG). Total PA time was measured at M3 using the Global Physical Activity Questionnaire (GPAQ) [3].

Results: A total of 27 patients (23 women) were included, including 15 with RA and 12 with AS. Mean age was 59 ± 12 years, and median disease duration was 10 years (IQR: 3-19). The majority of patients had background treatment (conventional and/or biological). At M3, 22 patients could be evaluated (11 GC patients and 11 GI patients), as 3 patients were lost to follow-up and 2 were unable to come in due to health or professional reasons. The 11 GI patients attended a median of 16 sessions (IQR: 8-22), i.e., approximately one session per week. At M3, the total PA time was not increased, regardless of the measurement method, GPAQ questionnaire (effect size and 95% confidence interval (CI): 0.03 [-0.60; 0.67], $p=0.91$) or accelerometer (effect size and 95% CI: 0.43 [-0.37; 1.24], $p=0.26$), and regardless of the intensity of the PA. No significant change was found for sedentary time, disease activity, fatigue, or anxiety. However, improvements were found in body appreciation as assessed by the Body Appreciation Scale 2 questionnaire ($p=0.016$), balance ($p=0.053$), wrist bending angle ($p=0.092$), and shoulder amplitude ($p=0.093$). The few participants in this study is explained by the geographic distance of the classes and their homes, the lack of availability of patients in professional activity, fatigue, or not liking dance (mainly among men).

Conclusion: The results of this pilot study suggest that one Argentinean tango session per week in CIR patients is more achievable than two sessions as originally planned. As the practice of classes in hospitals is constrained due to geographic distance, the sessions could be offered in adapted structures. Nevertheless, our pilot study shows that the Argentinean tango is beneficial for body appreciation in patients with CIR. A qualitative study is needed to better understand these effects.

REFERENCES:

- [1] Haute Autorité de Santé (2007). Rheumatoid arthritis: therapeutic aspects excluding drugs and surgery - medico-social and organizational aspects. Professional recommendations service - Medical-economic evaluation and public health service.
- [2] Haute Autorité de Santé (2008). Spondylarthritis: guide - long-term condition. Good Professional Practices Department - Communication Department.
- [3] Cleland CL, Hunter RF, Kee F, Cupples ME, Sallis JF, Tully MA. (2014 Dec). Validity of the global physical activity questionnaire (GPAQ) in assessing levels and change in moderate-vigorous physical activity and sedentary behaviour. BMC Public Health. 10;14:1255. doi: 10.1186/1471-2458-14-1255.

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POS1476-HPR THE NEED FOR INFORMATION AMONG PATIENTS WITH ANCA ASSOCIATED VASCULITIS DIFFERS BETWEEN GROUPS

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Background: Being diagnosed with ANCA associated vasculitis (AAV) can be a frightening experience and means facing changes that involves adapting to new situations. Patients that are provided adequate information are better equipped to make well informed decisions regarding their care and stay compliant to the treatment plan. In order to provide adequate patient-centered information at the appropriate time and to identify those who may need extra support, the information needs must be explored. There have been several studies on the information needs of rheumatological patients, although very few studies for patients with AAV.

Objectives: The aim of this study was to explore what information patients with AAV need from their rheumatological team and how it differs between groups (gender, disease duration).

Methods: Men and women over 18 years were included through a consecutive sample from a Rheumatology or Nephrology Clinic at Karolinska University Hospital in Sweden during 2008-2019. Patients with all forms of AAV (GPA, MPA and EGPA), that had the Rheumatology clinic as primary contact, were included.

The participants were given Educational Needs Assessment Tool (ENAT) that measures the patient's information needs. The initial question, 'Do you need information right now about something that can help you with your rheumatic disease?' is answered yes/no. ENAT then includes 7 domains (Managing pain, Movement, Feelings, Disease process, Treatments, Self-help measures and Support systems) each containing 4-7 items (4-point Likert scale, 'not at all

important = 0' to 'extremely important = 3'). The total sum is divided by the maximum score and gives the percentage response of maximum score (0-100%), 0% meaning no information need and 100% highest information need. The responses are presented as "mean % of the domain score". Independent-sample t-test was used to compare the mean between groups. One way ANOVA was used to compare the mean domain score between the different diagnoses and age groups.

Results: 178 individuals completed the questionnaire, equally divided by gender. Age ranged from 18-85, median 61. 33,7% had been diagnosed within 2 years. The mean total score was 56,8 % of the highest possible score (0-100%). The highest information need was found in the domains 'Disease process' (78,1%), 'Self-help measures' (68,5%) and 'Treatments' (63,6%) whereas lesser need for information was found in the domains 'Managing pain' (47,5%), 'Support systems' (46,5%) and 'Movement' (41,1%). The domain 'Feelings' was scored as moderate (55,5%).

Those who acknowledge a present information need also scored significantly higher overall in all the domains. Disease duration and gender showed significantly affect the information need. Highest scores were found among women with a disease duration < 2 years with significant difference in 3/7 domains. Age, disease activity, diagnosis and social status did not affect the ENAT scores.

Conclusion: Even though only 38% of participants stated a current need for information, the results indicate that there are certain areas that patients with AAV consider important to receive more information about. Special consideration needs to be taken to women with short disease duration since they were shown to have a significantly higher need for information.

REFERENCES:

- [1] Mooney, J., et al. (2013). 'In one ear and out the other - it's a lot to take in': a qualitative study exploring the informational needs of patients with ANCA-associated vasculitis. Musculoskeletal Care, 11(1)
- [2] Ntatsaki, E., et al. (2014). BSR and BHPR guideline for the management of adults with ANCA-associated vasculitis. Rheumatology (Oxford), 53(12)
- [3] Hardware, B., et al. (2004). Towards the development of a tool to assess educational needs in patients with arthritis. Clinical Effectiveness in Nursing, 8(2)

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POS1477-HPR GOUT PATIENTS IN REMISSION, AND THEIR PERSPECTIVES ON URATE LOWERING THERAPY TREATMENT STOP OR CONTINUATION STRATEGIES

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Background: Urate lowering therapies (ULT) are used to reduce hyperuricemia in gout patients (1). When gout remission is reached, patients often ask if ULT should be continued lifelong (treat to target strategy, T2T), or if tapering or stopping (a treat to symptom approach, T2S) can be attempted. In fact, although current rheumatology guidelines (1,2) suggest continuation, conclusive evidence for this is absent. Since ULT therapy adherence also remains suboptimal, exploring gout patients' beliefs on different long term ULT treatment strategies is of great value.

Objectives: To identify cognitions and emotions on ULT treatment strategies (T2T continuation and T2S cessation) of gout patients in remission with current or previous ULT use.

Methods: Purposive sampling (3) was used to recruit patients from a general practice and a rheumatology department (Nijmegen, the Netherlands), with a clinical diagnosis of gout, current or previous ULT use and remission according to adapted (without serum urate criterion) preliminary gout remission criteria (4). Semi-structured interviews were conducted by two interviewers and audio-records were fully transcribed. Inductive thematic analysis (5) was used to analyse and interpret our data using the ATLAS.ti software.

Results: From a total of 18 patients (16 male/2 female), 14 patients were treated by a rheumatologist (10 currently using ULT, 1 intermittent and 3 previously) and 4 were treated by a general practitioner (all currently using ULT). Patients were satisfied with a T2T strategy, due to the absence of flares, a feeling of certainty and the reassurance of serum urate monitoring. Reluctance towards medication was reported, the importance of indefinite ULT use was questioned and its chronic use was addressed as a drawback. Reducing medication use by a T2S strategy was assessed positively and this strategy was considered less burdensome. A wish for and the willingness to follow a T2S approach was expressed. Fear and concerns of flaring after ULT cessation were expressed and were deemed both acceptable and unacceptable. See Table 1 for a schematic overview of the results.