REFERENCES:

- [1] Osthoff A-KR, et al. 2018 EULAR recommendations for physical activity in people with inflammatory arthritis and osteoarthritis. *Annals of the Rheumatic Diseases* 2018;77:1251–1260.

Table major barriers to physical activity in RA qualitative studies

Major themes	Barriers	N° of studies	Facilitators	N° of studies
Physical health	Symptoms of RA	8	stable symptoms and Effective medication	3
Psychological	Belief and fear (increasing symptoms), loss of motivation	7	Positive beliefs, knowledge about benefits of PA	5
			Positive emotion and experience of PA	5
Setting	Bad weather	3	heat, warm climate, warm water	2
	Inaccessible facilities	2	convenient setting: community or gym setting, outside hospital	4
Social environment	Lack of time	2		
	Contact with other	2	external monitoring, support adherence (reminder)	3
	Lack of support, of exercise knowledge, of confidence, conflict in advice from healthcare	4	group, socialization, influence of other, social support	8
			Support form healthcare (advise, psychological issues addressed, emphatic specialist)	3

Tables for the authors, not the abstract

Characteristics	
Year of publication, mean (SD) [range]	2012 (5.8) [1999-2018]
Published in UK/other Europe/Europe	6 / 3 / 1
Number of patients, N [range]	148 [6-19]
Methods: group / individual	4 / 6
General exercise / supervised program	6 / 4
Age, mean, SD, [range]	56.7 (4.3) [50.0-63.5]
% female	78%
RA duration, mean, SD, [range]	14.7 (5.6) [6.9-21.0]

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THU0717-HPR CLINICIANS' AND PATIENTS' UNMET NEEDS IN EHLERS DANLOS SYNDROMES, THE EXPERIENCE OF ERN RECONNET

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Background: The European Reference Network for rare and complex connective tissue and musculoskeletal diseases (ERN ReCONNET) is a European network of 26 healthcare providers (HCPs), that aims at developing a comprehensive and harmonized approach to 10 rare and complex connective and musculoskeletal diseases (rCTDs). The network gathers the community of health care professionals and patients'

representatives. The involvement of patients is structured thanks to the creation of the European Patient Advocacy Groups (ePAG). 3 ePAGs representing each disease pillar are members of the steering committee. The Ehlers-Danlos Syndromes (EDS) are represented in the ERN ReCONNET with the exception of vascular EDS represented in the VAS-CERN ERN.

Objectives: To raise awareness on the unmet needs related to EDS in the EU through attracting and engaging more experts, specialists and HCPs in order to address those needs.

Methods: At present, the EDS is represented by 2 HCPs and 2 official ePAGs, senior and junior disease coordinators have been identified both among HCPs and ePAG, in particular the EDS ePAGs intensively sought for unmet needs of EDS into their wider European Community. All needs identified by ePAGs were discussed with the senior and junior coordinators and their contribution was added in a dedicated paragraph of the article, acknowledging them as co-authors. Among other activities, a state of the art on clinical practice guidelines (CPGs) has been performed also for EDS¹, in which patients and clinicians highlighted the most important unmet needs.

Results: As the new 2017 International EDS nosology² was only published in March 2017, EDS still lack Clinical Practice Guidelines and recommendations. The main EDS unmet needs identified concern the need to develop data on prevalence and clinical features, the identification of reliable biomarkers and the implementation of advanced instrumental imaging techniques. The management of pain, fatigue and psychological support have also been identified as a major topic to be addressed. More efforts should be put also on the education of healthcare professionals in order to provide faster diagnosis and better care to EDS patients. A stronger representation of EDS centres of expertise in the ERNs is needed, especially considering the crucial added value represented by the possibility of discussing clinical cases in the Clinical Patient Management System provided by the European Commission.

Conclusion: The ERN offers a real opportunity to develop better standards of care taking into account patients unmet needs. It is critical to increase EDS awareness and to attract HCPs for the follow-up and care of patients to be able to meet the unmet needs of the EDS patient population and healthcare professionals.

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THU0718-HPR OVERVIEW OF THE MOST EFFECTIVE PHYSIOTHERAPY MANAGEMENT METHODS IN PEDIATRIC RHEUMATOLOGY

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Background: The majority of patients with pediatric rheumatologic conditions present with joint pain, morning stiffness and a high degree of fatigue which in turn affect their functional status, psychological wellbeing and activities of daily living (ADLs). Juvenile idiopathic arthritis - with a prevalence of 0.1-0.2/100 children- is the most common chronic pediatric rheumatic disease. When compared to healthy children, patients with juvenile idiopathic arthritis show decreased physical fitness, which necessitates systematic physiotherapy management.

Objectives: The current research was carried out to investigate the most reported physiotherapy methods for the management of common pediatric rheumatology conditions.

Methods: Pubmed and Google scholar databases were searched. Keywords were categorized into three groups. The first group included the most common pediatric rheumatologic conditions (juvenile chronic arthritis, juvenile spondyloarthropathy, juvenile psoriatic arthritis, dermatomyositis, systemic lupus erythematosus, vasculitis, scleroderma); the second group included physiotherapy management methods (physiotherapy, physical therapy, hydrotherapy, aquatic therapy); and the third group included outcomes (pain, pediatric pain, range of movement, quality of life, activities of daily living). Only primary research studies regarding patients with the aforementioned pediatric rheumatologic conditions were included.

Results: Notable variability was observed between studies as regards to applied methods and recorded outcomes. Additionally, results were not separately reported for the different diseases. Nevertheless, findings indicate that physiotherapy and hydrotherapy rehabilitation methods, focusing on reducing joint pain, joint protection, conservation of energy, and conservation of joint range of motion, achieved the treatment goals of