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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

Charissa Hermine Frank¹, Jürgen Grunert². ¹Bindweefsel.be, Koersel, Belgium; ²Deutsche Ehlers-Danlos Initiative e.V., Fürth, Germany

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

Emmanuella Ioannou. European University Cyprus, School of Sciences, Egkomi, Nicosia, Cyprus

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

maintaining and/or improving joint mobility and strength, improving pain and function, as well as improving the psychological wellbeing, without increasing fatigue or joint symptoms.

Conclusion: Despite heterogeneity in study design and methodology, current evidence shows that various physiotherapy methods contribute to the achievement of treatment goals and improve the quality of life in pediatric rheumatology.

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THU0719-HPR THE PATIENT ACTIVATION MEASURE (PAM): WHAT DO PATIENTS WITH RHEUMATIC CONDITIONS THINK ABOUT IT?

Bethan Jones^{1,2}, Andrew Hunt², Diana Harcourt¹, Sarah Hewlett¹, Emma Dures^{1,2}.

¹University of the West of England, Bristol, United Kingdom; ²University Hospitals Bristol NHS Foundation Trust, Bristol, United Kingdom

Background: Patient activation describes the skills, abilities and confidence someone has to actively manage their health. The most common way of capturing patient activation is by using the Patient Activation Measure (PAM), and the NHS has begun to integrate use of the measure into services as an outcome measure or as a tool to tailor care. The PAM has been widely adopted and used in a variety of populations both within the NHS and internationally, but case studies have reported that some patients found that the PAM was too broad to capture the skills they used to manage their health. There has been limited research gathering patients' perceptions of the suitability and acceptability of the PAM, particularly within a rheumatology context.

Objectives: To gather participants' opinions on the PAM as a method of capturing patient activation.

Methods: Seventeen participants living with a rheumatic condition in the South West of England participated in semi-structured interviews as part of a wider qualitative study investigating perceptions of patient activation. Participants completed the PAM at the beginning of the interview. In the last phase of the interview, they were asked to review and reflect on the PAM, including individual survey items and how closely they matched their experiences. Relevant sections of the interviews were analysed iteratively and participants' perspectives were grouped into themes.

Results: Participants' feedback on the PAM ranged, and some participants reported that the PAM entirely captured how they perceived patient activation and the way that they managed their conditions. However, this was not the case for all participants. Aspects of the PAM that participants felt were not sufficiently recognised included how they managed the psychological impact of their condition, and how they discussed their condition with loved ones. Participants commonly reported that they thought the phrasing of certain PAM items did not match the lived experience of their conditions. For example, PAM items capturing how well patients could prevent further problems was identified as a challenge for participants living with a fluctuating condition, and participants commented that the PAM does not check from where participants received or sought this information. The distinction between whether patients independently researched information about diagnoses and medications or received this passively from healthcare professionals also appeared important to some participants, as well as whether this information was accurate.

Conclusion: The PAM survey is generally considered a reliable and valid measure of patient activation, but there may be aspects of it that do not capture the realities of living with a long-term fluctuating condition. Rather than a stand-alone measure, the PAM would be best used in conjunction with healthcare professionals' clinical judgement to capture peoples'

understanding of their conditions and how well they are able to recognise and respond to flare-ups and fluctuations.

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THU0720-HPR FACTORS ASSOCIATED WITH PAIN CATASTROPHIZING IN INDIVIDUALS WITH SYSTEMIC LUPUS ERYTHEMATOSUS

KINIKLI Gizem İrem¹, Emine Gözde Aydemir Gülöksüz², Müçteba Enes Yayla², Tahsin Murat Turgay², Aşkın Ateş², Gülay Kınıklı². ¹Hacettepe University, Faculty of Physical Therapy and Rehabilitation, Ankara, Turkey; ²Ankara University Faculty of Medicine Department of Internal Medicine, Rheumatology, Ankara, Turkey

Background: Systemic lupus erythematosus (SLE) is a chronic autoimmune disease with a wide spectrum of clinical manifestations such as organ damage, pain, fatigue, sleep disorders, depression and cognitive deficits. It is known that pain catastrophizing may have serious impact in individuals with SLE. Furthermore, catastrophizing and maladaptive coping strategies are linked to higher levels of functional impairment and depression in SLE.

Objectives: The aim of this study was to identify factors associated with pain catastrophizing to detect possible susceptible targets in individuals with systemic lupus erythematosus.

Methods: A total of 104 individuals (mean age: 55.54±12.09 years; BMI: 27.17±4.01 kg/m²) with SLE participated to the study. The Pain Catastrophizing Scale (PCS) was used to measure the extent to which people catastrophize in response to pain. The Tampa Scale for Kinesiophobia (TSK) was used to assess pain-related fear of movement. The Beck's Depression Inventory (BDI) was used to measure characteristic attitudes and symptoms of depression. The Body Awareness Rating Questionnaire (BARQ) was used to reflect on their self-reported body awareness. The multiple stepwise linear regression models with R-square (R²) were used to compare across the models and explain the total variance.

Results: Mean PCS was 22.12±12.09; mean TSK was 42.94±7.76; mean BDI was 15.63±11.18 and mean BARS was 88.94±19.85. Linear regression analysis revealed that TSK, BDI, BARS and BMI were independently associated with PCS in predicting pain catastrophizing in individuals with SLE (p<0.001; R²=0.52). There were no correlations between PCS and disease activity (mean SLAM-R: 5.39±3.68; r=0.105) and organ damage (mean SLICC-DI: 0.58±0.87; r=0.153) (p>0.05).

Conclusion: This study increases the understanding of the modifiable predictors to enhance pain coping behavior in accordance with the pharmacological treatment in SLE population. Results demonstrate major importance to explore the main stressors of pain catastrophizing such as kinesiophobia, depression level, body awareness and BMI that affect coping behavior. Thus, pain catastrophizing may limit the patients' ability to perform from simple to complex activities. In addition, body image concerns SLE patients as they experience weight gain which negatively impact their self-esteem. The patient reported outcomes could guide health professionals to identify unmet needs of patients at risk to facilitate incorporation of the biopsychosocial model into SLE management.

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THU0721-HPR WOMEN'S EXPERIENCE OF THE JOURNEY TO CHRONIC WIDESPREAD PAIN – A QUALITATIVE STUDY

Miriam Svensson¹, Ingrid Larsson^{1,2}, Katarina Ail^{1,2,3}. ¹Halmstad University, School of Health and Welfare, Halmstad, Sweden; ²RandD Spenshult, Halmstad, Sweden; ³Karolinska Institutet, Unit of occupational medicine, Institute of Environmental Medicine, Stockholm, Sweden

Background: Chronic widespread pain (CWP) is a major burden to both the person and the community. Non-tumor chronic pain is one of the most common causes for long-term sickness absence in Sweden. The prevalence of CWP in the general population is approximately 10%, and the condition is almost twice as prevalent in women, than in men. Increased understanding of how women with CWP describe triggering factors of pain and pain progress would be of importance when preventing poor pain prognosis, and when customizing the treatment strategy in a setting with person-centered care.

Objectives: To explore experiences of factors influencing the progress and severity of pain among women who have developed CWP within the last 21 years.

Methods: This is a descriptive study, using a qualitative content analysis with an abductive approach¹. Nineteen women reporting CWP in a survey 2016, between 45-67 (median 57) years of age, who had not reported CWP in a survey 1995, participated in the study. Data were collected through individual interviews with open-ended questions: "Can you describe how your CWP has developed the last 20 years?", "How did your CWP change over time?" and "Have you experienced any important events that have influenced the development of your CWP?" Data were analyzed through a manifest qualitative content analysis and six categories emerged.

Results: The women described their journey to CWP in terms of triggering, aggravating and consolidating factors. Six different categories emerged; physical strain, emotional strain, social strain, work-related strain, biological strain and environmental strain. *Physical strain* included strenuous physical activities in leisure time, having muscle tension, inactivity or sleeping problems. *Emotional strain* included being depressed, worried and stressed, as well as neglecting the pain. *Social strain* included to prioritize other people before oneself and to meet distrust from the social surroundings. *Work-related strain* included heavy, monotonous and stressful work but also sedentary work. *Biological strain* referred to heredity, age and infections. *Environmental strain* meant that the climate or weather aggravated the pain.

Conclusion: The women in the study described how their journey to CWP was influenced by both external and internal strains. The six categories representing different types of strains were recurrent in a context describing triggering, aggravating and consolidating factors. This highlights the complexity of individual pain progress and argues for the importance of person-centred care approaches and rehabilitation programs. The fact that women with CWP feel mistrust from healthcare professionals indicates that the current care approach needs to be changed.

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THU0722-HPR DESIGNING A DIET INTERVENTIONAL STUDY FOR AUTOIMMUNE RHEUMATIC DISEASE: ASKING PATIENTS WHAT THEY THINK

Lucia Martin-Gutierrez^{1,2}, James Wilton², George Robinson^{1,2}, Thomas McDonnell¹, David Isenberg¹, Chris Wincup¹, Anastasia Kalea³, Ines Pineda Torra⁴, Elizabeth Jury¹, Coziana Ciurtin². ¹UNIVERSITY COLLEGE OF LONDON, Rheumatology, LONDON, United Kingdom; ²UNIVERSITY COLLEGE OF LONDON, Arthritis Research United Kingdom Centre for Adolescent Rheumatology at UCLH, UCL and Great Ormond Street Institute of Child Health, LONDON, United Kingdom; ³UNIVERSITY COLLEGE OF LONDON, Institute of Liver and Digestive Health, London, United Kingdom; ⁴UNIVERSITY COLLEGE OF LONDON, Centre of Cardiometabolic Medicine, LONDON, United Kingdom

Background: Using diet to help alleviate disease symptoms or control drug side effects in patients with autoimmune rheumatic disease is gaining renewed interest but little is known about what patients think about using diet to control their disease or what dietary interventions they would prefer.

Objectives: Our aim is to obtain patient input in the design of a potential diet interventional study in autoimmune diseases and compare the experiences and ideas of patients relating to diet from various ages and disease groups during a patient and public involvement and engagement (PPIE) event.

Methods: 35 Adult and young adult patients with Sjögren's syndrome and/or systemic lupus erythematosus were approached to participate when attending outpatient clinics at UCLH. 10 female patients with age range from 18 – 80 agreed to take part in a face-to-face PPIE event held at UCL.

During group discussions, patients were split between three groups, each facilitated by 3-4 members of the research team with different backgrounds and skills (clinical, basic science and PPIE expertise). The main themes discussed were:

- 1) Barriers to taking part in a research study investigating the role of diet in autoimmune disease
- 2) The ideal clinical trial design
- 3) The most appropriate patient information leaflet design for this study

Results: The majority of patients (80%) would agree to participate in a diet-related study for up to 12 months including completing questionnaires, conducting interviews and providing blood samples. The qualitative analysis of the group discussions identified the following themes: recording the daily food intake either using an app or a diary was acceptable to patients, there were concerns about drug interactions and diet; however, patients did not think that their disease would affect their ability to take part in a diet interventional study. As a means of communicating study updates, the patients preferred to be contacted by e-mail, letter, text or phone call.

In terms of intervention allocation, patients found it acceptable to be on the placebo arm of a study, to go on a diet for up to 6 months or to be administered a combination of interventions (diet, food supplements in tablet). Patients preferred to be assessed monthly or when attending outpatient clinics, and would complete questionnaires, even if lengthy. We asked patients to assess leaflets commonly available from charities and the NHS providing diet advice. Most patients had not seen such leaflets previously and suggested including recipes and a section for vegetarian food.

Conclusion: This PPIE event provided valuable ideas to improve potential study design ensuring a diet intervention would be patient centred. The unexpected findings were the high acceptability of questionnaires and patients' acceptance of a placebo intervention. Further PPIE follow-up events are planned aiming to discuss trial protocols in detail.

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THU0723-HPR WHAT DO SJÖGREN'S SYNDROME PATIENTS THINK ABOUT RESEARCH?

Lucia Martin-Gutierrez^{1,2}, Coziana Ciurtin², Elizabeth Jury¹. ¹UNIVERSITY COLLEGE OF LONDON, Rheumatology, LONDON, United Kingdom; ²UNIVERSITY COLLEGE OF LONDON, Arthritis Research United Kingdom Centre for Adolescent Rheumatology at UCLH, UCL and Great Ormond Street Institute of Child Health, LONDON, United Kingdom

Background: Despite recent progress investigating the pathogenesis of Sjögren's syndrome (SS), there are currently no therapies able to influence disease progression. Patients with SS are usually treated symptomatically with variable success, therefore refining the research agenda according to patients' priorities could provide a valuable insight into the most appropriate research questions.

Objectives: The aim of this study was to explore patients' ideas and suggestions related to research in SS.

Methods: A questionnaire to investigate SS patient experience of diagnosis and ideas about research priorities in SS was designed. Over a 5 month period, patients attending outpatient clinics were invited to fill in the questionnaire. 27 patients completed our anonymous survey.

Results: The most important issue for patients with SS after they had been diagnosed was the lack of knowledge about this disease (25%), the diagnosis delay they had experienced (26%) and the persistence of symptoms of dryness (26%). Patients were interested in finding out what causes this disease (81%) and felt that our research should find a cure (92%) and better treatments (75%).

The main two research priorities selected by patients were improved understanding of the disease (89%) and attracting funding for supporting research in to SS (89%). In addition, patients wanted to have a voice