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

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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

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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?

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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

and contribute to raising awareness of SS and to participate in patient and public involvement and engagement (PPIE) events. The majority of patients interviewed were willing to take part in research by donating blood samples and/or filling in questionnaires (96%). 58% of patients who completed the survey would either definitely or probably take part in discussion groups helping researchers to design future studies in SS.

Conclusion: This survey highlighted patients' perception of the need for more meaningful research into the causes of SS, as their priorities were centred around finding a cure or better treatments for Sjögren's Syndrome. The survey also identified patients' lack of knowledge about their condition as well as their desire to help with shaping future research ideas and support funding for research. The results of this survey will be incorporated in our future PPIE events aiming at shaping our research strategy in SS.

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THU0724-HPR RELIABILITY AND VALIDITY OF AN ACTIVITY LIMITATION MEASURE IN PERSONS WITH INCLUSION BODY MYOSITIS (IBM)

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Background: Persons with Inclusion Body Myositis (IBM) are affected in their activities of daily living (1,2).

Objectives: The aim of this study was to test validity and reliability of the questionnaire Disability in the Arm Shoulder and Hand (DASH) for patients with IBM. A second aim was to describe activity limitation measured by the Canadian occupational Performance measure (COPM).

Methods: Persons diagnosed with IBM were identified through the Swedish Myositis Network (SweMyoNet) quality registry in Stockholm Sweden. A total of 36 persons with IBM were included in the registry and were invited to participate. A total of 17 men and 9 women agreed to participate. Median (Q1-Q3) age was 74 (70-79) years and the median (Q1-Q3) disease duration was 7 (3-8) years.

Activity limitation was assessed by the questionnaire Disability of the Arm, Shoulder and Hand (DASH) and the The Canadian occupational performance measure (COPM) which investigate patient derived areas of daily activities.

The data collection was performed at the Karolinska university hospital in Stockholm Sweden. At baseline both DASH and COPM were performed. The participants received a second DASH questionnaire to be answered within two weeks (Follow-up) and send back to the researcher.

Results: There were good correlations between baseline measure and follow-up on DASH (rs 0.997; p=0.01) indicating that the DASH is consistent over a short period of time.

The results from COPM showed a variety of activities persons with IBM experienced problem with. Area with most activity limitations were basic self-care area such as dressing and grooming, fall, feeding, managing communication.

Instrumental activities such as managing instruments, shopping and meal preparation. Leisure activities such as playing an instrument, run, paint and social activities such as visit friends, social engagements.

Some of these activities were found in the DASH but not all. E.g. missing socializing with friends and family, problems swallowing or were environment dependent.

Conclusion: The results indicate that DASH have a good test re-test reliability DASH includes some of the activities that persons with IBM experience difficulties with but not all. The participants experienced difficulties in all areas of life.

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THU0725-HPR SCREENING OF SILENT MYOCARDIAL ISCHEMIA USING A STRESS TEST IN RHEUMATOID ARTHRITIS PATIENTS: ASSOCIATION WITH TRADITIONAL RISK FACTORS AND DISEASE ACTIVITY

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Background: The rheumatoid arthritis is responsible of an increased risk of cardiovascular (CV) morbidity and mortality.

Objectives: The aim of the study is to determine, in established RA patients, the presence of silent myocardial ischemia using a stress test and its association with the disease activity and the CV risk factors and scores.

Methods: It is a transversal and prospective study in a rheumatologic center in Charles Nicolle hospital in Tunisia. 103 RA patients, asymptomatic for CV disease were submitted to a stress test. Demographic data, cardiovascular risk factors and the disease characteristics were assessed for all patients and risk factors of silent myocardial ischemia in RA patients were identified.

The comparison of qualitative variables was performed with the Chi square test and the comparison of qualitative variable and quantitative ones was performed with the Student's test. The significance level was set at 0.05.

Results: There were 103 patients (sex-ratio=0.3) with a mean age of 53 ±10 years. The evaluation of the disease activity showed that the mean DAS28 CRP, CDAI and SDAI were 3.9±1.38, 17.17±11.4 and 33.39±26, respectively. A screening for CV risk factors revealed: 13% of patients had a cardiovascular inheritance, 25% of patients were either smokers or hypertensives, 18% had diabetes, 70% were obese or overweighted and 14 patients had dyslipidemia. The ischemic ratio (CT/HDL) revealed that 42% of patients had a moderate to high myocardial ischemic risk. Heart-SCORE was high in 35% of cases. A silent myocardial ischemia in the stress test was found in 11 patients (10.6%) and was associated with male sex (p=0.03), advanced age (p=0.04), erosive character (p=0.05), the advanced age of the rheumatoid arthritis diagnosis (p=0.01) and the ischemic ratio (p=0.06). No relationship was found with the majority of traditional CV factors nor with disease activity variables.

Conclusion: Our results corroborated the hypothesis that the stress test could reveal subclinical CV dysfunction, supported the utility of the Heart-score as a screening tool, and put in perspective the potential usefulness of complementary approaches in CV risk assessment in RA patients.

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THU0726-HPR THE COMPARISON OF ARTERIAL STIFFNESS, FUNCTIONAL EXERCISE CAPACITY AND PHYSICAL ACTIVITY IN SYSTEMIC SCLEROSIS AND HEALTHY INDIVIDUALS

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Background: Systemic sclerosis (SSc) is characterized by abnormal production of fibrotic tissue in the skin and internal organs. SSc has a effect on large and conduit arteries damage as well as microvascular damage (1). It is known that sedentary lifestyle may contribute to vascular dysfunction (2). Therefore, it is important to evaluate arterial stiffness, exercise capacity and physical activity in people with SSc.

Objectives: The aim of this study is to compare arterial stiffness, functional exercise capacity and physical activity in SSc and healthy individuals.

Methods: Fifteen SSc (53 years) and 15 healthy (48 years) women were included in this study. Arterial stiffness was evaluated with pulse wave velocity that was obtained by measuring the carotid-to-radial pulse wave transit time. Functional exercise capacity was assessed by 6-minute walk test (6MWT). Physical activity was questioned International Physical Activity Questionnaire (IPAQ)-short form. The differences between the groups were analyzed with Mann-Whitney U test.

Results: Age, weight, height and body mass index were similar in the groups (p>0.05). There was significant difference in pulse wave velocity and pulse wave transit time between the two groups (p<0.05). The