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