

THURSDAY, 15 JUNE TO SATURDAY, 17 JUNE 2017

Psychosocial support**PARE0009 A TAXONOMY OF DISEASE EXPERIENCES OF WOMEN WITH SJÖGREN'S SYNDROME FROM THE PERSPECTIVE OF THE PATIENT**

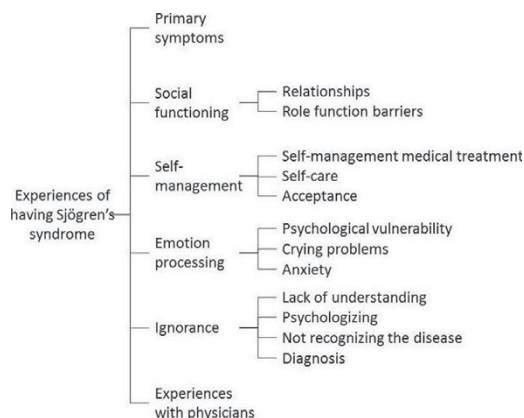
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Background: In earlier studies of experiences of patients with Sjögren's Syndrome (SS), professionals interpreted the data and drew conclusions and implications. In the current study, patients had a major share in the interpretation and structuring of experiences, and a patient research partner was part of the research group in all phases of the study: planning, collecting data, organizing, analyzing, and reporting.

Objectives: The aim of this study was to examine the full spectrum of life experiences of women with SS in an integrated, hierarchical model, and to examine the degree to which the research participants experienced the sorted experiences themselves.

Methods: Patients structured and interpreted the data using a concept mapping technique. In a card-sorting task, 52 patients with SS from the Netherlands grouped 75 experiences in piles. These experiences came from previous in-depth interviews with Chilean patients [1]. Hierarchical cluster analysis yielded an integrated, hierarchical model of these sortings. The 52 patients indicated on a 4-point Likert scale whether they had had these experiences themselves: agree, agree a little, disagree a little, disagree.

Results: Hierarchical cluster analyses showed a main 6-category clustering of experiences with primary symptoms, emotional processing, social interaction, self-management, ignorance, and physicians. Four of these categories showed underlying clusters of experiences (see Figure). Patients generally agreed to have common experiences of "primary symptoms", "role functioning barriers", and "diagnosis" and they commonly disagreed with the "psychologizing" symptoms, while they differed in the degree to which they had individually experienced the other experiences.



Conclusions: Life experiences of women with SS were summarized in an integrated, hierarchical model consisting of 14 clusters in 6 overarching categories. The results may be colored by the cultural background of the participants. This year this concept mapping study will be extended to patients from Chile, which will increase the generalizability of the findings and allow cross-cultural comparison. The final hierarchical overview with life experiences from the patient's view can be used to improve screening in clinical consults, develop a questionnaire, give direction to future research, and enhance education and self-management support [cf. 2]. The method gives ample room to really incorporate the patient perspective in research.

References:

- [1] Rojas-Alcayaga G et al. Illness Experiences in women with oral dryness as a result of Sjögren's syndrome: The patient point of view. *Musculoskeletal Care* 2016;14: 233–42.
- [2] Ammerlaan JW et al. Building a tailored, patient-guided, web-based self-management intervention 'ReumaUitgedaagd!' for adults with a rheumatic disease. *JMIR Res Protoc* 2016;5:e113.

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THURSDAY, 15 JUNE TO SATURDAY, 17 JUNE 2017

Arthritis research**PARE0010 SIGNIFICANCE OF FOOT PROBLEMS FOR PATIENTS WITH RHEUMATOID ARTHRITIS: A PATIENT-LED QUALITATIVE STUDY**

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Background: Patients with rheumatoid arthritis (RA) commonly report problems with their feet.¹ It is known that foot joint involvement begins early in the course of RA and even patients on biologic therapy and/or with low disease activity can still experience high levels of foot pain.^{1–3} Current UK guidance states that "All people with RA and foot problems should have access to a podiatrist for assessment and periodic review of their foot health needs".⁴

Objectives: To understand how foot health problems affect patients with RA.

Methods: Adult patients, with a diagnosis of rheumatoid arthritis and ability to converse in English, were recruited by clinicians based at a London hospital rheumatology outpatient clinic to participate in two focus groups on foot health. These were conducted by the lead patient researcher and comprised 8 females and 1 male of diverse ethnicities, aged 27–68 years old with 4–46 years disease duration. The focus groups were audio-recorded and transcribed verbatim. Transcripts were verified for authenticity by a random sample of 4 participants, and were systematically coded with the assistance of qualitative data analysis computer software. Themes were generated and cross-checked by the co-researcher to negate any potential bias by the lead patient researcher.

Results: Four interlinked themes were identified: 1) dependence on feet, e.g. needed for standing and walking; 2) physical impact e.g. pain, swelling and deformities; 3) social impact e.g. hard to keep appointments and participate in leisure activities; 4) psychological impact e.g. low self-esteem, worry and using humour to cope. The sole male participant was unaffected by theme 4. One patient in the group had not experienced foot problems since diagnosis. No differences were identified across age, ethnicity or disease duration.

Conclusions: Foot problems can significantly lower quality of life for patients with RA. It is therefore essential that foot health is adequately addressed during rheumatology outpatient consultations with onward referral to podiatry services as necessary.

References:

- [1] Grondal et al. The foot: still the most important reason for walking incapacity in rheumatoid arthritis: distribution of symptomatic joints in 1,000 RA patients. *Acta Orthopaedica*. 2008;79:257–61.
- [2] Otter et al. Comparison of foot pain and foot care among rheumatoid arthritis patients taking and not taking anti-TNF α therapy: an epidemiological study. *Rheumatol Int*. 2011;31:1515–9.
- [3] van der Leeden et al. Prevalence and course of forefoot impairments and walking disability in the first eight years of rheumatoid arthritis. *Arthritis Rheum*. 2008;59:1596–602.
- [4] National Institute for Health and Care Excellence. Clinical Guideline 79, Rheumatoid arthritis: the management of rheumatoid arthritis in adults. 2009.

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Best practice campaigning**PARE0011 ASK THE USERS - ESTABLISHING A DIGITAL USER PANEL**

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Background: A high level of user involvement is one way of assuring campaigns to be relevant to people with RMD's. This is true for all projects within the PARE organisations. The Danish Rheumatism Association would like to strengthen our political campaigning and we found this goal could be reached by establishing a representative digital user panel. A representative digital user panel would give us quicker, more relevant and high quality information about the opinion of the users and their experience within many different aspects of living with RMD's in Denmark.

Objectives: The Danish Rheumatism Association wanted to strengthen the impact of our political campaigning. We wanted to establish a representative user panel consisting of 1500 Danes with RMD's. A digital user panel was found to be a quick and efficient tool to secure real life experiences and knowledge from the users. The user panel would make us interact with our users in even better ways and through that we were able to strengthen our political campaigning.

Methods: In 2016 we tried to recruit participants among our members to assure that the panel was representative, but that was more difficult than we expected and we had to use other channels to recruit too. We wanted to ask the user panel about different themes 6–8 times each year. We investigated the collected data