THU0703-HPR A SANCTUARY FROM EVERYDAY LIFE: A QUALITATIVE STUDY OF THE EXPERIENCE OF IN-PATIENT MULTIDISCIPLINARY REHABILITATION, FOR PATIENTS WITH RHEUMATIC DISEASES

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Background: In Denmark, patients with rheumatic diseases can receive inpatient multidisciplinary rehabilitation at a hospital for rheumatic diseases or at rehabilitation centers.

Quantitative studies indicate that it is difficult to detect a general and lasting effect of 1-4 weeks of inpatient multidisciplinary rehabilitation, but few studies have explored patients' experience of in-patient multidisciplinary rheumatology rehabilitation.

Objectives: To explore how patients, experience the process and personal impact of an inpatient rehabilitation stay.

Methods: An exploratory qualitative phenomenological-hermeneutic study was planned. Adult rheumatic patients admitted for a two-week inpatient rehabilitation stay were invited to participate. Individual semi-structured interviews were conducted in the patients' home shortly after discharge or at the ward one of the last days of admission. The interviews were audio recorded and transcribed verbatim. The analysis was inspired by Paul Ricœur's interpretative philosophy (1).

Results: Fifteen interviews were conducted, 11(73%) female, age 28-89. The analysis derived a core theme, "A sanctuary", reflecting that the patients experienced to have sufficient time and mental resources to provide self-care. In addition, the analysis derived five subthemes: 1) "Being seen, heard and acknowledged as an equal and whole person". To feel acknowledged was vital for the patients' experience of quality and benefit. 2) "Professional care and compassion", which were considered by the patients as the most fundamental contextual factors to facilitate their self-care. 3) "Social relations and interactions between patients", reflecting the patients experience of feeling recognized by other patients and to experience common understanding. 4) "An individually planned rehabilitation stay, but challenges regarding shared decision making". The patients felt the rehabilitation was individually planned, but with room for improvement in relation to awareness of shared decision-making. 5) "Rehabilitation as a personal process but problems with transferability to everyday life". The patients experienced the rehabilitation stay as a part of a personal rehabilitation process, but expressed concerns about whether they were able to transfer new learning and habits to everyday life.

Conclusion: Patients with rheumatic diseases experience in-patient rehabilitation as a sanctuary, with rehabilitation at three levels; through multidisciplinary rehabilitation interventions at the hospital; through recognition from the multidisciplinary staff and through recognition, social relationships and interactions with fellow patients. There is a need for improved coordination of rehabilitation across primary and secondary health care, in order to ease transferal to the patients' everyday life.

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THU0704-HPR PATIENT ACTIVATION AND ADHERENCE TO BIOLOGICAL THERAPY AND TARGETED SYNTHETIC DMARD: PRELIMINARY RESULTS:

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Background: Medication non-adherence has been associated with treatment failure in chronic inflammatory conditions. A positive relationship between patient activation and adherence to treatment and between

activation and improved clinical outcomes has been shown for chronic conditions.

Objectives: To measure adherence to biological therapies and targeted synthetic DMARD (tsDMARD), and their relationship with the Patient Activation Measure (PAM) and with patient and therapy related factors, for chronic inflammatory arthropathies.

Methods: Cross-sectional observational descriptive study in a general tertiary university hospital.

Patients on treatment with the same biological drug (subcutaneous; phase 1) or tsDMARD (oral; phase 2) for ≥ 6 months were included in order of arrival and those with mental disability, which prevented understanding of the study, were excluded.

Demographic variables (sex, age, living environment, educational level), diagnosis and treatment were collected. Adherence was measured using the Simplified Medication Adherence Questionnaire (SMAQ) for biological therapies, the Compliance Questionnaire Rheumatology (CQR-19) for tsDMARD, and the medication possession ratio (MPR). Patients were considered adherent if MPR $\geq 80\%$ and CQR-19 $\geq 80\%$ or adherent SMAQ. To measure activation, PAM questionnaire, was used. Patients were classified as activated or not activated.

Statistical analysis: relationship between adherence to treatment and PAM was analyzed using chi-square, considering significance level $p < 0.05$. Statistical analysis was performed with spss v17.0.

Results: A total of 58 patients (57% women) were included. Mean age was 54 years (95% CI: 50 to 57), 86% lived in urban areas, 40% had completed elementary education, 31% high-school and 24% university studies.

Distribution by diagnosis: rheumatoid arthritis (81%), ankylosing spondylitis (14%) and psoriatic arthritis (5%). Distribution by treatment was: baricitinib (31%), tofacitinib (18%), adalimumab (16%), tocilizumab (14%), etanercept (12%), secukinumab (7%) and golimumab (3%). Median time of disease duration was 9 years (IQR 13) and time on treatment with the drug was 8 months (IQR 20), with significant differences between groups (27 (biological therapy) vs 7 months (tsDMARD)).

The proportion of adherent patients was 43%, being higher among tsDMARD (57%) vs biological treated ones (30%), with significant differences.

72% of patients were activated, being more activated biological (80%) than tsDMARD (67%) treated patients.

A higher adherent proportion of patients was found among the activated patients (48%) compared to the non-activated ones (27%) in all measures, even though the differences were not statistically significant.

Conclusion: Patients treated with biological therapies and tsDMARD have a high degree of activation for the self-management of their disease and its treatment. Adherence to treatment may be influenced by route of administration, type of drug (oral/tsDMARD 57% vs. subcutaneous/biological 30%) and time on treatment (longer time on treatment, lesser adherence).

The greater proportion of adherence found among patients with a higher degree of activation could indicate a positive relationship between activation and adherence, so analyzing and promoting patient activation seems important in order to improve adherence to drugs.

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THU0705-HPR PELVIC FLOOR AND SEXUAL DYSFUNCTION IN WOMEN WITH SJOGREN SYNDROME

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Background: Sjogren syndrome (SS) is a systemic autoimmune disease causing secretory gland dysfunction. This leads to dryness of the mainly salivary and lacrimal glands such as the mouth, eyes, nose, larynx, and vagina. The disease overwhelmingly affects middle aged women. These women have symptoms of decreased lacrimal and salivary gland function which usually precede involvement of other exocrine glands such as the upper airway, the gastrointestinal tract and the external genitalia (dyspareunia). Although genital tract symptoms are common in patients with sjogren, such as vulvar and vaginal dryness, dyspareunia, and pruritus, their pelvic floor health and functions have been rarely evaluated.

Objectives: The aim of study was investigation of pelvic floor and sexual dysfunction in patients with SS.

Methods: 23 patients with SS with an average age of 49.00 $\pm$ 8.71 were included in the study. Pelvic floor dysfunction of patients with SS were evaluated by the Pelvic Floor Impact Questionnaire-7 (PFIQ-7) and Pelvic

Floor Distress Inventory-20 (PFDI-20) and sexual dysfunction were evaluated by Pelvic Organ Prolapsed/Urinary Incontinence Sexual Questionnaire (PISQ-12).

Results: PFIQ-7 total score was 27.14 ± 27.73 (UIQ-7: 17.07 ± 17.88 , CRAIQ-7: 7.43 ± 10.14 , POPIQ-7: 2.32 ± 5.00); PFDI-20 total score was 116.36 ± 34.00 (POPDI-6: 31.48 ± 8.29 , CRADI-8: 35.59 ± 15.73 , UDI-6: 49.00 ± 16.56) and PISQ-12 total score was 16.78 ± 5.71 .

Conclusion: According to the results of the study, patients with SS had pelvic floor dysfunction and sexual dysfunction. This study showed that pelvic floor and sexual functions of patients with SS have been negatively affected. Therefore these functions need to be routinely assessed by health professionals. Further studies need to recommend pelvic health physiotherapy and educational programme about pelvic floor dysfunction.

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THU0706-HPR THERE IS ASSOCIATION BETWEEN THE LEVEL OF PHYSICAL ACTIVITY AND QUALITY OF LIFE OF WOMEN WITH FIBROMYALGIA?

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Background: Patients with fibromyalgia frequently present physical and mental symptoms associated with typical pain such as generalized fatigue, sleep disturbances, anxiety, depression and cognitive impairment. Moderate physical exercise is an alternative to promote health benefits of fibromyalgia patients, through the obstacles imposed by the symptomatology of this pathology.

Objectives: This study aimed to verify the association between the level of physical activity and quality of life of women with fibromyalgia.

Methods: It is a cross-sectional study with 177 women (42.1 ± 8.6 years) diagnosed with fibromyalgia registered in the Unified Health System (SUS) in the city of Maringá, PR, Brazil. The instruments used were: International Physical Activity Questionnaire (IPAQ) to assess the level of physical activity; Fibromyalgia Impact Questionnaire (FIQ) to assess the impact of fibromyalgia on quality of life; WHOQOL-Bref to assess overall quality of life in four domains. Data analysis was conducted through Mann-Whitney test, Spearman correlation and Structural Equation Analysis ($p < 0.05$).

Results: The sample consisted of a greater proportion of women aged between 40 and 49 years (37.9%). There was a higher proportion of women with active/very active level of activity (62.1%), 20.4% with sedentary status and 17.5% with irregular activity. Fibromyalgia had a moderate impact on the quality of life of women with fibromyalgia (76.5) evaluated by FIQ. The results showed positive associations between the level of physical activity and the quality of life domain in WHOQOL-Bref, with a significant difference in all domains of quality of life: physical ($p = 0.007$), psychological ($p = 0.007$), social relations ($p = 0.012$) and environment ($p = 0.012$), with higher scores among the very active/active.

Conclusion: This study shows that the level of active/active activity is a positive factor in all areas of quality of life in women with fibromyalgia and the impact of this disease on the quality of life is moderate. There is evidence of the need to maintain an active lifestyle independent of

symptomatology and incapacitating conditions in these cases. Above all, this information can help professionals who care for fibromyalgic patients about measures of maintenance of health and well-being.

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THU0707-HPR FOLLOW-UP CARE FOR PATIENTS WITH ESTABLISHED INFLAMMATORY JOINT DISEASES – A FOCUS GROUP STUDY ON PATIENTS' EXPERIENCES FROM REFRAMING THE ORGANIZATIONAL SUPPORT FOR INCREASED PATIENT INVOLVEMENT

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Background: Internationally, a Treat-to-Target strategy for proactive management of inflammatory joint diseases (IJD) is recommended.^{1,2} This includes continuous monitoring of the arthritis, which covers symptoms and the significance of the disease for everyday life.^{2,3} Control of disease activity has traditionally been ensured with fixed outpatient visits to rheumatologists.⁴ However, in general there is a growing interest to involve patients in the control and treatment of their own disease.

Open Assess in our outpatient clinic was implemented during October 2016 to respond to fluctuating needs among the patients with established IJD. Patient participation in Open Assess were primarily patient-initiated. They were expected to respond to symptoms and other disease-, and treatment-related needs. In addition, two half-yearly planned visits were offered patients: 1) An annual traditional medical consultation with a rheumatologist, and 2) A new Annual consultation with an experienced registered rheumatology nurse (RRN).

Objectives: To explore how people with established IJD in stable phase, experience Open-Access as a way to involve patients in their own disease and treatment.

Methods: We conducted a qualitative study based on four semi-structured focus group interviews among patients with established inflammatory joint disease (Rheumatoid arthritis (RA), axial spondyloarthritis (axSpA) and psoriasis arthritis (PsA)) participating in the Open Access set-up. The analysis of the transcribed interviews was based on content analysis. A patient research partner was involved in all phases of the study.

Results: In total 25 patients with IJD participated (20 female (80%), mean age 61.8 (range 28-79)) with RA (n=20), PsA (n=3), axSpA (n=1) and polyarthritis (n=1) participated. We identified three themes. **Changes in follow-up care do not affect patients' perceived support in disease control**, referring to patient's perception of more time available to both themselves and health professionals, as well as trust in access to professional support whenever needed. **Adequate information to act within a new patient role**, reflecting patients' uncertainty in the transition to Open Access combined with confusion about distribution of responsibilities in the new set-up. **Arthritis in a broader perspective**, expanding patients understanding of their illness by interaction over time with both a rheumatologist and a rheumatology nurse in a focused dialogue to involve the patient in managing their own health.

Conclusion: Patients following Open-Access welcome the flexibility and involvement in disease control. However, patients need relevant information to be able to act adequately to the new patient role. Interacting with both rheumatologists and nurses, combined with sufficient time for dialogue, broaden patients' perspective, make opportunities for action visible, and contribute to patient's ability to participate in the managing of their own condition.

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THU0708-HPR CORRELATIONS BETWEEN FATIGUE AND PATIENT REPORTED OUTCOME IN PEOPLE WITH INFLAMMATORY ARTHRITIS

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Background: Fatigue is one of the most common symptoms of people with inflammatory arthritis (IA) and often rated as high as or higher than pain. However, it remains unexplored how fatigue is associated with patient related outcomes (PRO) such as work impairment, quality of life, sleep, depression, physical functioning and pain.

Objectives: To explore fatigue and to analyze possible correlations between fatigue and PROs in people with rheumatoid arthritis (RA), psoriatic arthritis (PsA) and axial spondyloarthritis (axSpA).

Methods: A cross-sectional study. People ≥ 18 years with a confirmed diagnosis of RA, PsA or axSpA were consecutively recruited for the study over a 6-month period via routine visits to outpatient rheumatology clinics in two hospitals departments. Trained study nurses collected information on informed consent, diagnosis, medical treatment and disease activity status. Fatigue was evaluated by a self-completed questionnaire using the FACIT-Fatigue sub-scale. The questionnaire also included the following PRO scales: Work Productivity and Activity Impairment scale (WPAI), EuroQol (EQ-5D), Medical Outcomes Study Sleep Scale (MOS), Major Depression Inventory (MDI), and Health Assessment Questionnaire (HAQ) on quality of life and pain. Data was analyzed in SAS. Correlations were assessed by a) Pearson correlation coefficients and b) raw and adjusted linear regressions.

Results: In total 633 persons were invited and 487 (77%) (mean age=53.5, SD 14.5) were included (62% women). The mean fatigue score (range 0-52; lower = more fatigued) was 34.3 (SD 11.1) and there was no statistically significant difference between mean fatigue in the three diagnostic groups ($p=0.08$). Altogether 61% expressed that they were suffering from fatigue (i.e. had a FACIT-Fatigue sub-scale ≤ 39). Women generally had a lower overall fatigue score (mean=33.3, SD 11.1) than men (mean=36.0, SD 11.0). Fatigue did not differ between age groups ($p=0.33$). Those who had changed medical treatment within 0-12 months (21.1%) suffered more from fatigue than those with unchanged treatment (mean=30.1, SD 11.7 vs. mean=35.4, SD 10.7, $p<0.0001$). The average disease activity as indicated by DAS28, BASDAI and BASFI showed low disease activity in the cohort. Current medical treatment (csDMARDs and/or bDMARDs or none) was not associated with severity of fatigue ($p=0.85$). Fatigue correlated with all PROs (Pearson correlation coefficients, all p -values <0.0001) (Table 1). Increased work impairment, sleep problems, depression, and pain were all associated with increased fatigue, whereas decreased quality of life and physical functioning were associated with increased fatigue (raw and adjusted linear regressions). The associations did not change significantly after additional adjustment

for socioeconomic factors. Analyses stratified on type of disease did not differ significantly from the primary non-stratified analysis.

Table 1. Pearson correlations between fatigue (measured by FACIT-F) and PROs

	Pearson correlation coefficient	p-value	N
Work impairment (WPAI)	-0.6359	<0.0001	280
QoL (EQ-5D)	0.7010	<0.0001	487
Sleep (MOS sleep scale)	0.7009	<0.0001	481
Depression (MDI)	-0.7502	<0.0001	483
Physical Functioning (HAQ)	-0.3789	<0.0001	483
Pain (VA)	-0.6118	<0.0001	482

Note: Pearson correlation coefficients range from -1 to 1. A Pearson correlation coefficient of more than 0.80 or less than -0.80 indicates a strong correlation, a coefficient of 0.40 to 0.80 or -0.40 to -0.80 indicates a moderate correlation, and a coefficient below 0.40 or more than -0.40 indicates a weak correlation

Conclusion: Despite the study cohort represents a stable group with low disease activity, fatigue was a frequently expressed symptom across diagnoses. There was a significant correlation between fatigue and the other PROs why fatigue cannot be seen as a single problem, but rather a symptom that broadly affects people living with inflammatory arthritis.

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THU0709-HPR PERSONS WITH POLYMYOSITIS AND DERMATOMYOSITIS EXPERIENCE REDUCED WORK ABILITY AND QUALITY OF LIFE

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Background: A recent study have described that persons with Polymyositis (PM) and Dermatomyositis (DM) experience reduced work ability (1). Information about whether the reduced work ability affect quality of life is lacking.

Objectives: To describe self-rated work ability with two different assessment and quality of life in persons with PM and DM. To investigate correlations between self-rated work ability and quality of life

Methods: Participants were identified through the Swedish Myositis Network registry (SweMyoNet). Of 78 possible participants, 48 agreed to participate in this study. The median (IQR) age were 57 (45-61) years with a median disease duration of 6 (2-14) years. Fifty-three percent of the participants were women. Seventy-seven percent were working, and the remaining were on sick-leave.

Self-rated work ability was measured by the questionnaire Work Ability Index (WAI) and the Work Ability Score (WAS) which is a single item question. Quality of life by the SF-36.

Results: Self-rated work ability measured by WAI in persons with PM and DM varied between poor work ability and good work ability. The median value of the group was 34 which indicates less good work ability.

Self-rated work ability measured by WAS varied between poor work ability and good work ability. The median of the total group indicates less good work ability.

There was a strong correlation between self-rated work ability measured by WAI and WAS ($r_s 0.879$ $p=0.01$).

Quality of life measured by SF-36 were rated lower in persons with PM and DM when compared to the general population in dimensions; Physical Function, Role-Physical, General Health, Vitality and Social function ($p\leq 0.02$).

There were moderate to high correlations between self-rated work ability measured by both WAI and WAS, and all dimensions of SF-36 ($p<0.01$)

Conclusion: Persons with PM and DM self-rated their work ability as poor and the quality of life were significantly reduced when compared to the general population. The measures WAI and WAS correlates highly with each other and revealed comparable results indicating that WAS may work as well as WAI as a screening tool to identify reduced work ability. The WAS may also be more feasible with just one single question to use in clinical practice. Our results indicate the importance to measure self-rated work ability in persons with PM and DM in clinical practice.