### Table 1. Distribution of survey responses across Europe and education opportunities about MTX

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|---|---|---|---|
| | Patients and carers (n=1690) | Nurses (n=335) | Physicians (n=297) |
| European Region* | | | |
| % North | 22 | 52 | 21 |
| % South | 37 | 10 | 46 |
| % East | 21 | 17 | 22 |
| % West | 20 | 21 | 11 |

* According to United Nations geoscheme.

The priority ranking of topics to be addressed was also assessed, with agreement on the top one (side effects and their management) (Figure 1).

**Figure 1 – Top-ranked areas to address in patient education about Methotrexate**

Around 77% of patients had/have concerns about potential unpleasant side effects, which were discussed with health professionals (mainly with rheumatologists) in 68% of the cases, despite not being clarified 46% of the times.

**Conclusion:** PE and support about MTX are unequal across Europe and can be improved by providing opportunities to clarify concerns, namely by providing patients with more access to nursing consultations. There is an overall agreement between patients and clinicians regarding key information areas of education.

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**Keywords:** Patient information and education, Disease-modifying drugs (DMARDs), Systematic review

S. Logan1, S. Hider1, J. Green2, S. Ryan3, 1Keele University, School of Medicine, Keele, United Kingdom; 2Midlands Partnership NHS Foundation Trust, Rheumatology, Haywood Hospital, Staffordshire, United Kingdom; 3Keele University, School of Nursing and Midwifery, Keele, United Kingdom

**Background:** Guidelines recommend that people with Inflammatory Arthritis have access to tailored information when starting treatment with Methotrexate (MTX) [1]. It is not known what information people with Inflammatory Arthritis (IA) need to take MTX. Many people have concerns about the risk-benefit profile of MTX so do not start or continue MTX.

**Objectives:** To identify and synthesise knowledge of the characteristics, content and preferred format of information that people with IA need to take MTX.

**Methods:** A PROSPERO registered systematic literature search (CRD42022325249) was conducted using Medline, Embase, Cinahl, Psychinfo, GreyEU, Web of Science and Open Dissertation databases. All full-length articles and conference abstracts identifying information and support needs of people with Inflammatory Arthritis, and oral or sub-cutaneous MTX as the main conventional DMARD considered in the study were assessed for inclusion. The systematic review was conducted and reported in accordance with the Joanna Briggs Institute methodological guidance for Mixed Methods Systematic Reviews [2] using a convergent integrated approach and the standards of the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) Statement.

**Results:** 8468 studies were identified. 169 studies were reviewed by full text of which 13 studies met the inclusion criteria. Seven quantitative studies used cross-sectional internet (n=2), postal (n=2), and rheumatology clinic (n=3) surveys, two mixed methods studies, one cross-sectional survey with clinic observations and one cross-sectional survey and focus group, and four qualitative (one interview and three focus group) studies. The combined studies included 5425 adults over the age of 18 years (20-84 yrs), most were female (71%, n=2434). More people were enrolled into studies (n6) involving people with a diagnosis of Rheumatoid Arthritis (n=2278) than studies (n7) involving people with IA (n=840). Studies were conducted in the UK (n=4), Netherlands (n=3), Spain (n=2), Australia (n=2), Canada (n=1) and Japan (n=1) and reported in English. Quantitative results were qualitized. Three main themes were identified, with an overarching theme of a need for person-centred information about Methotrexate. 1: Information to support understanding and acceptance of the need for treatment with MTX. Learning about IA diagnosis, rationale for MTX in context of IA, benefits of MTX 2: Concerns about MTX: including risk, likelihood and management of side effects, drug interactions, impacts upon lifestyle, developing medication self-management skills 3: Content and methods of information delivery: information sources, importance of support from healthcare professionals (hcp), family and friends, value of a therapeutic relationship with hcp.

**Conclusion:** People with IA have individual, multi-faceted information and support needs about both their condition and MTX, to enable them to take MTX. Further research is recommended to explore a) the expectations of information and support before receiving information about MTX, b) experiences of people receiving information at the time of starting MTX and c) strategies to improve information and support during the course of taking MTX.

**REFERENCES:**


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**DAY-TO-DAY FLUCTUATIONS OF FATIGUE IN SYSTEMIC SCLEROSIS**

**Keywords:** Patient reported outcomes, Quality of life, Systemic sclerosis

A. Velathopappilai1, M. Vonk1, C. Van den Ende1, J. E. Vrijezekel2, 1Redbud University Medical Center, Rheumatology, Nijmegen, Netherlands; 2Sint Maartenskliniek, Research and Innovation, Nijmegen, Netherlands

**Background:** Systemic sclerosis (SSc) is a rare auto-immune disease with a huge impact on physical health as well as social well-being, with fatigue being the major problem experienced by patients with respect to their well-being [1].
While fatigue is being reported to be fluctuating and unpredictable, the dynamic nature of fatigue is not well understood [1, 2].

**Objectives:** To examine the within-person fluctuations and clinically meaningful changes in fatigue, as well as the within-person association of fatigue and time-varying determinants in SSc.

**Methods:** We performed a daily-diary study in adult patients with a clinical diagnosis of SSc. Patients with pulmonary hypertension or severe pulmonary function disturbances (i.e., vital capacity and diffusing capacity for carbon monoxide < 50%) were excluded. During 14 days patients completed daily assessments at four fixed time points (i.e., 9 a.m., 1 p.m., 5 p.m., 9 p.m.) of fatigue severity and time-varying determinants (i.e., negative affect, positive affect, pain, quality of sleep and perceived exertion of physical activity. As proxy for clinical meaningful change in fatigue the probability of acute change (PAC) was assessed, i.e., the chance that change in day-to-day fatigue levels exceeded the minimally clinically important difference for fatigue[3]. Using multilevel models the within-person fluctuations in fatigue and its association with time-varying determinants were examined. Based on the extent of clustering, the time-varying determinants were disentangled into their corresponding levels (within persons (within day as well as across days) and between persons) and added to the multilevel model. Models were adjusted for confounding (i.e., BMI, sex, age, and history of covid-infection) where appropriate.

**Results:** Fifty-seven patients with SSc, 35% male with mean(SD) age 54.3(14.6) years, participated. The disease duration was mean(SD) 6.9(4.8) years and 29.8 % was diagnosed with diffuse cutaneous SSc. Eighty percent of all observations were completed. During the study period, change in day-to-day fatigue levels exceeded the MCMID mean(SD) 5.7(1.9) times. The PAC was mean(SD) 0.44(0.14), ranging from 0.08-0.77. For fatigue a between-person variation of 49% and a within-person variation of 51% was observed. With respect to confounders, only BMI was significant in the models for time-varying negative and positive affect. The final models showed significant within-person association with fatigue fluctuations and changes in time-varying determinants within a day, between days and between patients (Table 1).

**Conclusion:** This is the first quantitative study showing that fatigue in SSc is characterized by a dynamic course and that approximately half of the day-to-day fatigue fluctuations are clinically meaningful, confirming the results of qualitative studies[2]. Moreover, when patients reported more fatigue than usual, they also reported more pain, more negative affect, less positive affect, more perceived exertion of physical activity, and worse quality of sleep than usual.

**Table 1. Association of within-person fluctuations of fatigue and time-varying determinants at each level. All β are significant (p-value<0.05).** * corrected for BMI, β level (95% CI) 2 not applicable.

<table>
<thead>
<tr>
<th>Fatigue fluctuation</th>
<th>level (95% CI) 1</th>
<th>level (95% CI) 2</th>
<th>level (95% CI) 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Negative affect</td>
<td>0.41(0.3-0.51)</td>
<td>0.41(0.3, 0.50)</td>
<td>0.72(0.46, 0.98)</td>
</tr>
<tr>
<td>Positive affect</td>
<td>-0.60(-0.60, -0.53)</td>
<td>-0.61(-0.69, -0.53)</td>
<td>-0.74(-1.05, -0.42)</td>
</tr>
<tr>
<td>Pain</td>
<td>0.46(0.39, 0.52)</td>
<td>0.48(0.37, 0.62)</td>
<td>0.48(0.33, 0.60)</td>
</tr>
<tr>
<td>Perceived exertion of physical activity</td>
<td>0.19(0.15, 0.24)</td>
<td>0.25(0.16, 0.35)</td>
<td>0.76(0.48, 1.04)</td>
</tr>
<tr>
<td>Quality of sleep</td>
<td>N/A</td>
<td>-0.20(-0.27, -0.14)</td>
<td>-0.48(-0.80, -0.16)</td>
</tr>
</tbody>
</table>

**REFERENCES:**


**Figure 1. Mean Symptom Domain Scores for Each Group**

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