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[Joint session HPR/ PARE/ ARP] Mastering Self-management: State of art in a New Era

OP0322-HPR

EMPOWERMENT AND ASSOCIATIONS TO DISEASE ACTIVITY AND PAIN IN PATIENTS WITH RHEUMATOID ARTHRITIS

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Background: The WHO describes empowerment as a process in which patients can take control and make informed decisions about their life and health. Empowerment is important for patients with rheumatoid arthritis (RA) since most of the care is provided by the patients themselves.

Objectives: The aim was to study levels of empowerment and associated variables in individuals with RA and to investigate longitudinal clinical data in patients with low and high empowerment.

Methods: This study involved patients with RA from the BARFOT (Better Anti-Rheumatic Pharmacotherapy) cohort, who were recruited between 1992 and 2006 and included in the study at the time for diagnosis (n = 2,837) [1]. The patients were assessed according to a structured protocol at inclusion and after 3, 6, 12, 24, 60, 96, and 180 months. At each follow-up DAS28-3, HAQ and pain were assessed. In 2017, a postal survey was sent to all still living patients (n=1542), with a response rate of 69% (n = 1,065). The questionnaire included disease characteristics, questions about lifestyle habits and the Swedish Rheumatic Disease Empowerment Scale (SWE-RES-23) [2]. The 844 patients who answered the SWE-RES-23 made up the study cohort. Differences in empowerment between groups (lowest third [LE], SWE-RES-23 ≤3.48 vs. highest third [HE], SWE-RES-23 ≥4.04) were analysed with t-tests. Logistic regression analysis was used to study associations with LE vs. all others. Thirdly, differences between LE and HE were studied with longitudinal data (seven time points) of pain, HAQ and disease activity.

Results: Responders were mean 65 (SD13) years old, disease duration 15.6 (3.9) years, and 74% were women. The LE group (n=282) were older and were more often women, and reported worse overall health compared with the HE group (n=270), Table 1.

Table 1. Descriptives at questionnaire 2017, including all participants and comparisons between highest and lowest third of SWE-RES-23

	All	Low SWERES*	High SWERES*	p-value
	Mean (sd)	Mean (sd)	Mean (sd)	
N	844	282	270	
Sex, women, %	74	78	69	0.015
Age	65 (13)	66 (13)	63 (12)	0.002
Disease duration, year	15.6 (3.9)	15.7 (4.1)	15.6 (3.8)	0.917
TJC28 (0-28)	5 (6)	6 (8)	4 (5)	<0.001
SJC28 (0-28)	3 (5)	3 (4)	3 (4)	0.334
PatGA (0-10)	3 (2)	4 (3)	2 (2)	<0.001
Pain (0-10)	3 (2)	4 (3)	3 (2)	<0.001
Fatigue (0-10)	4 (3)	5 (3)	3 (3)	<0.001
HAQ (0-3)	0.62 (0.61)	0.81 (0.69)	0.42 (0.51)	<0.001
EQ5D (0-1)	0.70 (0.25)	0.62 (0.29)	0.79 (0.19)	<0.001
SWERES	3.8 (0.7)	3.1 (0.3)	4.6 (0.3)	<0.001

*tricotomized data, lowest third vs. highest third

Figure 1. Panel showing mean DAS28-3 (A), ESR (B), VAS pain (C) and HAQ (D) over 15 years in the different groups.

Regarding lifestyle habits, there were no differences between the groups in smoking habits, diets, or drinking habits. Moderate physical activity for ≥150 min/week was reported by 27% in the LE group vs. 41% in the HE group, $p < 0.001$. Vigorous physical activity ≥60 min/week was reported by 22% vs. 37% in the LE and the HE group respectively, $p < 0.001$.

In the logistic regression analysis (n=844), several factors were associated with LE: being a woman (OR 1.40, 95% CI 1.00-1.97), pain-related factors as higher tender joint count (OR 1.04, 95% CI 1.01-1.06), worse patient global assessment (OR 1.19, 95% CI 1.12-1.27), pain (OR 1.14, 95% CI 1.08-1.21), fatigue (OR 1.14, 95% CI 1.09-1.21), HAQ (OR 2.08, 95% CI 1.64-2.64) and EQ-5D (OR 0.16, 95% CI 0.09-0.28). There were also associations between moderate physical activity (<150 min/week) (OR 1.60, 95% CI 1.16-2.19) and vigorous (< 60 min/week) (OR 1.50, 95% CI 1.07-2.10) and LE.

Analysing longitudinal data, the LE group reported worse pain and HAQ at all timepoints, a worse DAS28-3 at year 2 and 8, and a worse ESR at 15 years follow-up compared with the HE group ($p < 0.05$).

Conclusion: In patients with RA, low empowerment is associated with worse all over health. Interventions aimed to improve empowerment may include mastering of pain, physical function, and improved physical activity.

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Members and Volunteers – Unknown beings? How to explore their interests, establish contacts and support

OP0323-PARE

“CELEBRATING THE 50TH ANNIVERSARY OF OUR ORGANISATION IN TIMES OF PANDEMIC: HOW WE USED DIGITAL TOOLS TO OVERCOME CHALLENGES AND DIFFICULTIES AND CAME INTO CONTACT WITH MORE PARTICIPANTS AND VIEWERS THAN EVER ENVISAGED!”

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Background: The German League against Arthritis (DRL) with about 300.000 members wanted to celebrate its 50th anniversary in 2020. The original idea to perform a large jubilee gala was crossed by the limitation of contact and the precaution for members our organisation in times of pandemic.

Objectives: It was a big challenge to transfer the celebration into a digital form in the pandemic. Our goal was to reach as many people (with RMDs, their family, colleagues, politicians) as possible, not only members of our organisation. We wanted to generate even more awareness for people with RMDs, their needs and difficulties nationwide.

Methods: We decided to focus on digital formats and produced video clips and podcasts that were presented online. Some of the topics of the videos: Voluntary work,

Young people with RMDs, Participation, Doctors and Patients as Partners. Furthermore, in 17 podcasts our member organisations highlighted their activities for people with RMDs. Volunteers vividly described their inside view in the podcasts. In addition, we created a historical timeline for the website. Special highlight was a radio programme based on our videos, summarising our activities that was broadcast by 19 radio stations. **Results:** The video clips attracted more viewers than could have been reached with an event in Berlin. For example we generated 35.000 viewers on our YouTube channel by presenting the birthday speech by our president. Altogether we reached successfully approximately 1.5 million people national wide. I will present the numbers of people our activities reached and feedback we received.

Conclusion: We are convinced going on the right track using digital media as one of our priorities not only in times of pandemic but as a valuable enrichment for all RMD patients on national and international level.

These examples of best practise experiences shall encourage other patient organisations to take on the challenge in pandemic times. By using digital tools and formats patient organisations can succeed in reaching more RMD patients and in staying connected with their members.

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OP0324-PARE PATIENT INFORMATION IN TIMES OF CRISIS: LESSONS LEARNED FROM COVID-19 COMMUNICATION IN RHEUMATOLOGY

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Background: The rapid global spread of COVID-19 required swift action to provide people with rheumatic and musculoskeletal diseases (RMDs) with reliable information. Important issues included the risk of infection and severe illness, (continued) use of medication, temporary closure of clinics, and organization of (semi-) virtual care. People with limited health literacy are a particularly vulnerable group that might have difficulty accessing, understanding, and applying health information.

Objectives: To evaluate (a) key aspects of crisis communication and (b) explicit consideration of people's health literacy needs in communication to people with RMDs during the first wave of COVID-19 in the Netherlands.

Methods: We conducted an explorative qualitative study including seven interviews in May and June 2020 with representatives of organisations (a mixed regional/academic hospital, the association for RMD professionals and two patient organisations) responsible for information provision to people with RMDs in the Netherlands. Interviewees were asked about preparedness (1) and strategy (2) for crisis communication, and content (3) and reach (4) of communication, considering principles of good crisis communication and health literacy. In addition, through systematic screening of websites, social media and emails, we identified and analysed 13 written communications provided to people with RMDs by these organisations during the first three months of the COVID-19 pandemic. We assessed comprehensibility and applicability with the Dutch adapted version of the Patient Education Materials Assessment tool (PEMAT), the outcome being a percentage of adherence to 24 criteria. We assessed difficulty level using an online assessment application (Figure 1), with Common European Framework of Reference for Languages (CEFR) level B1 being the highest acceptable level.

Figure 1. Example of textual assessment using the application. Note: Dutch-language text was used for analysis; the English translation is provided as a reference only and might be of different difficulty.

Results: While admittedly being underprepared, respondents generally perceived their crisis communication as adequate. They quickly adapted to people's needs and changing circumstances and attempted to adapt written and verbal communication to people with limited health literacy. Respondents reported challenges related to the scientific uncertainty, lack of reach, difficulty simplifying information, and being unsure if their communication approach was adequate. Textual assessment showed great variation in applicability (range 60-100%) and comprehensibility (range 58-100%) of these texts, and 69% of communications were more difficult than B1-level. Considering principles of crisis communication and health literacy, we propose several lessons to be learned for future crises (Table 1).

Table 1. Recommendations for improvement of crisis communication

Preparedness:

Use current experience to establish a future crisis communication plan
Train staff and management in crisis communication and health literacy communication

Strategy:

Collaborate with relevant organisations to ensure consistency in messages
Inform people early and frequently
Remain transparent about uncertainty

Content:

Adapt information to different people's needs, considering e.g. age, cultural background
Check difficulty level of written information (aim at B1) and adapt accordingly
Ask your audience for feedback
Make sure information is directly applicable in practice
Combat fake news through acknowledgement and counterarguments

Reach:

Use multiple channels
Use diverse outreach strategies to cater to a diverse audience

Overall:

Consider people's health literacy throughout

Conclusion: The rheumatology organisations mostly adhered to principles of crisis communication, and made efforts to adapt information to their audience's needs, including health literacy needs. Nevertheless, important recommendations were drawn which are potentially also relevant for other clinical fields.

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LB0001 MAVRILIMUMAB IMPROVES OUTCOMES IN PHASE 2 TRIAL IN NON-MECHANICALLY-VENTILATED PATIENTS WITH SEVERE COVID-19 PNEUMONIA AND SYSTEMIC HYPERINFLAMMATION

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Background: Granulocyte/macrophage-colony stimulating factor (GM-CSF) is a cytokine both vital to lung homeostasis and important in regulating inflammation and autoimmunity^{1,2,3} that has been implicated in the pathogenesis of respiratory failure and death in patients with severe COVID-19 pneumonia and systemic hyperinflammation.⁴⁻⁶ Mavrilimumab is a human anti GM-CSF receptor α monoclonal antibody capable of blocking GM-CSF signaling and downregulating the inflammatory process.

Objectives: To evaluate the effect of mavrilimumab on clinical outcomes in patients hospitalized with severe COVID-19 pneumonia and systemic hyperinflammation.

Methods: This on-going, global, randomized, double-blind, placebo-controlled seamless transition Phase 2/3 trial was designed to evaluate the efficacy and safety of mavrilimumab in adults hospitalized with severe COVID-19 pneumonia and hyperinflammation. The Phase 2 portion comprised two groups: Cohort 1 patients requiring supplemental oxygen therapy without mechanical