

Questionnaire (KQ) is available in spondyloarthritis (SpA) (ref 1) and needs to be updated according to the recent recommendations for SA and the patients' needs (ref 2).

Objectives: To develop and validate a new KQ in SpA

Methods: 4 steps. Step1. Selection of knowledge considered essential for patients with SpA through Delphi rounds by a working group of rheumatologists, health professionals (HPs) and patients, leading to a list of consensual items (ref2). Step2. Two rheumatologists and a rheumatology nurse constructed the first version of the KQ, each question of the KQ referring to a selected item on the list. The formulation was then amended by the working group. A new version was elaborated during a face-to-face meeting of 3 health professionals and one patient. Step3. The KQ was submitted to ten patients for cognitive debriefing, comments were analyzed and a final version was elaborated. Step 4. Multicentric validation in 13 rheumatology departments: acceptability was measured by the rates of missing data per item, reproducibility and sensitivity to change were assessed respectively by test/retest at a 2 weeks interval (Lin's concordance correlation coefficient) and by testing the KQ before and after patient education sessions.

Results: Step1 obtained 42 items, 32 considered essential and 10 considered useful, selected respectively by more than 2/3 or more than 50% of participants to the Delphi rounds, leading to the SPAKE: a 42-items questionnaire, with a 32-items short form. The SPAKE contains 6 knowledge domains: disease knowledge (12 items), pharmacological treatment (11), non-pharmacological treatment (8), comorbidities (1), self-care for pain and fatigue (4), adaptative skills to psychosocial, professional issues and health care system (6). The validation included 130 patients, 67 (51.5%) men, mean age 43.5±12.9 years, median disease duration 8 years [3;16]. There were no missing items in the KQ. The SPAKE's internal validity (Kuder-Richardson) was 0.85. Reproducibility (in 61 patients) was 0.81 [95% CI, 0.72; 0.89]. Sensitivity to change was measured in 55 patients. A statistically significant difference in total knowledge score was observed between the two assessment times: 29.1±6.4 vs. 34.7±5.9 (p<0.001), representing an effect size of 0.92 [0.52; 1.31]. The questionnaire's external validity was confirmed by a significant correlation with the patients' educational level (p=0.02).

Conclusion: This study enabled the development and the validation of the SPAKE, a knowledge questionnaire for patients with SpA, with a good acceptability, reproducibility and sensitivity to change. This KQ will be helpful to assess the process of knowledge acquisition in patient education approaches.

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SAT0679

EFFICACY OF A NURSE-LED PATIENT EDUCATION INTERVENTION IN PROMOTING SAFETY KNOWLEDGE AND SKILLS OF PATIENTS WITH INFLAMMATORY ARTHRITIS (IA) TREATED WITH BIOLOGICS: A RANDOMIZED CONTROLLED TRIAL

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Background: Biologic disease modifying drugs (bDMARDs) are highly effective treatments of IA such as rheumatoid arthritis (RA) and axial or peripheral spondyloarthritis (SpA). However, they lead to risks of infections and other side effects. Some of these adverse events may be prevented by patient education (PE) aimed at promoting patients' safety skills.

Objectives: To investigate the effect of a nurse-led PE on safety skills of patients with IA at the introduction of a first subcutaneous bDMARD.

Methods: Multicentric randomized controlled trial comparing an intervention group (IG) to usual care (UC) at the time of the introduction of a first bDMARD. Inclusion criteria: patients with RA or SpA, biologic naïve, eligible for a subcutaneous bDMARD according to the rheumatologist's opinion. Intervention: a face-to-face nurse-led PE at baseline (BL) and 3 months later, ie, assessment by the nurse of the patients' health beliefs and educational needs, education focused on safety skills, self-injections and motivation. The primary outcome was the acquisition of safety skills at 6 months measured by the Biosecure Questionnaire (0-100 scale), a 55 item validated questionnaire assessing competences to deal with fever, infections, vaccination, and other daily life situations (ref). The secondary outcomes were quality of life, severe infections rate, coping, psychological well-being and disease activity. Data were analysed as intent-to-treat using multiple imputations.

Results: 128 patients were included from 9 rheumatology departments between January 2017 and April 2018, 39 (30.7%) with RA, 72 (56.7%) with axial SpA, 16 (12.6%) with peripheral SpA; mean age 47.0 ±12.8 years, mean disease duration 6.1 ±7.5 years, 120 (94%) completed the study. BL mean self-reported information on RA treatments (0-10 numeric scale) was similar: 7.1±2.0 in IG; 6.8±2.1 in CG. The mean duration of the intervention was 65.5 ±17.9 minutes. The primary outcome was met: the Biosecure score at 6 months was 81.2 ±13.1 versus 75.6±13.0 in the IG and CG respectively (p =0.016), showing better skills in the IG. Secondary outcomes were also favorable.

Conclusion: Safety is an important issue in the management of IA treated with bDMARDs. In this trial, a nurse-led patient education was shown for the first time to be effective in teaching patients the essential safety skills.

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SAT0680

EDUCATIONAL NEEDS OF A LARGE COHORT OF PATIENTS WITH DIFFERENT RHEUMATIC AND MUSCULOSKELETAL DISEASES ATTENDING A HEALTH FACILITY IN AUSTRIA

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Background: Patient education is an important part of the management of rheumatic and other diseases. Since patients do not have the same needs, it is crucial to assess needs of a targeted group to be able to tailor educational interventions.

Objectives: To assess educational needs of a large cohort of patients with different rheumatic and musculoskeletal diseases attending a health facility in Austria.

Methods: We conducted an online survey with patients attending the Gastein Healing Galleries in Bad Gastein, Austria. Approximately 12,000 patients with a variety of diseases are treated in the centre every year. Of those, 6,465 patients were invited by email to fill out an anonymous online survey. Socio-demographics and health outcomes were collected from all respondents. In addition, the Educational Needs Assessment Tool (Austrian version - OENAT) was administered to a subset of respondents. The OENAT (39 items) assesses 7 domains of educational needs: Managing Pain, Movement, Managing Feelings, Arthritis/Disease process, Treatments, Self Help Measures, Support Systems.

Results: In total 2017 (31%) patients responded of which 516 had data on educational needs: AS (63%), RA (14%), and FM (24%). Their mean (SD) age was 56 (11), and 54% were male. Level of education was: Elementary School (32%), Junior High School (22%), High School (21%), College (12%), and University (14%). Table 1 presents differences in educational needs across disease groups. Across the groups, there were significant differences in following OENAT domains: Managing Pain, Feelings, Treatments, and Support Systems. There were no differences in the level of educational needs in Movements, Disease Process, and Self-Help Measures. Patients with FM had significantly lower needs for managing and higher needs for feeling education, compared to those with AS and RA ($p < .05$). The RA group had significantly higher needs than the AS ($p < .05$) and FM ($p < .05$) groups for treatments education - the AS group had significantly higher needs than the FM group ($p < .05$) in the same domain. AS patients had significantly higher needs for support system education than FM ($p < .05$) and RA patients ($p < .05$).

Table 1. Differences in educational needs across disease groups

	Managing Pain	Movements	Managing Feelings	Disease Process	Treatments	Self-Help	Support Systems
AS:	14.54	10.20 (4.86)	8.33	16.74	13.98	15.07	7.85
Mean (SD)	(5.41)		(4.39)	(6.29)	(7.26)	(5.45)	(4.18)
FM:	9.98	9.53 (5.13)	9.39	16.87	11.91	14.09	6.80
Mean (SD)	(6.49)		(4.53)	(6.37)	(7.57)	(6.36)	(4.54)
RA:	15.30	10.07 (4.64)	7.94	18.15	16.85	15.82	6.41
Mean (SD)	(5.07)		(4.41)	(6.71)	(6.76)	(5.31)	(4.04)
F-Statistic	33.22***	.84	3.27*	1.43	10.34***	2.31	4.91**

* $p < .05$, ** $p < .01$, *** $p < .001$

Conclusion: Educational needs vary by disease groups and depend on the domain under consideration.

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DEVELOPMENT, ACCEPTABILITY AND USABILITY OF HIBOOT : A SMARTPHONE APP TO IMPROVE MEDICATION ADHERENCE, SAFETY AND SELF-ASSESSMENT IN PATIENTS WITH INFLAMMATORY ARTHRITIS

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Background: There is an increasing interest for mobile health applications (Apps) to enhance patients self-management in rheumatology. However few have been developed involving patients and health professionals.

Objectives: 1. To develop an App to improve medication adherence, safety and self-assessment in patients with inflammatory arthritis (IA) treated by biologics and/or methotrexate (MTX). 2. To assess its acceptability and usability.

Methods: 4 steps. Step1. In 2016, a qualitative ethnographic study and a quantitative study including 21 and 344 patients respectively explored 1. the impact of IA in daily life, treatment practices, relationship between adherence and safety 2. the patients' use of health Apps in general, their needs in terms of content and potential use (refs). Step2. A multi-disciplinary team including 7 rheumatologists, 3 patients association representatives and 4 members of a Digital company developed the first version of the App through face-to-face meetings and qualitative interviews of patients along the development process. The content was collectively reviewed to be understandable by the patients and general population. After the launching of the App (step3), the assessment (step4), consisted in a) a qualitative study including 7 patients with different profiles (current users or non-users, satisfied or not) and 3 rheumatologists, having or not counselled the App to their patients, and b) the number of loadings and current users.

Results: Preliminary studies indicated numerous safety issues and needs on adherence and daily life counselling, leading the 5 main functionalities of the App: a) a treatment reminder, b) a global well-being self-assessment c) a safety checklist before administration, d) help in daily life situations related to self-management and safety e.g. symptoms requiring to stop their treatment (infections, surgery) etc...e) periodic counselling messages. The presentation was a friendly companion called HIBOOT (OWL in English) that interacts with the user. The content was based on the French recommendations of the Club Rhumatismes Inflammation (www.cri-net.com) for biologics and MTX management, the drug leaflets and the public national health websites. In May 2017 : launching on the stores (GooglePlay and iTunes, with free uploading); May 2017-January 2018 : communication toward patients, rheumatologists and health professionals (flyers, postal letters, Facebook, Tweeter). Assessment showed 2 types of usability: a regular use by the patients who have adopted the HIBOOT companion and are in demand of more functionalities; a more punctual use on specific questions with the need of quick answers. The reminder system was particularly appreciated and the messages considered understandable and reliable. Patients suggested ways of improvement on the App navigation system and the check list. Rheumatologists appreciated the independent scientific content although having a low knowledge of the App. To date, the mean loading is ~500/months with a regular use of ~1500-1800 patients monthly.

Conclusion: The free App HIBOOT for patients with IA was developed through a formal methodology using preliminary qualitative studies, inclusion of patients all along the process and has a scientific validated content. Its acceptability and usability is good and will be improved according to patient's advices. Communication is still necessary to enhance rheumatologist's adherence to promoting the App.

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PATIENT EDUCATION IN THE EUROPEAN REFERENCE NETWORK ON RARE AND COMPLEX CONNECTIVE TISSUE AND MUSCULOSKELETAL DISEASES (ERN RECONNET): UNMET NEEDS FROM THE HEALTH CARE PROVIDERS SIDE AND FROM THE PATIENTS' SIDE

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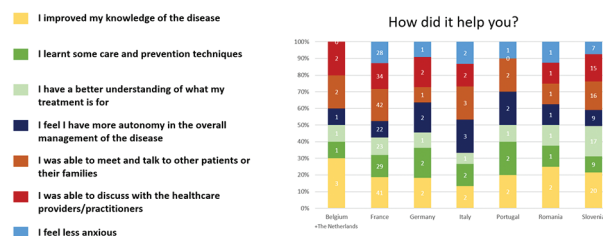
Background: The ERN ReCONNET (European Reference Network on Rare and Complex Connective Tissue and Musculoskeletal Diseases) is the ERN aimed at improving the management of Rare Connective Tissue and Musculoskeletal Diseases across the European Union (EU). The ERN ReCONNET involves 26 health care providers (HCPs), from eight different EU countries: Belgium, France, Germany, Italy, the Netherlands, Portugal, Romania, Slovenia and 7 European Patient Advocacy Group (ePAGs). An intense collaboration has been established between HCPs and ePAGs. Patient Education (PE) was defined in 1998 by the World Health Organization as a continuous process including organized awareness information, self-care learning and psychological support regarding the disease, treatment, care and health care setting. It is designed to help patients to maintain or improve their quality of life with specific PE programmes designed to help them acquiring new skills.

Objectives: To evaluate PE practice in the ERN ReCONNET based on a survey sent to the HCPs members and to the patients of the corresponding countries.

Methods: A questionnaire designed on a google form was sent to the HCPs members asking about their practices in PE in their department and an other one was sent to ePAGs who translated the patients' survey in the different languages. Various versions of the same questionnaire was then sent to patients' associations in the different countries.

Results: 33 HCPs members or representatives answered the survey. 52.9% (18) had no specific staff members dedicated to PE. In the department with staff trained in patient education, 33% (4) had no specific PE programmes. In the HCPs with dedicated staff for PE, 83.3% (10) estimated care providers are insufficient to meet the patients' needs. 1608 patients answered the patient survey (France, n=246; Germany, n=23; Italy, n=500; Portugal, n=339; Slovenia, n=240; Belgium, n=190; the Netherlands, n=42), mostly women (84.5%, n=1359), around 48.5 years old (SD=13.6). Patients suffered mostly from Connective Tissue Diseases and Ehler-Danlos disease. 68% (1093) of the patients had never heard about PE and were for 74% (804) interested in taking part in a PE programme. In the remaining patients who had heard about PE, 66% (342) never took part in a programme. For patients who had

already taken part in a PE programme, they expressed satisfaction in several domains listed in the following bar chart: For all respondents, patients expressed needs for a better knowledge in disease and symptoms, treatments, well-being, nutrition, exchanging experiences with other patients, and daily life with the disease.



Conclusion: Based on the EULAR recommendations for PE (Zangi HA et al.), PE should be apply in all EU countries. E-learning on PE for staff members and ePE for patients will be developed by the ERN ReCONNET.

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SAT0683

NORMATIVE DATA FOR THE DISEASE AND TREATMENT ASSOCIATED KNOWLEDGE SCORE (DATAK-RA) IN PATIENTS WITH RHEUMATOID ARTHRITIS

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Background: Having adequate disease-related knowledge is essential for patients with RA, since it may influence treatment decisions, shared-decision making, and the ability to perform self-management behavior. Patient Knowledge Questionnaires can be used to measure disease-related knowledge. We recently developed and validated the item response theory (IRT) based Disease and Treatment associated Knowledge in Rheumatoid Arthritis (DataK-RA) item bank, containing 42 multiple-choice items. In the present study we establish normative data to facilitate the interpretability of DataK-RA scores.

Objectives: To produce normative data for DataK-RA (IRT)-scores, stratified by sex and educational level.

Methods: Consecutive patients recruited from three hospitals in the Netherlands were asked to complete a form containing either 27 or 26 DataK-RA items. DataK-RA IRT-scores and standard errors (SEs) were obtained using the weight maximum likelihood estimator. The Dutch Committee on Tests and Testing (COTAN) quality criteria for test norms were followed. DataK-RA IRT scores and the precision of the scores (SE) were summarized using the mean (SD) or median and 1st – 3rd quartile in case of non-normal distribution. Scores were compared between male