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

Meryem-Maud Farhat1, Alain Cornet2, Charissa Frank3, Ilaria Galetti4, Juergen Grunert5, Vera Guimaraes6, Lisa Matthews7, Ana Vieira6, Eric Hachulla8.

1Hôpital Claude Huriez, Department of Internal Medicine and Clinical Immunology, Lille, France; 2University of Special Medical Sciences, University of Maastricht, Belgium; 3AstraZeneca R&D, Wilmington, Delaware, USA; 4Department of Endocrinology, Clinical Immunology and Laboratory Medicine, Umeå University, Umeå, Sweden; 5Hôpital Claude Huriez, Department of Internal Medicine and Clinical Immunology, Lille, France; 6Lupus Europe, Brussels, Belgium; 7Department of Internal Medicine and Clinical Immunology, Lille, France; 8Lupus Europe, Brussels, Belgium.

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 Groups (ePAGs). An intense collaboration has been established between HCPs and ePAGs. Patient Education (PE) was included 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 send to the HCPs members and to the patients of the corresponding countries.

Methods: A questionnaire designed on a google form was send to the HCPs members asking about their practices in PE in their department and an other one was send to ePAGs who translated the patients’ survey in the different languages. Various versions of the same questionaire was then send 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% (844) 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.

REFERENCE


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

Lisanne Renskers1, Martijn Oude Voshaar2, Mariëke J de Jonge3, Sanne Aa Rongen-van Darrel1,3, Anita M.P. Huis1, Mart van de Laar4, Piet L.C.M. van Riel1,3,1, Radboud University Medical Center, Nijmegen, Netherlands; 2University of Twente/Universiteit Twente, Enschede, Netherlands; 3Beroehm, Rheumatology, Uden, Netherlands; 4Ziekenhuis Medisch Spectrum Twente, Rheumatology, Enschede, Netherlands.

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 calculated 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