UPDATING THE PATIENT PARTNER EDUCATIONAL PROGRAM FOR RHEUMATOID ARTHRITIS IN BELGIUM: A SYSTEMATIC, SCIENTIFIC-BASED APPROACH LED BY PATIENT EXPERTS

J. Van Rompay, A. Hoet, C. Geysen, E. Binnard, G. Patteet, L. Ovaere, W. Wilmots, K. Van der Elst, R. Westhovens

Patient Partners® Program Belgium, Vosselaar, Rheumatology, University Hospitals Leuven, Leuven, Belgium

Background: Patient Partners (PP) are expert patients who train medical students, general practitioners and other healthcare providers about the clinical presentation of rheumatoid arthritis (RA). A direct objective is to improve musculoskeletal examination skills, facilitating appropriate referrals, fast diagnosis and early treatment initiation.

Objectives: We sought to critically review and update the PP Program for RA in Flanders because of changing needs based on new data about early intensive treatment strategies, patient beliefs and preferences in early RA, as well as about the hurdles to implement optimal care strategies.

Methods: We followed a structured plan of action, in which we aimed to make the course content more applicable to the new needs, and this for patients who are also more likely to present themselves without joint deformities, continuing their normal life as much as possible. Four content modules were developed by seven patient partners with RA who took the lead in this project. The other members of the project team were one rheumatologist, one nurse specialist and two doctoral researchers active in the field of early RA.

Results: After a brainstorm session by PP, a first team meeting was held to review their ideas and to add scientific input. They particularly indicated that the patient perspective (e.g., perceptions, impact of disease, general health advice) could be improved in the course content. Subsequently, the current content was reviewed and part of it was removed (focus on classical joint deformities), part of it was differently clustered. During this first debriefing, four content modules were proposed: aspects of treatment delay, treatment strategies and perceptions about medication (from a patient and healthcare provider perspective), the patient and his/her environment, and active participation. Next, the PP formed subgroups and worked out the modules. In a second debriefing, the modules were further refined and the new course structure was discussed including necessary adaptations to course material. We agreed on the implementation strategy. Thereafter, the updated program was presented to the entire group of PP during their annual meeting, and a credibility check was performed with a general practitioner and a medical student. Final changes were integrated based on their feedback. Lastly, during a two-day meeting, all PP were trained by the project team to implement the new content and structure in their lessons.

Conclusions: The update of the Belgian PP program for RA is an example of how expert patients can substantially be involved in updating educational programs. We strived to include new insights about RA and the patient perspective to a higher extent in the course content. Four content modules were implemented: aspects of treatment delay, perceptions about medication, the patient and his/her environment, and active participation. Making medical students and healthcare providers aware of the patient perspective is an important step towards optimal care in RA.

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