

EULAR
03.06.22
2.35PM CEST
Kilchberg,
Switzerland

PATIENT INVOLVEMENT AND EMPOWERMENT: COPING WITH RHEUMATIC DISEASES

Projects benefit from inclusion of the patient voice

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Having a rheumatic and musculoskeletal Disease (RMD) has an impact on daily activities, work, relationships, and quality of life. Patients may also feel a sense of invalidation. EULAR – The European Alliance of Associations for Rheumatology – has made efforts to raise awareness for the burden imposed by RMDs and promote the best quality of care, including recognition and psychosocial support. However, it is unclear how frequent and severe the problem remains nowadays. Several groups presenting findings at the 2022 EULAR Congress on patient empowerment and research aimed at helping people cope with living with an RMD.

At the 2022 EULAR Congress, Joana Vicente presented the findings of a survey which set out to identify the levels of invalidation and lack of understanding felt by adults with RMDs from health professionals and other people. The group also looked at the relationship between invalidation, sociodemographic characteristics, and disease, and its impact on people's life and health outcomes.

From over 1,500 responses, 86% reported feelings of invalidation, mostly from family (56%), health professionals (48%), friends (39%) and social environment (38%). The impact of this invalidation is mainly on the psychological well-being, but it also reduces seeking health care and therapeutic adherence. The burden appeared to be greater for people with fibromyalgia. The results also demonstrated that people with higher education felt more discounting and more lack of understanding. No differences were observed for gender or civil status. This survey highlights that invalidation remains a source of suffering, affecting well-being and health outcomes. Specific awareness and educational campaigns are needed to target this problem.

Research shows that people with an RMD are often insufficiently aware that they can talk the challenges they face with their health care team, and that they may impact treatment choices. A conversation aid can help people to become aware of challenges or problems they face, and then use these to set an agenda for a good conversation in the consultation room. At the 2022 EULAR Congress, Petra Borsje shared news about development of four conversation aids developed by patient partners in the Netherlands. The resulting tools focus on the disease, daily activity, lifestyle, and relationships and well-being. The group have also put together a list of points to support shared-decision making.

Patient empowerment was also the topic of a presentation from PhD Kristine Marie Latocha, looking at the effect of group-based cognitive behavioural therapy for insomnia (CBT-I) in patients with rheumatoid arthritis (RA). Insomnia is common in RA, and may exacerbate symptoms and burdens, such as fatigue, depression, and pain. CBT-I has been shown to produce positive effects in other clinical populations.

The results of this randomised controlled trial showed that nurse-led, group-based CBT-I over 6 weeks did not improve objectively measured sleep efficiency or other outcomes measured by polysomnography. However, CBT-I showed long-term improvement on patient-reported outcomes such as insomnia, sleep disturbances, fatigue, impact of disease, depression, pain, and patient global assessment – a finding that could have important clinical implications.

HIPPOCRATES is a large, international research project addressing the needs of people with psoriatic arthritis (PsA). It aims to improve early identification in people with psoriasis, as well as therapeutic options and outcomes for people living with PsA. A key strength of the project is that patient representative organisations are highly integrated, and will be important avenues for dissemination.

Lars Werner shared experiences of the first 6 months of patient involvement in HIPPOCRATES based on results from a survey and online workshop with patient research partners (PRPs).

The findings are positive: almost all PRPs have been invited to their work package meetings and included in email exchanges, and all feel well-included in assigned groups and roles. Nevertheless, it was reported that some PRPs may be reluctant to raise their voice or to be involved in discussions at virtual meetings.

Source

Borsje P, et al. Development of conversation aids: How to get the most out of your RMD appointment and advance your quality of life. Presented at EULAR 2022; abstract OP0005-PARE.

Vicente J, et al. "I will never forget the shame I felt": A survey to people with a rheumatic disease about invalidation from health professionals and other people. Presented at EULAR 2022; abstract OP0001.

Latocha KM, et al. The effect of group-based cognitive behavioural therapy for insomnia in patients with rheumatoid arthritis: A randomised controlled trial. Presented at EULAR 2022; abstract OP0295-HPR.

Werner L, et al. Meaningful patient involvement is critical to successful international grant applications: the case of the HIPPOCRATES consortium. Presented at EULAR 2022; abstract OP0204-PARE.

About EULAR

EULAR – the European Alliance of Associations for Rheumatology – is the European umbrella organisation representing scientific societies, health professional associations and organisations for people with rheumatic and musculoskeletal diseases (RMDs). EULAR aims to reduce the burden of RMDs on individuals and society and to improve the treatment, prevention and rehabilitation of RMDs. To this end, EULAR fosters excellence in education and research in the field of rheumatology. It promotes the translation of research advances into daily care and fights for the recognition of the needs of people with RMDs by the EU institutions through advocacy action.

About the EULAR European Congress of Rheumatology

Since its introduction in 2000, the annual EULAR European Congress of Rheumatology has become the primary platform for exchange of scientific and clinical information in Europe. It is also a renowned forum for interaction between medical doctors, scientists, people with arthritis/rheumatism, health professionals and representatives of the pharmaceutical industry worldwide. The EULAR congress is usually held in June in one of the major cities in Europe.

The scientific programme covers a wide range of topics on clinical innovations, clinical, translational and basic science. Meetings set up by associations of people with arthritis/rheumatism, health professionals and the health care industry complement the programme. The poster sessions, offering lively interaction between presenters and participants, are regarded by many as the heart of the congress.

Over the years, the EULAR Congress has gained a reputation of being a most innovative platform for the practicing physician particularly with respect to the acquisition of information on novel clinical research. The congress attracts more than 18,000 delegates from more than 130 countries.

The aim of the EULAR European Congress of Rheumatology is to provide a forum of the highest standard for scientific, both clinical and basic, educational, and social exchange between professionals involved in rheumatology, liaising with patient organisations, in order to achieve progress in the clinical care of people with rheumatic diseases.

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