

Patient involvement and empowerment: Coping with rheumatic diseases

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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 about 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 Ph.D. Kristine Marie Latocha, looking at the effect of group-based [cognitive behavioral 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 randomized 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 organizations 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.

More information: Conference: www.congress.eular.org/

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