

Oral Presentations

Addressing the effect of Placebo, Nocebo and Contextual factors in RMDs

OP0001

“I WILL NEVER FORGET THE SHAME I FELT”: A SURVEY TO PEOPLE WITH A RHEUMATIC DISEASE ABOUT INVALIDATION FROM HEALTH PROFESSIONALS AND OTHER PEOPLE

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Background: The term invalidation refers to the patients' perception that their medical condition is not recognised, either in denying, lecturing, not supporting or not acknowledging the condition. This may be felt from health professionals themselves but also from family, friends, at work and in other social areas, imposing great suffering.[1] The European Alliance of Associations for Rheumatology (EULAR) has made efforts to raise awareness for the burden imposed by rheumatic and musculoskeletal conditions (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.

Objectives: The aims of this national survey were: (i) to identify the levels of invalidation and lack of understanding felt by adults with RMDs from health professionals and other people, (ii) to investigate the relationship between invalidation, sociodemographic characteristics and disease; and (iii) to understand its impact on people's life and health outcomes.

Methods: An online survey was developed by the national health professionals in rheumatology and patients' organisations and opened between May and December of 2021. The questionnaire included demographic and disease information, the Illness Invalidation Inventory (3*I), [1] with additional questions in a Likert format and open questions for a detailed understanding of the phenomenon. The 3*I is composed of 8 items, measured from 1 (=never) to 5 (=very often), forming two factors: Discounting (mean of 5 items; lower scores indicating more discounting) and Lack of understanding (mean of 3 items; Higher scores representing higher lack of understanding).

Quantitative data were analysed using descriptive statistics. Associations were tested with a t-student and ANOVA one-way test (Bonferroni correction). Open responses were categorised using the content analysis technique, and themes were defined a posteriori.

Results: From the > 1500 responses obtained, 1410 responses were filled out completely (mean age of 46 years [SD=11], 95% females, 60% with FM, among which 59% were diagnosed in the last 5 years).

Invalidation was reported by 86% of the participants and 70% rated ≤5 on a scale from 0 (nothing) to 10 (totally) on feeling understood by other people. Invalidation was mostly felt from family (56%), health professionals (48%), friends (39%) and social environment (38%). The impact of this invalidation is mainly on the

psychological well-being (58%), also reducing seeking health care (41%) and therapeutic adherence (17%), affecting work (41%), and to a less extent, (family) relations (31%).

Figure 1 shows the frequency of responses and means scores on the 3*I items and factors for participants with and without FM. The burden is greater for people with FM, which was statistically significant. People with higher education felt more discounting and more lack of understanding. No differences (p>0.05) were observed for gender or civil status.

Elucidative expressions of invalidation were shared, mostly by people with FM, encompassing their ability to work and need for social support, faking pain and treatment efficacy, and even intimacy aspects. These emotionally uncomfortable situations can be linked to lesser engagement with healthcare and disease management, and therefore, with worse health outcomes.

Conclusion: Invalidation remains a source of suffering, affecting well-being and health outcomes. Specific awareness and educational campaigns are needed to target this problem on different play-actors.

REFERENCES:

[1] Kool MB, et al. Ann Rheum Dis 2014;73:551–556. doi:10.1136/annrheumdis-2012-201807

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Bench to Bedside: The complement system in rheumatic diseases

OP0002

LOW COMPLEMENT LEVELS IN THE FIRST TRIMESTER PREDICT DISEASE FLARE IN SLE PREGNANCY: A NETWORK META-ANALYSIS ON 532 PATIENTS.

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Background: The complement system is a key-player in the pathogenesis of systemic lupus erythematosus (SLE); its decreases correlate with disease activity and precedes flare. Since synthesis of complement proteins increase during gestational course, it is debated whether complement levels exert a prognostic role in pregnant women with SLE.

Objectives: We performed a network meta-analysis to assess the prognostic role of complement in pregnant SLE women, to evaluate the possible role of complement fluctuations during pregnancies.

Methods: Data from available prospective studies (Jan 2002-Dec 2020) investigating pregnancies in at least 50 SLE patients, excluding miscarriages before 12 weeks, were pooled together. After a systematic literature search, corresponding authors of 19 retrieved studies meeting inclusion criteria were invited to contribute with additional data, including complement levels [6 months before pregnancy, at conception, 1st trimester (T1), 2nd trimester (T2), 3rd trimester (T3) and 3 months after delivery].

Results: A total of 532 SLE women from four eligible studies were included in the analysis [1-4]. Lupus Nephritis (LN) was diagnosed in 237 patients (44.5%) and Antiphospholipid Syndrome in 68 (12.8%). A total of 170 patients (32%) experienced a flare during pregnancy, defined as need of new Immunosuppressants or increase of prednisone > 9 mg/day.

Patients with LN had significantly lower mean levels of complement (C3 at conception; C3 at T1; C3 after 3 months of delivery; C4 at all timepoints except for C4 at T3). SLE patients who experienced flares during pregnancy had significantly lower mean levels of complement (all timepoints for both C3 and C4). Table 1 shows the mean C3 and C4 levels in different timepoints according to diagnosis and flare during pregnancy. The lowest levels of complement were observed in patients with a concomitant diagnosis of LN and presence of flare, particularly during the T1 (Figure 1). Nevertheless, both in LN and flare groups the lowest levels of C3 and C4 were documented at T1.

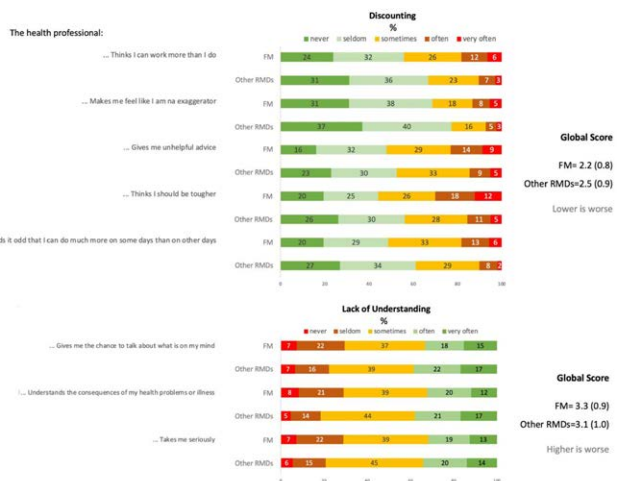


Figure 1. Percentages of responses per type of disease for the eight items of the Illness Invalidation Inventory.