

Network models of fatigue and pain in rheumatic and musculoskeletal diseases

Blanca Gavilán-Carrera¹, Rinie Geenen², Ciara M Hughes³, Lurdes Barbosa⁴, Marianne Visser⁵, Joseph G McVeigh⁶, Ricardo JO Ferreira⁷, Fernando Éstévez-López⁸

¹ University of Cádiz, Spain, ² Utrecht University, The Netherlands, ³ Ulster University, UK, ⁴ Hospital Garcia de Orta, Portugal, ⁵ EULAR PARE Patient Research Partners, The Netherlands,

⁶ University College Cork, Ireland, ⁷ Centro Hospitalar e Universitário de Coimbra, Portugal, ⁸ University Medical Center Utrecht, The Netherlands

BACKGROUND Fatigue and pain are main symptoms of Rheumatic and Musculoskeletal Diseases (RMDs). Healthcare providers in rheumatology have a primary role in helping patients to manage symptoms that are influenced by a complex network of mutually interacting factors including disease severity, social support, body weight, psychological distress, physical activity, sleep problems and perhaps also diet. The importance of these distinct factors, as well as the strengths with which each factor influences fatigue, pain and other factors in the model are assumed to differ between RMDs and individual patients (an example is pictured in figure 1).

AIM The current proposal aims to picture these network models for subgroups of people with RMDs.

METHODS Adults with at least one RMD will be recruited for this online cross-sectional project. To get a complete overview, a large sample size from different countries (Ireland, Portugal, Spain, The Netherlands, and the UK) cultures is included. A brief online survey, using 0-10 numeric rating scales, will determine for the past month, levels of fatigue and pain as well as biopsychosocial factors that are assumed to play a role in the networks model of fatigue and pain. These factors were derived from literature and identified by interviews with patients, health professionals and rheumatologists. Using this input, the steering committee of the project decided the factors to be measured, giving priority to those that can be modified in self-management support in community health centers worldwide.

RESULTS, STRENGTHS / LIMITATIONS & CONCLUSIONS

- Data collection is now being conducted with more than 800 patients having participated so far.
- This is the first study on networks models of fatigue and pain in RMDs.
- The study will yield information for clinical practice by showing whether networks of fatigue and pain and its maintaining factors differ between RMDs and between patients with high scores on specific maintaining factors.
- This research was developed in partnership with people with RMDs who participated during all stages of the research.
- Both a strength and potential limitation of the study is that the cross-sectional associations reflect reciprocal and mutual influencing pathways between factors, but preclude to infer specific causal directions of the associations under study.
- Selected factors will be assessed, which limits the generalizability to all factors that may hold for any person with RMD.

Patient and public involvement: you are welcome to participate!

We expect to culturally adapt the study by organizing additional meetings led by researchers (including people with RMDs as research partners) who show their interest in conducting the study in other countries. The steering committee will support researchers from other countries as well as the responsibilities that the latter will acquire. Do not hesitate to contact us if you are willing to join us!

Acknowledgements The authors would like to thank the study participants for their collaboration. This work is supported by the EULAR health professionals research grant (HPR045).

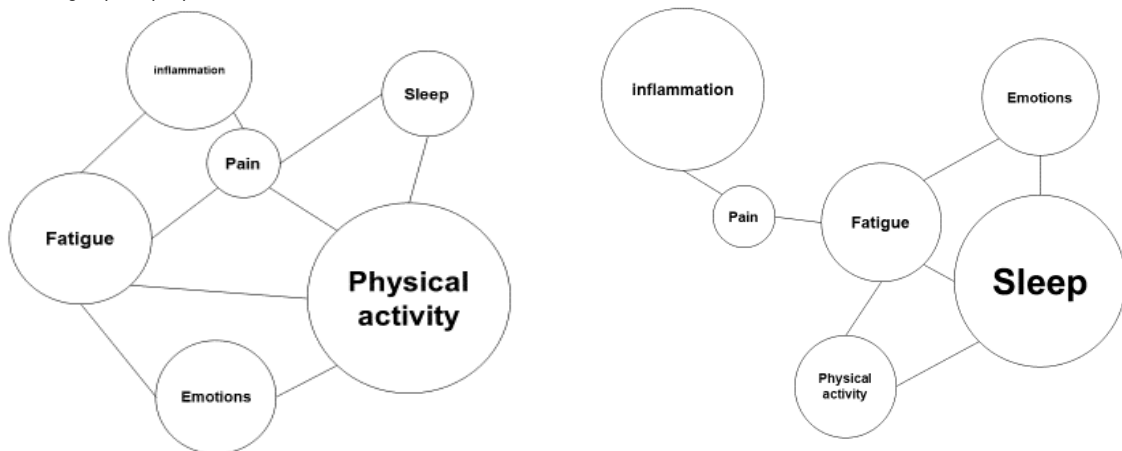


Figure 1. Network models of two subgroups reflecting factors that are associated with pain and fatigue. The size of the nodes (strength of the factor) and distance between the nodes (strength of the relationships between factors) differ between subgroups.