

Self-management of symptom clusters in people with Inflammatory arthritis – “SCOTIA”

Bente Appel Esbensen, senior researcher, professor, mail: bente.appel.esbensen@regionh.dk

COPECARE (Copenhagen Center for Arthritis Research); Center for Rheumatology and Spine Diseases, Rigshospitalet, Glostrup

Aim

The overall aim of this study is to design, develop and test a symptom cluster self-management intervention targeting patients with IA with symptom burden, following the MRC framework.

The objective is to investigate the effect of group cognitive behavioral therapy (CBT) for symptom clusters self-management, compared with groups receiving information alone on illness intrusiveness among people with inflammatory arthritis.

The goal is to provide patients with techniques that can lead to a sense of control over their lives, despite suffering from symptom burden.

Method

Study design

The Medical Research Council (MRC) provides a framework for developing and evaluating a complex intervention targeting symptom clusters in people with inflammatory arthritis.

Population

People with inflammatory arthritis (IA) which covers a group of diseases caused by an overactive immune system that results in inflammation. The most common types of IA are Rheumatoid Arthritis (RA), Spondyloarthritis (SpA), and Psoriatic Arthritis (PsA); age > 18 years, understand and speak Danish.

Setting

The intervention will be developed and conducted at the Center for Rheumatology and Spine Diseases, Rigshospitalet, Denmark. We wish to develop an intervention suitable for this setting and á priori include the interdisciplinary staff employed in this clinic in the development phase.

Patient involvement

Two to three patients will be involved in the design of the project, including the development of the intervention. The patients will also act as research partners in the project group in all project phases. Studies have shown that this helps maintain the patient perspective, the relevance of the project focus and structure, and the results.

Studies

Before developing and subsequent test of a nurse-led intervention targeting systematic symptom clusters in people with IA, there is a need to explore the current evidence, understand perspectives of individuals with IA and symptom clusters. Thus, this project is planned to consist of five sub-studies:

- 1) A scoping review to map existing knowledge on symptom clusters and symptom burdens in people with IA
- 2) A qualitative study to examine perspectives of people with IA and symptoms
- 3) Developing a nurse-led intervention based on results from sub-study 1-2
- 4) Feasibility study testing
- 5) Qualitative and quantitative evaluation of the feasibility study

More knowledge of possible symptom clusters can increase the understanding of the complex symptom burden that the patients experience.

Status

The protocol for the entire project SCOTIA is in progress.