

## Even patients with well-controlled disease can have high levels of fear



The FAIR questionnaire could be useful both in routine doctor visits and clinical trials to identify a person's fear levels about their disease and its treatment

### INTRODUCTION

Rheumatoid arthritis is a chronic (long-term) inflammatory disease that affects a person's joints, causing pain and disability. It can also affect internal organs. Rheumatoid arthritis is more common in older people, but there is also a high prevalence in young adults, adolescents and even children, and it affects women more frequently than men.

Spondyloarthritis is a chronic inflammatory disease. It mainly involves the joints, but may be associated with other diseases, such as psoriasis (a skin disease), inflammatory bowel disease and uveitis (an inflammation in the eye). These non-joint symptoms are known as extra-articular manifestations and they may arise from similar underlying causes, typically inflammation in the body.

Patients can also be classified as having axial spondyloarthritis or non-axial (also called peripheral) spondyloarthritis, according to which joints in their body are affected. Axial disease affects the sacroiliac joint (in the back part of the pelvis) and the spine, causing back pain and stiffness. Non-axial disease affects the shoulders, hips or knee joints.

### WHAT DID THE AUTHORS HOPE TO FIND?

The authors wanted to develop a tool that would help them to understand the most common fears of people with rheumatoid arthritis or axial spondyloarthritis concerning their disease and its treatment.

### WHO WAS STUDIED?

The study looked at 672 people: 432 with rheumatoid arthritis, and 240 with axial spondyloarthritis. Most people included in the study had moderate levels of disease activity.

### HOW WAS THE STUDY CONDUCTED?

An initial study had been performed in which 25 people with rheumatoid arthritis and 25 with axial spondyloarthritis took part in interviews to find out their fears about their disease and its treatment.

All views that were expressed by more than two people in that initial phase were then rephrased as statements (e.g. "I am afraid that my disease will progress quickly"). Any duplicated or similar statements coming out of this step were removed. This resulted in a set of ten statements, which together were named the 'Fear Assessment in Inflammatory Rheumatic Diseases (FAIR)' questionnaire. The people in the study could rate their agreement on a 0–10 scale (where 0='completely disagree') with each statement in the questionnaire.

The authors aimed to test this tool, by asking the 672 people in the study to complete the questionnaire. The scale helped to establish 'fear levels' based on responses. Then the authors explored what the people who fell into each fear level might have in common.

### WHAT WERE THE MAIN FINDINGS OF THE STUDY?

The study identified three groups – those with "high" fear scores (17.2%), "moderate" scores (41.1%), and "low" scores (41.7%). As expected, people with high fear scores often had greater psychological distress. The authors also found that people with high fear scores tended to have a low level of education, to be unemployed, to be living alone, or to be immigrants.

### ARE THESE FINDINGS NEW?

While it was previously known that rheumatic diseases are associated with psychological distress, this is the first tool to our knowledge designed to assess the specific fears that might cause this distress.

### WHAT ARE THE LIMITATIONS OF THE STUDY?

It is possible that there is a potential cultural bias, since the items in the questionnaire were derived from a study conducted in France. Further studies will be required to assess whether this tool could be used by people in other cultures. There may also be overlap with tools that already exist for collecting patient-reported outcomes in people with rheumatic diseases.

### WHAT DO THE AUTHORS PLAN ON DOING WITH THIS INFORMATION?

Now that the questionnaire has been tested, the authors hope that it will be used by doctors to help them to have conversations about fears that their patients might have. It is also hoped that it will be used in clinical trials to measure improvements in patients' fears following a specific treatment.

### WHAT DOES THIS MEAN FOR ME?

If you have a rheumatic disease such as rheumatoid arthritis or axial spondyloarthritis, you may have fears about the disease and its treatments. Your doctor might use this questionnaire with you to start a dialogue and help you to communicate your fears. If you are worried about anything, your doctor should be able to give you the information you need to dispel any fears that are unwarranted, and help you to cope with those that aren't.

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Date prepared: February 2018

Summary based on research article published on: 12th January 2018

**From:** Gossec, R. *et al.* Development and Psychometric Validation of a Patient-Reported Outcome Measure to Assess Fears in Rheumatoid Arthritis and Axial Spondyloarthritis: The Fear Assessment in Inflammatory Rheumatic Diseases (FAIR) Questionnaire. *Ann Rheum Dis* 2018;77:258–63. doi:annrheumdis-2017-212000

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