

Having Patients and Providers Identify Meaningful Changes in Rheumatoid Arthritis Symptoms

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What was the research about?

Patients and their healthcare providers, such as doctors and nurses, can use survey scores to track the symptoms of illnesses like rheumatoid arthritis, or RA, over time. Tracking symptoms in this way can help them understand if a treatment is working well for a patient.

When researchers create and test these surveys, they want to be sure that patients' survey scores match how severe patients feel their symptoms are. Researchers also want to know what changes in survey results show that symptoms have changed so much that patients might want to change treatment.

In this study, the research team had patients with RA and providers read stories that described what patients felt like with higher and lower scores of two symptoms:

- Fatigue, or lack of energy
- Pain interference, or how much pain interferes with their lives

Patients and providers decided whether each story showed a mild, moderate, or severe level of symptoms. They also gave their views about how large a change in scores would need to be to show that pain or fatigue was getting better or worse.

What were the results?

The research team found that patients varied in their opinions about which stories showed mild, moderate, or severe symptoms. Providers varied less. When choosing which stories show mild, moderate, or severe symptoms, patients chose higher scores compared with providers.

Patients and providers also agreed on the amount of change in scores that showed

- Pain and fatigue were getting better
- Fatigue was getting worse

But compared with providers, patients felt that a larger change in scores would be needed to show that pain was getting worse.

Who was in the study?

The study included 11 patients receiving treatment for RA and eight RA providers. Of the patients, six were white, three were black, one was Asian, and one was mixed race. The average age was 55. On average, patients had RA for 20 years. Of the providers, all were white, and the average age was 49.

What did the research team do?

First, the research team created a series of written stories about patients with RA and their symptoms. Each story represented a specific level of symptoms and included four or five descriptions of symptoms at that level.

The research team sorted the stories from least to most severe symptoms and then presented these stories to patients and providers. Patients and providers categorized which stories showed mild, moderate, or severe symptoms.

Next, patients and providers viewed a story that showed a patient with severe symptoms, followed by stories showing less severe symptoms. They then decided how much the symptoms would have to improve to show that a treatment for RA was working. They also viewed a story of a patient with mild symptoms, followed by other stories showing more severe symptoms. Patients and providers said how much symptoms would have to worsen to show that a patient needed a change in treatment.

Patients with RA and patient advocates helped design the study, analyze data, and interpret results.

What were the limits of the study?

The study included patients who'd had RA for a long time. Results might differ for patients who were diagnosed with RA more recently.

Future research could include patients who have more recent diagnoses of RA to understand how these patients think about symptom severity.

How can people use the results?

Researchers who work on surveys to track RA symptoms can take into account this study's findings that patients and providers differed in the level of symptoms they thought were mild, moderate, or severe.

To learn more about this project, visit www.pcori.org/Bingham234.