PROJECT INFORMATION

June 2018

Adding Disease-Specific Concerns to Patient-Reported Outcome Measures

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What was the research about?

Patient-reported outcome measures are surveys that ask patients about their health or well-being. These surveys may include questions about sleep, depression, or pain. Many of the surveys now in use don't focus on a specific health problem.

The research team wanted to create and test a process for adapting patient-reported outcome measures for specific health problems. To test this process, the team developed surveys for two health problems, one for heart failure and one for knee arthritis.

What were the results?

The survey for heart failure had 86 questions in 18 categories. The new categories based on patient concerns were

- Health behaviors
- Illness burden
- Independence
- Life satisfaction
- Symptoms

The survey for knee arthritis had 76 questions in 14 categories. The new categories based on patient concerns were

- Independence

- Life satisfaction
- Symptoms

Testing the surveys with patients showed that

- Patients understood the questions
- Patients answered the questions similarly when they retaken the surveys a few days later
- The surveys accurately measured patients' thoughts and feelings about the health problems and changes over time

Who was in the study?

The study included 847 patients with heart failure. Of these patients, 66 percent were white, 23 percent were African American, and 11 percent were other races. The average patient age was 56, and 44 percent of patients were female.

The study also included 979 patients with knee arthritis. Of these patients, 77 percent were white, 14 percent were African American, and 9 percent were other races. The average patient age was 57, and 63 percent of patients were female.

What did the research team do?

First, the team conducted focus groups with patients living with heart failure or knee arthritis. These patients gave feedback on what concerns related to their specific condition were missing from the general surveys now in use. Then the team wrote questions to fill those gaps. Next, the team interviewed some of

these patients about whether the new questions were easy to understand and made changes based on patient recommendations. Finally, the team sent the surveys to patients across the United States. Three to seven days later, the team asked some of the patients to retake the surveys to see if they answered questions similarly. Other patients completed a follow-up survey after three months.

Patient advisors and doctors gave the research team feedback throughout the study.

What were the limits of the study?

The patients in the focus groups didn't represent all the racial or ethnic backgrounds of people in the

United States. People of other races or ethnicities may have different concerns. Future research could test the surveys with patients of different racial and ethnic backgrounds. Researchers could also create shorter versions of the surveys for use in health care.

How can people use the results?

Researchers can use the process developed in this study to create patient-reported outcome measures for other specific health problems.

To learn more about this project, visit www.pcori.org/Fisher109.