What was the research about?
Pulmonary fibrosis (PF) is a health problem that causes scarring in the lungs. Patients with PF have a hard time breathing, feel tired, and may have poor quality of life. Fifty percent of people with PF die within three years of diagnosis.

Many doctors prescribe treatment with oxygen for patients with PF. The equipment for oxygen treatment can be hard to handle and can make it hard for people to leave the house. Little research has been done on whether oxygen treatment helps patients with PF.

The research team wanted to learn how patients and caregivers felt about oxygen treatment, including its benefits and downsides. The team wanted to find out if oxygen treatment improves

- Breathing
- Coughing
- Quality of life
- Tiredness
- Physical activity

What were the results?
Patients with PF took surveys before and after oxygen treatment. From the surveys, the research team found that

- After one month of oxygen treatment, patients felt less tired than before. But there were no changes in breathing, quality of life, coughing, or physical activity.
- Nine to 12 months after oxygen treatment, patients had a harder time breathing and coughed more than they did 1 month after treatment. Patients said that coughing affected their quality of life and their health was worse than it had been one month after treatment.

The team also talked with 5 patients with PF who were on oxygen treatment and 20 caregivers of patients with PF who had been using oxygen for at least eight months. The research team found that

- Before treatment, all patients thought oxygen would help them feel better. After treatment, four patients said it improved symptoms. But patients felt frustrated with the oxygen equipment. They also felt judged by other people in public.
- Caregivers thought oxygen treatment helped patients feel better. But caregivers also said that they had to do more physical work at home. They also felt that the burden of oxygen treatment strained their relationships with patients.

Who was in the study?
The study included 43 patients with PF who received oxygen treatment. Ninety-three percent of patients were white.
What did the research team do?
The research team surveyed the patients by email three times: one week before starting oxygen treatment, one month after starting treatment, and 9 to 12 months after starting treatment. The team asked patients to wear a GPS and an activity monitor for seven days around the time the surveys were taken. The surveys asked patients about ease of breathing, quality of life, tiredness, and coughing. The team compared results from the surveys and monitors across the three timepoints.

The research team also interviewed 5 of the patients with PF and the 20 caregivers by phone. The team asked about the benefits and downsides of oxygen treatment. The team interviewed patients one week before starting oxygen treatment, one month after starting treatment, and 9 to 12 months after starting treatment. The team interviewed caregivers after patients had been on oxygen treatment for at least eight months.

What were the limits of the study?
The study had few patients. Results might be different if more patients took part in the study. Also, the research team didn’t know if patients used oxygen correctly or took other medicines. These actions could affect how well oxygen treatment helped patients.

Future research could compare patients with PF who receive oxygen treatment with those who don’t.

How can people use the results?
Patients with PF and their doctors can use the results of this study to talk about the potential benefits and downsides of oxygen treatment.

To learn more about this project, visit pcori.org/Swigris055.