Is it Possible to Collect Patient-Reported Data in Inpatient Rehabilitation Facilities?

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What was the research about?
Patients who have health problems that affect the central nervous system, such as stroke, Parkinson’s disease, or brain injury, often go to an inpatient rehabilitation facility, or IRF, to help them recover. IRFs measure the quality of care they provide in many ways. One way is to use data from patient-reported surveys. These surveys tell us about the care from the patient’s point of view.

The research team wanted to learn if it was possible to collect patient-reported data from patients with health problems that affect the central nervous system. Doctors may assume that these patients have trouble reading and answering survey questions. To find out, the research team developed and tested a 55-question survey.

What were the results?
The results of this study suggest that it’s possible to collect patient-reported data from patients who have health problems that affect the central nervous system.

- **Completing the first survey.** Most patients completed the survey in about 15 minutes. Also, 73 percent of patients completed the first survey without help. After the survey, most patients who did an interview said they would be willing to complete this survey as a regular part of their stay at the IRF.

- **Completing the follow-up survey.** One month after they left the IRF, 71 percent of patients completed the second survey. Before completing that survey, 58 percent of patients needed one or more reminder calls. Patients who had trouble doing daily activities were less likely to complete the second survey than patients who didn’t have such trouble. Compared with patients who went to another place for care, such as a nursing home, patients who went home were more likely to complete the second survey.

Who was in the study?
In total, 402 patients who had health problems that affect the central nervous system completed the first survey. The patients had health problems such as stroke, Parkinson’s disease, or brain injury. Two facilities in the Chicago area provided care to patients. Patients were 18 to 91 years old, with an average age of 58. In this study, 55 percent of patients were male, 74 percent were white, 18 percent were African American, and 8 percent were other races.

What did the research team do?
The research team held focus groups with 30 patients, 12 caregivers, and 50 doctors, therapists, and nurses. These focus groups helped to identify topics to include in the survey. To ask patients about those topics, the team used questions from other surveys.

Patients took the surveys using a tablet computer or pen and paper up to seven days before leaving the IRF. Patients could ask the research team for help taking the survey. A month after leaving, patients completed the survey again. The team called patients who hadn’t responded to remind them to do the second survey.
The team also used patients’ medical records to get information on their ability to do daily activities.

An advisory group of patients, clinicians, and others guided the research team.

**What were the limits of the study?**
The study included patients from two IRFs in one urban area. Results may be different for patients in other locations or with other health problems.

Future research could test how well the survey works in different locations or with patients with other health problems. Researchers could also study ways to make it easier for patients to take the survey.

**How can people use the results?**
IRFs could consider using surveys to help understand the views of patients who have central nervous system problems on the quality of their care.

*To learn more about this project, visit pcori.org/Heinemann073.*