

Can Personalized Encouragement Help People with Sickle Cell Disease Take Hydroxyurea Therapy Regularly?

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What was the research about?

Sickle cell disease, or SCD, causes red blood cells to change shape and block blood flow, causing pain or damage to the body. Hydroxyurea, or HU, is a treatment that helps keep red blood cells healthy. But many patients find it hard to take HU every day. Some worry that it won't help or will cause side effects.

In this study, the research team looked at whether encouraging adults and children with SCD helped them take HU every day. Patients and parents earned \$1 every day that they uploaded a video for the research team of themselves taking an HU pill. The team sent reminders daily and followed up if patients had not uploaded a video three times in the past month. They encouraged patients by phone, text, or in person. Patients received reminders for one year.

The research team compared patients who got encouragement with those who received usual care. In usual care, adults with SCD and children with SCD and their parents received reminders about clinic visits and help paying for transportation.

What were the results?

Patients who got encouragement and patients who received usual care didn't differ in

- How often they said they took HU
- The proportion of days they had HU pills available from their prescription each month

After six months, patients who received encouragement to take HU had more red blood cells that were healthy than patients who received usual care. But by one year, there was no difference. Compared with children who got usual care, children who got encouragement had less pain and anxiety.

Patients receiving encouragement uploaded videos an average of 34 percent of days. Patients said the video system and reminders worked well, but they sometimes didn't want to record videos.

Who was in the study?

The study included 79 adults with SCD and 85 children with SCD and their parents. Among adults, 96 percent were black; 4 percent identified as Latino. The adult average age was 24, and 55 percent of adults were men. Among children, 96 percent were black; 2 percent identified as Latino. The average age was 13, and 45 percent of children were boys.

All patients received treatment at one of three hospitals and had a prescription for HU for at least six months before the study.

What did the research team do?

The research team assigned patients by chance to get usual care or encouragement to take HU.

Using pharmacy records, the research team tracked how often patients filled their HU prescriptions and had HU available. Patients or parents completed surveys at the start of the study and 6 and 12 months

later. The surveys asked how often patients took HU, and about pain, fatigue, and sleep. The team also looked at hospital records to see how often patients went to the hospital with pain or other problems caused by SCD. Finally, the team interviewed some patients and parents to find out how they felt about uploading the videos.

Youth and adults with SCD, parents of youth with SCD, and SCD community groups helped plan and conduct the study.

What were the limits of the study?

The research team couldn't get pharmacy records for all patients, and 26 percent of patients stopped taking

part in the study. Some patients got HU refills in the hospital. As a result, the patients might have had HU available more, or less, often than the research team knew.

Future research could compare other ways to help people with SCD take HU regularly.

How can people use the results?

Clinics that care for people with SCD can use these results when considering ways to help people take daily treatment.

To learn more about this project, visit www.pcori.org/Krishnamurti200.