

Researchers uncover obstacles that prevent people with RHD in Uganda from receiving life-saving penicillin

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Penicillin has nearly eradicated rheumatic heart disease (RHD) in the United States. But 15 million people still suffer with the disease worldwide, and 1.4 million die each year, according to World Heart Federation.

Access to [penicillin](#) can prevent deaths from RHD. Researchers from Case Western Reserve University, Makerere University and the Uganda Heart Institute at Mulago Hospital, a national referral hospital in Kampala, collaborated to learn about those obstacles to receive the medication and find ways to overcome them.

The researchers heard from some Ugandans that paying for an injection meant that other family members might go without food. Others didn't want to pay because they believed the person with [heart](#) disease would die anyway.

Their findings were reported in the *Global Heart* article, "A Qualitative Examination of Secondary Prophylaxis in Rheumatic Heart Disease."

RHD, which develops as an inappropriate immune system response to strep infection, is the most common cause of [heart disease](#) for Ugandans between age 15 and 49. The body develops an autoimmune reaction that causes an inflammation and destruction of the heart valves. Penicillin controls the inflammation by preventing strep infection.

Reaching people with information about the penicillin injections hasn't been easy, said Allison Webel, assistant professor of nursing at Case Western Reserve's Frances Payne Bolton School of Nursing and one of the researchers.

Webel collaborated with Case Western Reserve researchers Daniel Huck (School of Medicine), Scott Frank (Department of Epidemiology and Biostatistics and Family Medicine, School of Medicine), and Chris Longenecker (Division of Cardiology, School of Medicine) and Ugandan collaborators Haddy Nalubwama (School of Public Health, Makerere University) and Emmy Okello (Uganda Heart Institute, Mulago Hospital).

The researchers organized five focus groups, with six to eight participants each, and asked questions about their experiences in accessing and receiving monthly penicillin injections.

The biggest reasons people gave for not getting injections were money and transportation, followed by pain, fear of the injection and poor knowledge about the consequences of a missed treatment.

While many families were supportive, the individuals felt a stigma for having the health condition and being a burden to their families. Webel said some people with RHD were uncomfortable having penicillin injections that might be mistaken for treatments for syphilis by the health-care workers. Also, system-wide barriers prevented easy access to treatments: lack of clinics in their local communities, unskilled health-care workers giving injections that were painful, a shortage of penicillin and long waits at the clinics.

The researchers found that while there were significant barriers, there were also important factors that helped them get injections. For example, patients reported that their symptoms worsened when they

missed their monthly injections, which helped keep them motivated to go. Injection reminders and personal motivation also kept them on schedule.

Provided by Case Western Reserve University

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