Closing the Hepatitis C Treatment Gap

Here's why so few Americans have been cured of hep C—and how we can do better.

August 1, 2024 By Tim Murphy

Rachel Melson, DNP, FNP-C, has a tale to tell. The nurse practitioner is the director of the outreach clinic at Swope Health in Kansas City, Missouri. Her tale provides insight into why, according to the Centers for Disease Control and Prevention, in 2022 only one in three people diagnosed with hepatitis C virus (HCV) received treatment within 12 months of their diagnosis. And this, even though for the past decade, a new era of hep C treatment not only cures the vast majority of people but is also almost completely free of side effects.

Swope Health treats many people who are currently or formerly homeless or have experienced imprisonment and drug use. Recently, says Melson, a nurse on her staff spent 35 minutes on the phone with an insurance company trying to get prior authorization to cover someone's HCV treatment. Insurers often set high barriers for the treatment, which costs tens of thousands of dollars per course.

Recalls Melson, "They were asking my staffer questions like 'Is this patient young?' 'Have they ever had treatment before?' 'Do they have cirrhosis [liver scarring indicating advanced hep C]?' 'Are they in a drug treatment facility?'"

All these questions, she says, were meant to find reasons not to cover the treatment, such as that the person was too old, that their hep C was not far enough along, that they had tried and failed previous treatments or that they used drugs and thus were a poor risk for treatment, which requires taking a daily pill for eight to 12 weeks. "It's none of their business if they use or used drugs," says Melson. "All that matters is that I think they're a good candidate for treatment."

But, she says, insurers often put providers through hours of such hoop jumping over the course of weeks or months because they're hoping that people will give up at some point in the process. "We're not willing to do that."

What's Driving the Treatment Gap?

Melson's work speaks to an ongoing frustration among people living with or aiming to eliminate the slow-moving but potentially deadly hep C virus, an often chronic blood-borne infection most commonly spread through sharing injection-drug paraphernalia but also through unsafe medical practices and, sometimes, sexual activity.

The frustration is that although between 2.5 million and 3 million Americans are living with HCV and although treatments that have been available for almost a decade now can quickly and easily cure the virus, far too few people living with the virus are getting them, especially in the crucial window of 12 months within diagnosis. Many of them often fall through the cracks of the health care system after that.

Rachel Nelson, DNP, FNP-CCourtesy of Rachel Nelson

Why? A major factor, as Melson points out, is that insurers—usually private plans rather than public ones, like Medicare or Medicaid, which largely do cover hep C treatment—raise hurdles to

coverage because the treatments are still so expensive.

“A lot of providers say that they don’t have time to spend hours faxing back and forth with insurers arguing why a patient deserves to be treated,” says Daniel Raymond, policy director for National Virus Hepatitis Roundtable, a national network of patients, providers, advocates and community leaders working to expand access to HCV treatment. “They say to themselves, ‘I’m a primary provider at a small community health center, so I guess I can’t treat them.’ And many patients hear that and think, Oh, well, I guess treatment just isn’t a reality for me.”

But insurance barriers are not the only reason for the treatment gap. Another is that far too few such frontline primary providers, even those who do hep C testing, think they can prescribe and oversee the treatment themselves despite the fact that, according to Melson, “It’s easier than managing someone’s diabetes.”

Or worse, because there hasn’t been a sufficient awareness and training push on a federal, state or community level, providers might not even know that simple, highly curative treatment is available. They also may be unaware that the American Association for the Study of Liver Disease and the Infectious Disease Society of America have issued easy-to-follow guidance for providers in the form of their HCV Guidelines.

“Individuals are often diagnosed in health care settings that don’t provide treatment,” says Risha Irvin, MD, MPH, a hep C treatment access expert at Johns Hopkins School of Medicine in Baltimore. “When they’re referred to a second site for care, we often lose them.”

Furthermore, according to Melson, localities or states often don’t mandate that providers report hep C cases or rates of treatment to health departments—a double documentation required for other infectious diseases, such as syphilis.

Another explanation for the treatment gap is that people with hep C are disproportionately represented in prisons, where people are often not covered by the state Medicaid program but by a private correctional health company looking to spend as little money as possible on care.

Finally, some people have no health insurance at all and only have the option of seeking treatment directly from a drugmaker’s charitable patient assistance program, for which paperwork, screening and wait times can be burdensome.

And yet none of these reasons trump the fact that, according to Irvin, “Hepatitis C treatment is extremely effective and very easy to take, so we must do more in this country to make sure that everyone has access to hepatitis C testing, care and treatment.”

What to Do About It?

Experts like Melson, Irvin and Raymond all say the barriers between hep C diagnosis and treatment in the United States are too systemic to put the burden of closing the gap solely on patients or providers—or even states.

They say Congress must pass initiatives like the one the Biden administration has included in recent budget proposals, which would earmark $5 billion for a federal program that would establish a “subscription” contract (sometimes called a “Netflix model”) whereby the government would pay hep C drugmakers a lump sum in return for treatment for everyone who wants it.

The plan, now reflected in a bill brought by Senator Bill Cassidy (R–La.) and Senator Chris Van Hollen (D–Md.), would also raise public awareness about the disease, train providers to prescribe and oversee treatment and promote treatment at community health centers, prisons and drug treatment centers. Advocates say such a program could put the United States on track to eliminate its HCV epidemic, a feat countries such as Egypt, Canada and Australia have achieved.

The subscription model has already had modest success in some states, including Louisiana, which has treated more than 16,000 people since launching its own model in 2019. (However, treatment rates have dropped dramatically since the emergence of COVID-19 as a pandemic).

Lacking federal help thus far, other states have devised ways of getting more people on treatment. In New Mexico, The New York Times reported recently, the ECHO program connects primary providers with specialists in sparsely populated areas. Also in the state, lawmakers in 2020 dedicated $22 million specifically to treating prisoners with hep C. Additionally, ECHO and the state corrections department collaborated to set up a program wherein prisoners talk to other prisoners to overcome personal hesitancy about starting treatment. All these efforts have gotten more than 10,000 people in the state on treatment.

Experts are also excited about a new hep C test that the Food and Drug Administration approved in June. The test, which looks directly for HCV instead of antibodies, was designed with prisons, drug treatment centers, needle exchange programs, emergency rooms and urgent care centers in mind. The hope is that such places could, in the event of positive test results, start people on treatment that very day, rather than have to refer them elsewhere and risk losing them to follow-up.

This test-to-treat approach has become increasingly common with HIV. Many states and localities have established programs to ensure that people who test positive for HIV are connected to treatment that very day—sometimes even walking or driving them from the testing site to the treatment site.

Yet unlike with HIV—which, absent a cure, requires lifetime treatment to suppress—hep C is almost always cured after eight to 12 weeks of treatment. If most people with hep C could get on treatment, “then maybe the market for these drugs, as expensive as they are, will disappear in 15 years because most people are cured,” says Raymond.

Success in Missouri

A federal response is likely needed to truly end the U.S. hep C epidemic, say advocates, but, as Louisiana and New Mexico demonstrate, important gains can be made at the state or local level.

Missouri is another example. According to Melson, in the first year after her state's Medicaid program, MO HealthNet, eliminated the need for prior authorization for those seeking a hep C cure, the rate of people on treatment went up 23%.

"That's 6,000 to 7,000 people," she says. "Now, if my patients get their diagnosis and know they need to start treatment, they can go to our pharmacy and pick up their meds and start that day. Before, we'd wait up to six months. That's life-changing."

Irvin, Raymond and Melson all stressed how rare it is to find an easy-to-take cure for a disease that affects millions and still leads to death for some 15,000 people a year when untreated. Indeed, the advent of new therapies in the past decade have been nothing short of a miracle.

"We don't get to say the word cure a lot in medicine, but I get to do that every day with hep C," says Melson. Recently, she recalls, a patient who was living under a bridge and was experiencing opioid and meth addiction, asked her whether she could help get rid of his hep C. "I had to check my biases [about whether he was fit for treatment] because he wanted it," she says. And so he began treatment.

"He came to every single appointment and is now not only hep C–free, he's in a recovery program."

That, says Melson, is why she's so passionate about what's needed, at the macro level, to close the gap between hep C diagnoses and treatment nationwide. "I could cry talking about how patients who've been cured tell me they never knew they could feel so good. The treatment we have today is truly life-changing. As a health system, we really need to give people that chance."

To read "How to Get Hepatitis C Treatment," click here.
