The Washington Post
Democracy Dies in Darkness

For seniors, medical care can be a slog, but there are ways to rein it in

Older patients often churn through appointment after appointment. Doctors or social workers may be able to design an easier care plan.

By Judith Graham
March 24, 2024 at 7:00 a.m. EDT

Susanne Gilliam, 67, was walking down her driveway to get the mail in January when she slipped and fell on a patch of black ice. Pain shot through her left knee and ankle. After summoning her husband on her phone, she made it back to the house with difficulty.

And then began a runaround so many people face when they interact with America's uncoordinated health-care system.

Gilliam's orthopedic surgeon, who managed previous difficulties with her left knee, saw her that afternoon but told her: "I don't do ankles." He referred her to an ankle specialist who ordered a new set of X-rays and an MRI. For convenience's sake, Gilliam asked to get the scans at a hospital near her home in Sudbury, Mass. But the hospital didn't have the doctor's order when she called for an appointment. It came through only after several more calls. Meanwhile, scheduling physical therapist visits for her knee and ankle several times a week took hours of her time.

"The burden of arranging everything I need — it's huge," Gilliam told me. "It leaves you with such a sense of mental and physical exhaustion."

The toll the U.S. health-care system exacts is, in some respects, the price of extraordinary progress in medicine. But it's also evidence of the poor fit between older adults' capacities and the health-care system's demands.

How specialty medicine complicates care

"The good news is, we know so much more and can do so much more for people with various conditions," said Thomas H. Lee, chief medical officer at Press Ganey, a consulting firm that tracks patients' experiences with care. "The bad news is the system has gotten overwhelmingly complex."

That complexity is compounded by the proliferation of guidelines for separate medical conditions, financial incentives that reward more medical care and specialization among clinicians, said Ishani Ganguli, an associate professor of medicine at Harvard Medical School.

“It’s not uncommon for older patients to have three or more heart specialists who schedule regular appointments and tests,” she said. If someone has multiple medical problems — say, heart disease, diabetes and glaucoma — their health-care interactions multiply.

Ganguli is the author of a new study showing that Medicare patients spend about three weeks a year having medical tests, visiting doctors, undergoing treatments or medical procedures, seeking care in emergency rooms, or spending time in the hospital or rehabilitation facilities. (The data is from 2019, before the covid-19 pandemic disrupted care patterns. If any services were received, that counted as a day of health-care contact.)

That study found that slightly more than 1 in 10 people 65 and over, including those recovering from or managing serious illnesses, spent a much larger portion of their lives getting care — at least 50 days a year.

“Some of this may be very beneficial and valuable for people, and some of it may be less essential,” Ganguli said. “We don’t talk enough about what we’re asking older adults to do and whether that’s realistic.”

A ‘treatment burden’

Victor Montori, a professor of medicine at the Mayo Clinic in Rochester, Minn., has sounded an alarm for years about the “treatment burden” that patients experience.

In addition to time spent receiving health care, this burden includes arranging appointments, finding transportation to medical visits, getting and taking medications, communicating with insurance companies, paying medical bills and following recommendations such as dietary changes.

Four years ago — in a paper titled “Is My Patient Overwhelmed?” — Montori and several colleagues found that 40 percent of patients with chronic conditions such as asthma, diabetes and neurologic disorders “considered their treatment burden unsustainable.”

When this happens, people stop following medical advice and report poorer quality of life, the researchers found. Especially vulnerable are older adults with multiple medical conditions and low levels of education who are economically insecure and socially isolated.

Older patients’ difficulties are compounded by medical practices’ increased use of digital phone systems and electronic patient portals — both are hard for many seniors to navigate — and the time pressures on physicians. “It’s harder and harder for patients to gain access to clinicians who can problem-solve with them and answer questions,” Montori said.

Meanwhile, clinicians rarely ask patients about their capacity to perform the work they're being asked to do. "We often have little sense of the complexity of our patients' lives, and even less insight into how the treatments we provide (to reach goal-directed guidelines) fit within the web of our patients' daily experiences," several physicians wrote in a 2022 paper on reducing treatment burden.

Consider what Jean Hartnett, 53, of Omaha and her eight siblings went through after their 88-year-old mother — who also cared for their ailing father — had a stroke in February 2021.

In the year after the stroke, both of Hartnett's parents — fiercely independent Nebraska farmers — suffered setbacks, and medical crises became common. When a physician changed her mom's or dad's care plan, new medications, supplies and medical equipment had to be procured, and new rounds of occupational, physical and speech therapy arranged.

Neither parent could be left alone when the other needed medical attention.

"It wasn't unusual for me to be bringing one parent home from the hospital or doctor's visit and passing the ambulance or a family member on the highway taking the other one in," Hartnett explained.

Hartnett moved in with her parents during the last six weeks of her father's life, after doctors decided he was too weak to undertake dialysis. He passed away in March 2022. Her mother died months later in July.

What to ask your doctors

So, what can older adults and family caregivers do to ease health-care burdens?

To start, be candid with your doctor if you think a treatment plan isn't feasible and explain why you feel that way, said Elizabeth Rogers, an assistant professor of internal medicine at the University of Minnesota Medical School. Ask which interventions are most important in terms of keeping you healthy, and which might be expendable.

Doctors can adjust your treatment plan, discontinue medications that aren't yielding significant benefits, and arrange virtual visits if you can manage the technological requirements. (Many older adults can't.)

Ask whether a social worker or a patient navigator can help you arrange multiple appointments and tests on the same day to minimize the burden of going to and from medical centers. These professionals may also be able to connect you with transportation and other services. (Most medical centers have staff of this kind, but physician practices do not.)

If you don't understand how to do what your doctor wants you to do, ask them: What will this involve on my part? How much time will this take? What kind of resources will I need to do this? And ask for written materials, such as self-management plans for asthma or diabetes.

“I would ask a clinician, ‘If I chose this treatment option, what does that mean not only for my cancer or heart disease but also for the time I’ll spend getting care?’” said Ganguli of Harvard. “If they don’t have an answer, ask if they can come up with an estimate.”

KFF Health News, formerly known as Kaiser Health News or KHN, is a national newsroom that produces in-depth journalism about health issues and is one of the core operating programs at KFF.