

Fixing the 5 Percent

“Super-users” with complex medical needs make up a small fraction of U.S. patients, but they account for half of the nation’s overall health-care spending. Now, innovative efforts are providing better care at lower costs.



Elaina Natario / Katie Martin / The Atlantic

KAREN WEINTRAUB AND RACHEL ZIMMERMAN

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AN OVERSIZED POSTER of the *Seinfeld* character Kramer watches over Phil Rizzuto’s daily routine. When Rizzuto, named for the famous New York Yankees shortstop, swallows his 6 a.m. pills, Kramer is looming over him, looking quizzical. Same for the 9 a.m., noon, 6 p.m., and midnight doses, each fistful of pills placed in a carefully labeled Dixie cup. “I live on medication,” he says.

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Rizzuto's daily life in Haverhill, Massachusetts, is a litany of challenges: His aides have to hoist his paralyzed legs from his bed to his motorized wheelchair and back again; keep the bag that collects his urine clean; tend to the gaping wound on his backside, which developed when he was left to lie still in bed too long; and help him avoid the panic that could claim anyone in his situation—that last one is particularly difficult since Rizzuto's obsessive-compulsive disorder drives him to want to do everything for himself.

After more than a year of emergency and rehabilitative care following a devastating car accident, Rizzuto moved into a YMCA-run housing complex in this gritty New England town. But he still endured constant medical emergencies. "I was back and forth and in and out of the hospitals so much, it was like I didn't know I had an apartment here," the 56-year-old says, sitting in his small studio. His open wound kept getting infected; his diaphragm, weakened by his injury and his inability to quit smoking, left him gasping for breath; his urine-collection bag slipped out; his demons kept getting the better of him. The government eventually covered the cost of his care, but the relentless need for medical attention was exhausting and demeaning.

Then he opted into a Massachusetts health-care program called [One Care](#) that focuses on people with complex medical needs who are on Medicare. One Care provides 71 hours of aide support a week, a twice-weekly visit from a massage therapist, twice-monthly psychiatric care, a wheelchair support group, and a nurse practitioner who oversees and coordinates Rizzuto's care. If he struggles between

visits—or just wants to talk—she’s available by phone, even on weekends and after hours. Now, his life has a routine and a discipline that keeps emergencies at bay. “The difference it’s made ...” he says, unable to fully express his gratitude. He estimates his hospital visits have dropped at least 75 percent since the One Care program took charge of his health. “I would hate like hell to not have them.”

The program that has helped Rizzuto is part of a nationwide movement to improve care for people struggling with very complicated medical needs—so-called *super-users*—the 5 percent of patients who account for about half of the [country’s health-care spending](#). (Surgeon and *New Yorker* writer Atul Gawande outlined the problem and one solution in a definitive 2011 [piece](#) about the [Camden Coalition of Healthcare Providers](#).) Some of these super-user programs say they provide cost savings of as much as 20 to 40 percent after a few years, as well as provide the kind of advantages offered to Rizzuto: fewer stressful hospital visits, better mental and physical health, and the satisfaction of being treated like a person instead of a package of problems. The program accomplishes this by shifting the focus of medical care. Instead of responding to complications, the care team tries to prevent them. “You can’t even get to the medical issue until you’ve figured out: Do they have a place to sleep, do they have housing they’re not going to lose, do they have food in their refrigerator, do they have a refrigerator?” says Christopher Palmieri, the president and CEO of the nonprofit [Commonwealth Care Alliance](#), which manages 80 percent of One Care patients, including Rizzuto.

Despite its successes, this care movement, which doesn’t go by any catchy name—one doctor gave it the clunky title “high-impact, relationship-based primary care”—is scattered among a handful of states and is advancing only very slowly across the country. There is general agreement that these programs must address a range of social and pragmatic needs, like transportation, housing, nutrition, isolation, emotional well-being, and medical problems. But the details of each program are different. “Everyone’s trying their home brew,” says Dr. Harlan Krumholz, a cardiologist and health-care researcher at Yale University and Yale-New Haven Hospital.

The one thing all of the super-user care programs have in common is a mantra that could have come from Cosmo Kramer himself: Stay the hell out of the hospital. Hospitals, these folks argue, often make sick people sicker. They're sources of infection to vulnerable patients. They're disorienting. They run costly tests and look for issues that are better left alone. Super-users, says Krumholz, "represent a failure of the system."

MEDICAL CARE IS DANGEROUS," says Dr. Rushika Fernandopulle, the co-founder and CEO of [Iora Health](#), a leading practitioner of a more holistic approach to health. Fernandopulle says a big part of his company's business model involves fighting to keep people out of the hospital—not just because it's expensive, but because the care they will get puts them at higher risk for other problems. Medicare patients saw roughly a 40 percent drop in hospitalizations after Iora took over their care, Fernandopulle says.

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For Fernandopulle, one patient in particular illustrates this phenomenon of snowballing medical care. That patient was an 80-year-old woman, fairly healthy but with hypertension and arthritis, who one day saw red in the toilet after urinating. She told her primary-care doctor, who sent her to a urologist; the urologist worried it might be cancer and ordered a catheter inserted. Before the procedure, a nurse asked the octogenarian if she ever felt weak or dizzy. (Of course she did—think about it.) When the woman said yes, a heart monitor was ordered: It showed a dip in her overnight heart rate. A cardiologist then scheduled the woman for a pacemaker.

“This is what I mean by the vortex,” Fernandopulle says, noting that inserting a pacemaker would be risky and provide no clear benefit. The woman's condition might be explained in a much more low-tech way: a beet salad, for example, could be the culprit behind the red pee, and a prescribed medication might trigger the

heart irregularity. “I called the cardiologist and politely declined the pacemaker for this patient,” Fernandopulle says. Part of the problem is that, while each doctor gets paid for each procedure he or she performs, usually no one gets paid for taking a step back and using common sense to think about what would genuinely help the patient.

“The health-care system as a whole is out of balance,” says Dr. Donald Berwick, the former head of the Centers for Medicare and Medicaid Services under President Obama. “We put far more into hospital care than we do keeping people from having to be in the hospital.” Hospital stays cost more than anything else in the health-care system; an average inpatient admission runs nearly \$2,000 a day, and an intensive-care stay can easily cost \$7,000 a day. In 2012, a typical hospital stay topped \$10,000, according to the federal [Agency for Healthcare Research and Quality](#). Caring for an Iora patient, on the other hand, typically costs about \$3 a day and can reduce hospitalizations by 40 to 50 percent, Fernandopulle says. All of the physicians and advocates we interviewed who support this type of high-needs care are quick to note that their goal isn’t to deprive people of medical care. If someone doesn’t get needed heart surgery, they will end up in worse shape; no one will benefit. Their aim is appropriate, Goldilocks care: not too much, not too little.

Cory Sevin, a senior director with the [Institute for Healthcare Improvement](#), a policy center in Cambridge, Massachusetts, says providing more appropriate treatment is also better for the caregiver. Kim Tremblay, a nurse practitioner with the Commonwealth Care Alliance, says that while the work is intense, she has enjoyed managing Rizzuto’s health team for three years and watching him slowly improve. “We give a lot to these patients,” she says. “We get a lot back.”

The model hinges on establishing strong, trusting relationships—but that doesn’t always come easily. “Some patients jump on board; sometimes it takes six months to establish a connection,” Tremblay says, recalling one patient who refused to talk to her for nearly five months before finally accepting help. She has become profoundly invested in her patients’ care. “Every time we send someone to the

hospital, it's stressful," for both the patients and caregivers, Tremblay says. "We send someone in [and] we kind of shudder, *Are they going to come out better?*"

ONE BIG CHALLENGE to providing care for patients with complex needs is finding them. Commonwealth Care, for instance, has struggled to identify people who will benefit from its program. Any Massachusetts resident who receives both Medicare and Medicaid is eligible to join One Care. Commonwealth Care Alliance, which serves most of these patients, had to hire extra staff to track down potential clients. When Commonwealth Care started four years ago, 43 percent of these potential clients were considered "unreachable," for reasons like having an unknown address. Today, that rate has shrunk to 32 percent.

Why is it so hard to track down needy patients? Some people are so isolated and disengaged that they're largely invisible. Others patients are expensive and challenging today but might soon recover. And still others are doing fine now but might have a setback that throws them off balance for months. In fact, 60 to 80 percent of patients who are super-users now won't be a year from now, Sevin says, and different people will be.

There are also people who will be perennially expensive—because their disease requires a costly drug, for instance. And there are those who will be expensive for a short time—say, for the few months after an organ transplant. There's no point in wasting time trying to bring either group's medical expenses down.

Fernandopulle says the only effective way to identify people at risk for super use is to ask them two questions: "How do you think your health is?" and "How confident are you in managing your health?"

"If they answer, 'Poor, poor,' they are at huge risk," he says.

ON A RECENT SWELTERING day, Rizzuto met his wheelchair support group at a small zoo in suburban Boston. Keeping cool in the above-90-degree heat wasn't easy for Rizzuto. Paralysis robs people of their ability to regulate body temperature. One of Rizzuto's aides, Bill Regan, came prepared with

water, ice packs, sandwiches, and a spray bottle that he frequently spritzed on Rizzuto's face and legs.

Rizzuto says these interactions with other people in wheelchairs help lift his mood, though on this trip he seemed more focused on watching a brown bear, several snakes, and tiny, hyperactive cotton-topped tamarins. He never could have made it around the zoo without a motorized wheelchair—though it took Rizzuto a year to convince the state to buy it for him. One of the first things Commonwealth Care Alliance does when signing on a new One Care client is to assess the person's equipment needs, Tremblay says.

One Care is a partnership between Massachusetts's Medicaid agency and the federal Centers for Medicare and Medicaid, and it focuses solely on patients ages 21 to 64 with multiple, complex medical and behavioral issues. (An older program, Senior Care Options, takes the same approach for patients over 65.) Most of Commonwealth Care's 13,500 One Care [clients](#) earn less than \$20,000 a year; some are homeless; the majority of them have a serious mental illness or substance-use disorder, as well as multiple other chronic health conditions.

This high-touch care approach is beginning to save money, says Palmieri. A [report](#) last year by the [Commonwealth Fund](#) found that among 4,500 members of One Care, patients enrolled for 12 continuous months had 7.5 percent fewer hospital admissions and 6.4 percent fewer emergency-room visits. For those enrolled in the program for at least 18 months, hospital admissions dropped 20 percent, the [study](#) found.

“Most health-care systems are still operating in an environment where reducing emergency-department and inpatient use hurts the bottom line.”

Although each model of high-touch care is different, the basics are the same: focusing on prevention, ensuring basic needs are met, reducing unnecessary treatment, and building relationships with patients. At Stanford University, for

example, one young man with severe anxiety and obsessive-compulsive disorder required constant reassurance (in addition to his multiple medications) from doctors and emergency departments. In a traditional care system, emergency-room staff might roll their eyes and quickly send him on his way. Instead, Dr. Alan Glaseroff, the co-founder of Stanford's [Coordinated Care](#) program to treat high-needs university employees and their family members, gave the 19-year-old his phone number. At first, whenever his anxiety or OCD took control, the young man called Glaseroff or another care coordinator as many as seven times a day.

But slowly, over the course of three years, the man learned to think before he called. If he saw spots in his eyes, he'd wait for a few minutes to see if they went away. He was taught to use mindfulness techniques, and if the symptom persisted, he would run through a checklist to see if it was really something to be concerned about. He ended up calling the clinic every two to three weeks, rather than multiple times a day, and learned not to lean on the clinic's staff for minor issues. "Now, he hardly needs us," Glaseroff says.

Creating viable long-term plans like this means far fewer emergencies. In fact, in its first three years, the Stanford program cut emergency-room visits for its 253 patients by 59 percent, hospital admissions by 29 percent, and total cost per patient by 13 percent, says Glaseroff, who teaches this model of care in two-day workshops across the country. According to the study, the Stanford practice saved the university \$1.8 million and now has nearly twice as many patients.

The secret to the cost-savings, Glaseroff says, is for patients to use hospitals and doctors only when absolutely necessary and to rely for most of their care on empathetic—and relatively inexpensive—medical assistants, who check in with each patient about once a week. In the past four years, in an industry known for its high burnout and turnover, not one of his practice's care coordinators has left, Glaseroff says. "They're not allowed to diagnose and treat, but they're really good at the people stuff," he says. "The core is being given responsibility for people, not for tasks."

Patients in the program have responsibilities as well as rights, Glaseroff says. They are expected to show up for their medical appointments and to come on time out of fairness to others. They're told to call the clinic if they can before heading to the emergency room and then wait a few minutes for a call back, Glaseroff says. They are expected to do their part to engage with their care coordinator, even if the medical system hasn't always treated them well in the past. "It's patient self-management—what people do within their chronic illness 365 days a year—that matters the most," he says.

FOR THE HIGH-TOUCH model to work financially, large numbers of patients have to stick around long enough to recoup the upfront investment in their care. Today, there are only a few pools of people stable enough to sustain this model: people who work for major employers, like Stanford University, and those insured by the federal government.

Iora provides health care to workers at large, stable employers like the Dartmouth College Employees, the New England Carpenters Benefits Fund, a union trust, and members of Medicare Advantage plans, like Humana and Tufts Health Plan. This gives them a big group of customers with high needs and the corporate muscle to avoid being pushed around by hospitals that don't want to lose patients, Fernandopulle says.

If he loses customers to other insurance carriers in the first year or two, he'll have all the upfront costs and none of the savings. A five-year time horizon allows Iora to recoup its upfront investment and get ahead of problems—controlling diabetes before it leads to a heart attack, for instance, says Fernandopulle, whose company oversees care for about 20,000 patients in eight states.

Iora and another company with a similar approach, Landmark Health, also provide care to people on Medicare Advantage—a government-funded, privately run program. About a [third](#) of people on Medicare now belong to Medicare Advantage programs, which were created by the Affordable Care Act. The Trump administration and Republicans have proposed huge cuts to Medicaid over the next decade. It's unclear, however, whether such cuts would paralyze efforts at

innovation or provide more urgency to reduce health-care spending. “It is a bipartisan issue that the current costs of health care are unsustainable,” Yale’s Krumholz says, “whether driven by empathy for those who are disadvantaged and suffering or by economic imperative.”

But there are also built-in disincentives to this kind of high-touch care. One of the most obvious is that hospitals make money on patients. If they succeed in decreasing readmissions, they also limit their own earnings. Despite efforts to replace fee-for-service care with so-called global payments, “the fact is that currently most health-care systems are still operating in an environment where reducing emergency-department and inpatient use hurts their bottom line,” says Dr. Seth Berkowitz, a primary-care doctor at Massachusetts General Hospital who studies how addressing patients’ social needs improves their health and lowers costs.

Moreover, the model is challenging to scale, because all health care is local. State laws, hospital structures, and needs differ from place to place. What works in Florida doesn’t work in Washington state, and vice versa, notes Fernandopulle, whose frequent-flyer miles attest to his attempts to learn about new markets.

Slowly, though, these scattershot efforts may be coalescing into a larger movement. Fernandopulle says it’s getting easier for companies like his to raise money in the private sector. Other factors seem to be coming together, too. Technology allows health-care companies to more easily identify people at risk of becoming super-users, track their progress, and standardize some of their treatments. There’s broad public consensus, gaining momentum in recent years, that health-care costs need to come down, says Dr. J. Michael McGinnis, the executive officer of the National Academy of Medicine, an advisory body formerly known as the Institute of Medicine. “Now the issue is not whether; it’s how.”

Rizzuto is lucky that he was treated for his 2012 car accident in Massachusetts. If he’d had to recover in neighboring New Hampshire, where someone else’s road rage landed him in a ditch and then in a month-long coma, he’d probably still be making near-weekly trips to the emergency room. The crash left his spine broken in

two places and exacerbated his post-traumatic-stress disorder and a concussion that still makes him feel like “I have some scramblage with my brain.”

The paralysis has left him with limited control of the outer three fingers on each hand—restricting his ability to play his beloved guitar—and he can’t breathe deeply enough or with enough control to sing anymore. His core muscles are weak, too, Rizzuto says, explaining why his torso wobbles uncontrollably as he speaks. “I’m so close to being a quadriplegic, it’s crazy,” he says. Rizzuto lifts his t-shirt to reveal small, circular burn marks dotting his chest. He knows he needs to quit smoking—and will have to before his upcoming surgery to close the wound on his back, but it has been a struggle. Rizzuto says he often spaces out with a cigarette between his fingers and doesn’t notice he’s doing himself damage until it’s too late. “There’s just so much to get used to,” he says.

But he has also come to terms with his current life. Despite everything that has happened, he still has his adult twin sons, a daughter, a granddaughter, a safe place to live, and caregivers who really care. And so he goes on living the best life he can. He even hopes to start talking to high-school kids about his experiences. “I’m very fortunate,” Rizzuto says. “I don’t know why. Maybe it’s because I’m supposed to do something with this stupid accident that happened to me.”

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ABOUT THE AUTHORS

KAREN WEINTRAUB is a health and science journalist based in Cambridge, Massachusetts.

RACHEL ZIMMERMAN is a health reporter at WBUR in Boston.
