One bright July morning last year, Orlando Chavez stepped out of the Hotel Travelers, his home in downtown Oakland. Chavez seems younger than his 63 years; when he strides through Chinatown, he looks like an Apache-Mexican giant. On his head rests a Ché Guevara-style beret, and under his arm a stack of paper—medical journals, statistical data, surveys—to have the details on hand. He still felt this nervousness every time he spoke publicly.

Chavez had been invited onto “Forum,” a popular Bay Area radio show, to talk about the hepatitis C virus, known in medicine as HCV. Chavez is the director of the viral hepatitis program at the Berkeley Free Clinic, where he runs screening programs and tracks the number of people who test positive for HCV. He gets invited to talk as an epidemiologist with street credit. In addition to a hep C diagnosis his history includes decades-long heroin use and several prison stints.

The radio show on that summer day was pegged on national news: the FDA had just approved a new hep C drug, which was expected to dramatically increase cure rates.

Recent estimates put the number of Americans with hep C at 6 million. The virus is so tiny it can survive for days even in dry blood. For this reason, HCV spreads most virulently among injection drug users. Though it progresses slowly over decades, without obvious symptoms for many, hep C now kills more Americans annually than HIV, over 15,000 in 2008.

The new drugs are supposed to bring that number down substantially, with direct-acting antivirals—telaprevir and boceprevir. Adding them to the existing treatment nearly doubled the cure rate for people with genotype 1, the most treatment-resistant—and most common—form of HCV.

Because most people with hep C don’t feel serious symptoms for literally decades, it has an ominous label, “the silent killer.” For many, perhaps over half of hep C patients, the virus will never harm their health.

If untreated, the longer hep C lives in the body, the more likely it will cause significant health problems. Chronic hep C is now the number one cause of liver cancer, fibrosis and cirrhosis—a scarring which prevents the liver from detoxifying the body—and liver failure.

This fact poses a paradox for health providers: most cases idle innocuously in the body, but cases that do progress tend to make people very sick.

As a former heroin user who contracted hep C, Chavez is intimately familiar with the harms of the disease. Addicts live in the shadow of hep C; They are most likely to be infected, and least likely to know about it. More, if diagnosed, they stand slim chances of being offered treatment.
On the occasions when he sought medical attention, Chavez’s symptoms were lumped together with his drug problems—fatigue, joint and belly pain, soreness—all too vague, he thought, to merit thorough examination.

Chavez had read the new drug studies; twenty years in the making, their release generated buzz in his line of work. But Chavez was just as troubled as others were excited about the medical breakthrough. No matter the effectiveness of the medicine, he expected that most people with hepatitis C would not be considered for treatment.

People that inject drugs are a tiny fraction of the overall population, but they represent the majority of HCV infections.

He wondered how to point out this disconnect in a persuasive manner. The great distance, between encouraging new medicines and discouraging lack of access for people with addiction problems, mirrored a paradox in the larger field of medicine. When a disease—or in this case an infection, HCV—affects an underground population, the separation of addiction from medical care for other ailments becomes a daunting obstacle for public health.

Chavez knew many considered people like him—at least the way he was eight years ago—an irrelevant patient base.

Chavez’s own treatment arrived as a rare stroke of good luck in the form of a local doctor. Diana Sylvestre, a Harvard-groomed internist turned addiction doctor, is one of the only people in the country that treats people with severe addictions for hep C.

When they met he was a bona fide junkie with end-stage liver disease that probably would have killed him by now. For him, the hope sparked by this new medicine has a gloomy counterpart. Very few from this particular underclass—people like him—will actually get treated for the disease.

On KQED that July morning, the enthusiasm around a breakthrough eclipsed this problem. The other guest, a respected liver doctor named Natalie Bzowej, was a lead researcher of the telaprevir trial published in the New England Journal of Medicine.

“It’s a very exciting time for the field,” Bzowej said. “[This new medication] marks a turning point in the treatment of hepatitis C.”

Chavez quickly spotted the casting: he, an ex-addict, ex-con, hep C survivor, was the liaison from the streets.

Whereas the previous drug cocktail worked for less than half of people with genotype 1, explained Dr. Bzowej, the addition of telaprevir brought good outcomes above 70 percent of
patients. Furthermore, it had the added boon of shortening the length of treatment—a physically and psychologically brutal chemotherapy regimen—from a year to six months.

This new cocktail would add side effects while shortening the existing treatment, interferon plus ribavirin.

As is well known, Interferon brings intense side effects, among them severe depression and other neuropsychiatric confusion, which make drug adherence a problem. That, in turn, makes the treatment less effective. These psychiatric issues are cited as a reason that addicts, and others thought to be unstable, are ill-suited to withstand hep C treatment.

The radio host’s question about sobriety brought from Bzowej the common response from doctors.

“We do like patients to be alcohol and drug free for a period,” said Bzowej: “I have had the unfortunate experience of some patients relapsing, even after thirty years sobriety.”

The host turned to the other guest. “Orlando Chavez, can you give us a personal view,” he asked, “of what it has meant for your life to have dealt with hepatitis C?” he asked.

Chavez spoke in his slow, gravelly voice, about being diagnosed and confused about what it meant. He knew the answer was more complicated than the time allowed.

“Fortunately, I met a doctor,” Chavez said. "Diana Sylvestre, who had opened up a hep C clinic in Oakland. I was able to get treatment—“

Short on time, the host cut in. “And the treatment—worked?”

The last decade appeared in a flash, and for a moment, Chavez felt a wave of gratitude—and disbelief, at the state he was in when he first met Dr. Sylvestre. Other doctors would have seen a terminal addict, a “train wreck”—Chavez saw himself that way, too. But Sylvestre conveyed a peculiar optimism about his chances.

“It did work,” Chavez replied. “I did it for 11 months and cleared the virus. That was eight years ago.”

Gastroenterologists—the main specialists in a position of treating hepatitis C—have little training (or perhaps interest) in also treating drug abuse and mental illness.
Moreover, scant data exists about treating HCV in people with drug problems and psychiatric issues, making things harder for doctors willing to manage these comorbidities.

The sheer prevalence of infected people in the United States—estimates range from six to eight million in the U.S.—means that the costs of hepatitis C are vast, in deaths and in dollars. Medicaid and Medicare are still the largest payers for hepatitis C treatment; public money is being spent. The CDC predicts that medical expenditures directly attributable to HCV will exceed $10.7 billion in the next decade.ii

Many doctors hold to the convention that patients need to resolve their addiction before they can benefit from other health care. This informal rule might have benign intentions, but literature on addiction says people react poorly to threats or ultimatums.

Diana Sylvestre has a strategy for this. By treating addiction as simply as aspect of medical care—rather than a precondition to it—she is challenging the underpinnings of traditional medical care and traditional addiction treatment at the same time.

This is in stark contrast to usual medical practices—and strangely enough, addiction treatment centers—that draw a bold line between addiction and overall health. If you use, you’re out; and until you’re clean—usually for six months—you’re not ready for anything else. Sylvestre put her patients on the map by inviting them into medical care for hep C, regardless of the phase of their addiction.

“She showed that patients didn’t have to be pure as newly-driven snow,” says Joan Zweben, an addiction psychologist at the University of California, San Francisco. “For many years they said you can't be treated for hepatitis C unless you've been clean and sober for 6 months, and she said ‘Well, who knows whether that's true.”

When Sylvestre first encountered Orlando Chavez in 1998, at a Richmond, California, methadone clinic, neither of them knew that they would later be acting side by side in the same big play, trying to get the world to pay attention.

Hepatitis C was already a full-scale epidemic, but it lived mostly in places not studied or written about in medical journals. The clinic in Richmond, a rough city just north of wealthier Berkeley, was just such a place. It looked like many methadone clinics across the country: an unmarked doorway on a mostly empty street in the ghetto.

Chavez spent seven years in San Quentin for felony drug possession. That year, he was free from parole for the first time he could remember. He’d wrangled with the system and won disability
benefits to cover methadone, or “opiate replacement therapy.” He was thinking maybe he was finally getting his shit together; he was still using heroin, but much more rarely now that he had a methadone routine.

Chavez was waiting for his dose when he observed a little white woman cruising the lines, unceremoniously working the waiting room. Carrying a clipboard and dressed in black denim jeans, black sweater, and black sneakers, she took rapid-fire medical histories.

Sylvestre had not been working there long before she noticed strange abnormalities in the liver enzymes of her patients. Methadone clinics required some basic evaluation of patients on intake, but although HIV was among the blood panels tested, hepatitis C was absent. Sylvestre seemed to be on a mini-crusade to get everyone tested.

Chavez had never heard of hepatitis C, but by the time he found out what it was, it had already all-but-destroyed his liver. When Sylvestre spotted him, he was slumping lethargically in a chair. He couldn’t figure out why he was so tired. Even when he was heroin-free sometimes, he would doze off mid-day in a coffee shop, looking like a man who’d just shot a little too much.

Sylvestre made a mental note: it’s not always drugs that are causing people’s problems.

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Raised in rural Florida, Sylvestre never encountered addiction directly in her family. When Diana was three years old, her father, an army psychiatrist, was killed in the Vietnam War. As wars tend to do, the Vietnam years brought addiction home for Americans; the image of heroin addict changed, from a poor black man to somebody’s son. By the time methadone clinics were legal, Sylvestre was at the University of Florida, majoring in animal sciences with dreams of becoming a veterinarian. She soon migrated to medicine. In 1997, finishing a fellowship studying molecular immunology at New York’s Sloane Kettering Cancer Institute, she followed her husband, a cardiologist, to California, where he’d taken a position at a lucrative biotech company.

The young Sylvestre was a sought after medical recruit; her acute mind for research was paired unusually with a clinician’s ease with patients.

In New York, Sylvestre had moonlighted in homeless clinics and soup kitchens; but the divide between research science and patient care didn’t trouble her.

“I’ve always liked street people,” she says.

The prestigious teaching hospital at the University of California, San Francisco, offered her a faculty job in the rheumatology lab, but she gravitated across the Bay.
With “some time to kill,” she says, she took a job doing intake at the Richmond methadone clinic.

Sylvestre, eyebrows permanently raised at a you've-got-to-be-kidding angle, administered blood and urine tests mandated by law to monitor illicit drug use, but soon had a different idea.

The methadone clients provided Sylvestre an entrée into the world of public health.

While perusing an article in the New England Journal of Medicine, a light bulb went off. The article reported the rising incidence of hepatocellular carcinoma, a cancerous tumor in the liver. By far, it said, hepatitis C and B were the primary causes of these tumors.

The abnormal liver enzymes Sylvestre was seeing in methadone patients were not because of drinking, cocaine, or cigarettes, as she first assumed, but of a pathogen that travels through blood. When they shared needles, drug users were sharing the disease. She had landed squarely in an epicenter of a major public health crisis, one that very few people were talking about.

Hep C screening was still a relatively rare phenomenon, and the majority of people who had it didn’t show symptoms, which added to the belief that it wasn’t especially worrisome. She thought another reason it was being ignored was because of the people it tended to infect. Treating HCV effectively in these people meant treating addiction, too.

When Sylvestre launched her one-doctor campaign for routine screening at methadone clinics, she thought at least she could get an idea of how many people have it. The numbers were astonishing: nine out of ten people she screened had been exposed.

The rates of infection being reported nationally were misleading—they did not enter the stomping grounds of injection drug users. “If there are cop cars instead of beautiful views from where I was practicing medicine,” says Sylvestre, “I got a lot of positive hep C tests. You know how they usually reconfirm positive tests? But I’d only reconfirm if I get a negative test. That’s how rare a negative was.”

At the same time as she was discovering the extent of hepatitis C, she saw the extent to which addiction could submerge people underground. Sylvestre likes a challenge.

In order to address the hepatitis C crisis, doctors would have to confront a much more complex disorder. But apart from the few who had got regular health care, people with opiate addictions rarely knew they had hepatitis C, let alone had doctors to evaluate them for treatment. Anyone who could address hepatitis C in addicted patients would have to finesse a notoriously difficult patient base. Usual symptoms of addiction include erratic behavior, lying to doctors, getting arrested, and general mental distractedness.
This would be her patient base. Sylvestre likes a challenge. Soon, she says, “I learned how little I knew about the entire discipline.” Her methadone patients taught her the first rule of opiate addiction—it’s really, really hard to quit.

“The big clue,” she recalls, “was that everyone went into the 21-day detox thinking they’d be free of opiates at the end, but nobody ever got free of opiates.” As the intake doctor, Sylvestre says she saw people cycling through the clinic endlessly, using the methadone to wean off heroin, and then tapering off methadone to brave the streets opiate-free. “There were people who’d been there a dozen times,” she says. “Over and over again, I’d see them. They’re like ‘Hey, I’m back.’ And this is the norm, not the exception.”

It wasn’t that people didn’t want to stop using heroin; it was that they just couldn’t.

“I thought, ‘OK, this is a lot more complicated than simple physical dependence.” In other words, though physical symptoms of withdrawal may go away, the urge to do drugs is unchanged.

The methadone clinic, in this way, provided essential information about what not to do. Detox—monitor the patient as he weans off the drug, then send him on his way—is the default method of addiction treatment, both in and out of the medical system. Detox, preferably followed by therapy, AA, and lifestyle changes.

That seemed glaringly wrong now. The 21-day detox was a microcosm of the whole addiction treatment system: a brief intervention for a lifelong disorder. When people relapsed, they became unhooked from the whole system of care. If anything, active users avoid doctors; the mutual mistrust between addicts and medical professions is deep.

Sylvestre spotted a gateway in hepatitis C: unlike addiction, infections seemed to lure people into medical care. Perhaps, she thought, this sneaky little virus could open the door.

But much to her annoyance, the ‘abstinence first’ custom interfered with her new practice. Methadone patients would tell her that they sought advice from doctors about hep C, but were told they’d have to get off methadone first. It didn’t make sense to her, but apparently, methadone counts as a drug.

She’d clearly observed methadone being a stabilizer, making patients less likely to use street drugs, needles, or overdose. Sylvestre also had stable, long-term methadone users. They would dose every morning, and could raise kids, go to work, and otherwise carry on; they relapsed infrequently to heroin.
“What’s that all about?” says Sylvestre. “The last thing you want to do is destabilize your patient before hep C treatment!”

Why would doctors want their patients to discontinue it? The tenacity of opiate addiction was such that, without methadone to pacify it, “six months to a year” of abstinence could be a long time, maybe never.

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As Sylvestre became more expert in hepatitis C, she effectively began specializing in other things as well. Addiction disorders—usually entangled with psychiatric disorders—became the medical subtext of everything that would happen in Sylvestre’s clinic. She even named it OASIS, the Organization to Achieve Solutions in Substance Abuse. Standing on the edge of Oakland’s “Ghost Town” ghetto, the brick building blends in with storefronts of weaves and wigs, furniture rentals, and check-cashing stores.

The first study she conducted at OASIS addressed her curiosity about the reasoning for discontinuing methadone before HCV treatment. If no evidence existed, as doctors claimed, that patients maintained on methadone could safely be treated for hepatitis C, she would just have to make the evidence herself.

In the first U.S. study of its kind, Sylvestre showed that heroin addicts on methadone, some of who relapsed during HCV treatment, could tolerate the tough regimen and fared as well as the general population in beating the virus.

Sylvestre’s obsession with hep C and addiction started attracting attention soon after she reported the results of that first methadone study. This happened not so much because she was the first to show active drug users could be compliant, but she had then treated more people with hepatitis C than any individual physician in the country.

In a series of studies following that, Sylvestre expanded her lens and offered forth a unique model for successfully engaging drug users with serious medical problems.

“Diana put it into peer-reviewed journals that current and former drug users could be as adherent as the rest of us,” says Tracy Swan, who directs the Hepatitis/HIV Project at Treatment Action Group, a New York nonprofit that advocates for inclusion of “real-life” populations in HIV and HCV drug trials. “And she actually proposed a structure for doing this. She wrote the blueprint.”

In the three years after opening OASIS, Sylvestre and her small staff of physician assistants had screened over 3,000 injection drug users for HCV and treated hundreds. Though participants were frequently active drug users—people who used drugs during treatment, whether heroin, cocaine, or alcohol—many managed to complete treatment and clear their hepatitis C.
The standard measurement for success with hep C treatment is SVR: sustained virologic response, meaning the virus is still undetectable after six months, most likely means its gone for good. If treated in time, the liver has a remarkable to heal itself.

The SVR rates of Sylvestre’s patients were comparable to those reported in non-addict populations, despite facing more challenging social, medical, and economic circumstances.

The results challenged two long held conventions about addiction: that people who use drugs aren’t interested in addressing other medical problems, and that even if they were, they wouldn’t be treatable.iv

In a shift credited largely to Sylvestre’s work, a 2002 consensus of medical experts in the National Institutes of Health changed one important sentence in their guidelines. Treatment for hep C in active drug users, they wrote, should now be considered on a “case-by-case” basis, rather than categorically disqualified.

But in challenging this convention, Sylvestre and her core of patients—many of whom have joined in her hep C activism—confronted another drawn out and noiseless controversy in medicine.

Guidelines do little to intrude on medical practice. Studies show doctors are more likely to be guided by personal dispositions and opinions. Judging by the continued anti-methadone bias Sylvestre observed in her medical colleagues (even addiction specialists), attitudes persevere despite evidence. The safety and efficacy of methadone, for instance, has been documented for decades; it can take a generation or more for attitudes to catch up with science.

Oakland’s county hospital asked Sylvestre to oversee its hepatitis C clinic, and she found herself wrangling with them over referral guidelines.

“They had all this stuff like, ‘How much alcohol is the patient drinking? Drug use? How long abstinent?’” says Sylvestre. “I said, ‘That really, really does not matter.’ That's something we've very clearly shown at our clinic here in Oakland.”

When speaking publicly, Sylvestre avoids moralizing: “I can say a whole thing about stigma, and how our system is not geared up for these complicated patients,” she says. “But you don’t change policy by doing that. You change it with a cost benefit analysis.”

Hepatitis C, everyone could agree, was beginning to be very costly when unattended. Insurers balked at the expensive treatment, and non-cancer doctors were reluctant to begin patients on what is essentially chemotherapy. In a happy coincidence for the makers of hepatitis C drugs,
Sylvestre has successfully persuaded state and local clinics to integrate hep C treatment into their formularies.

“Spend $15,000 now to treat him,” she likes to say, “and save the $80,000 later when he infects four other people.”

Beyond this “public health opportunity,” as Sylvestre likes to call it, one of internal medicine’s costliest procedures – liver transplantation—has multiplied as a result of hep C-related liver failure.

Freaked out by cost projections, the medical establishment—including the FDA, big pharma, and federal health agencies—is starting to think that hep C is a bigger deal than they thought. High on the new research, now is an especially good time to talk about getting treatment to more people.

Sylvestre had been invited as an expert speaker to an FDA public hearing on “Expanding access to HCV treatment.” Sylvestre was the twelfth speaker in a panel of researchers, clinicians, and FDA officials, but the first one to mention addiction or injection drug use. She contained her frustration about this fact, but barely.

“We’ve gotten through almost this whole day without talking about the main issue. Hepatitis C is driven by injection drug use, and we haven’t talked about drug users,” she said. “Until we start getting these drugs into these kinds of patients we are not going to get anywhere with this epidemic.”

She pointed to a study that predicted, given current practices, that of the 300 hep C patients in a clinic, only 21 were likely to be treated.

“I have never had a patient accepted into a clinical study. They are routinely rejected from these studies of hepatitis C. They’re ruled out for things like psychiatric disorders, things that happen when you have hepatitis C,” Sylvestre went on. “This is the real world.

Sylvestre, careful not to scare her patients into thinking hepatitis C is a death sentence, has no qualms about scaring public officials into action, if she can.

“So, you know—why should we care all of sudden? Well, my patients are driving your epidemic.”

When Sylvestre approached him at the methadone clinic, Chavez was struggling as much as ever with his addiction.

“You couldn’t just say I had heroin problem,” says Chavez. “I had a monstrous heroin habit.”
Heroin had stopped being fun a long time before—by then he wasn’t getting high, but took it just to feel, which was to not feel sick.

Chavez’s parents were Mexican-Indians—his dad light-skinned, his mother very dark—who moved to California shortly after Orlando was born. Chavez came of age in East Oakland in the 1970s; then as now, the city was well stocked narcotic-wise, and Chavez was using by sixteen, dealing by seventeen. He remembers feeling depressed as a kid, but beyond that has few memories of his life before heroin.

For a long time after that, he organized his life around his addiction, managing legitimate jobs at times but hustling drugs to maintain a sufficient cash flow, an occupation that landed him a handful of prison stints for felony drug possession. As he paced in and out of lock-up, he had spells of drug-free days; but pressed for money and back in his old setting, Chavez always fell back to selling and using. At his worst, he says he would ingest nothing but drug for days at a time.

When Chavez arrived in Sylvestre’s office in 1999, he was the prototype of the patient that makes doctors recoil when he. Chavez was still injecting heroin, though less than before. Still, abscesses covered his arms, neck, and feet—staff infections from every point of needle entry— turning a blood draw into an advanced procedure. In run-ins with doctors in emergency rooms, Chavez says they resented him, as if begrudgingly attending to self-inflicted wounds.

Sylvestre didn’t flinch; instead, she boasted about her phlebotomy skills.

“Don’t worry,” she said, “I’m good.” She found a vein in his leg and drew a blood sample.

“We’re gonna have to take care of these infections before we think about treating,” she told Chavez. Active infections, she explained, do not mix well with Interferon, which hyperactivates the immune system.

“She doesn’t sit and talk about the drugs,” says Chavez. “She talks about the harms associated with it.” With clinical curiosity, he says, Sylvestre removed the moral element completely.

Sylvestre was looking for patients to enroll in her methadone-maintenance study. Chavez, who had irreversible liver disease—what they call decompensated cirrhosis—was an even riskier bet than her average drug user. Beyond exacerbating his existing depression, Interferon could also cause anemia and worsen ascites, the accumulation of fluid in the abdomen, already evident in Chavez’s swollen belly.

Chavez believes Sylvestre is a benign, mad scientist. “She took a chance on me,” he says. “I was going to be her guinea pig.”
Not only was every person enrolled in the OASIS studies a drug user, many had other advanced medical issues. Her only criteria for considering treatment was showing up every week, for the hour-long peer group. These meetings were followed by medical science lessons, taught by Sylvestre in a highly interactive style. The scope of subjects went from epidemiology and statistics to microbiology.

As Chavez showed up every Tuesday for a month, Sylvestre observed his quick medical intellect. He was still struggling to stay clear of drugs, but he had natural science talent, easily synthesizing aspects of anatomy and biochemistry.

By the time he began treatment, Chavez’s liver had badly deteriorated. His ankles and torso swelled painfully, his skin was dry, red, and itchy, and he felt shaky and disoriented.

One of the most hazardous effects of an impaired liver is swelling in the brain, or encephalopathy. In its more severe forms, the brain gets so confused that it inverts the sleep-wake pattern. Chavez had tremors at night, and by day he was overwhelmed by lethargy. He finally had an explanation for why he was still nodding off in coffee shops, now being heroin-free for a year.

When Chavez learned about encephalopathy, he felt relieved at the diagnosis, but with a tinge of despair. That he had been so close to death, his brain filling with fluid, was staggering.

“Encephalopathy,” he said. “That must be the ugliest word in the English language.”

Interferon-plus-ribavirin therapy, the 11-month ordeal to treat hep C, temporarily exacerbated all of these symptoms. But, Chavez says, it made the health he felt when it was over seem miraculous.

“I couldn’t even imagine fixing after that,” says Chavez. “It was the worst. And the chance of reinfecting, and having to go through that again? I wouldn’t even consider it.”

In Orlando Chavez, Sylvestre observed a weird phenomenon never reported in medical journals. People that made it through hepatitis C treatment were then more likely to stay sober and abstinent. A grueling medical experience—at least one that tended to form the social bonds that hep C seemed to—seemed like a better treatment for addiction than, well, addiction treatment.

“I have a patient that’s using heroin. Drinking alcohol. Smoking crack and cigarettes, and has hepatitis C with cirrhosis. What do we do?” she asks. “You look at him and it’s ‘Oh my god, he has all this stuff going on.’ But he’s here because of hepatitis C.”

In many respects, Sylvestre’s criteria were practically the opposite of every other study or guideline about getting patients into hepatitis C treatment. Rather than excluding patients with addiction problems, she tested how far they would push themselves to defeat hep C.
It gives us an opportunity because often these are people who don’t trust us doctors,” she says. “I represent a system that has not done well by them over the years. In a very twisted way, we use hepatitis C as a carrot to draw people in, to come to our clinic, and deal with their other issues.”

In this way, Sylvestre challenges a fundamental posture of medicine: that doctors always know what’s best for their patients. Seeing the long and complex process of addiction play out, Sylvestre learned her patients had their own schedule for recovery, which was far more complicated than weekly checkups.

What she learned, and then proved, is that if addicts can’t stay abstinent, that does not mean they are impervious to health care.

“Look at Orlando, he’s a perfect example,” says Sylvestre. “He picked up on the science right away, and now he chairs the peer group meetings and you know, I never would have predicted that. He cleared hep C eight years ago, but he’s still dealing with his addiction. I mean, addiction doesn’t go away the way a virus does.”

The outcomes at OASIS have made an impression on the field. At least one of Sylvestre’s three core studies is cited in almost every medical article broaching the subject of HCV in people with addiction problems.

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In over fifty years of modern study about substance use, relapse rates—marked by a patient’s return to drug use after a short stint of treatment—are stubbornly high, with opiate users among the highest. Outside a specific clinical framework, it’s easy to attribute the relentlessness of this particular disease to moral failure. With all the expensive rehab centers that combine therapy with seclusion from substances, Alcoholics Anonymous is still considered the program most effective in helping addicted people get and stay sober—still, most people relapse within a year of their first thirty days clean.

As a medical doctor, Sylvestre approaches addiction as one of many chronic conditions her patients live with. But OASIS offers something that no one physician could.

In many respects, the hep C peer groups mirror traditional support meetings. With its low-ceilings and yellow light, OASIS could easily be mistaken for a church basement.

“Peer support is the key to keep marginalized patients coming back,” says Sylvestre.
But while the OASIS model embraces some aspects of Alcoholics Anonymous, it discards others. Spiritual tangents happen at OASIS, but they emphasize relationships to fellow humans over connection to a higher power.

The good feeling inspired by “service” is one aspect of AA that Sylvestre thinks works. What AA calls “service” is called “peer education” at OASIS.

No doubt fostered by AA, the language we use to talk about addiction has long emphasized “disease.” But disease in a spiritual context is a disease of the soul. Critics say this important facet of AA—the “God” facet—serves the concept of moral failure, and intensifies the shame that addicts feel when upon relapse.

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Everyone in the room says a piece at the meeting’s start—minus “I’m Bob and I’m an alcoholic” and “Hi, Bob.” OASIS regulars have adopted other things to represent unity.

The group gathers every Tuesday at OASIS. Roughly forty people grab a slice of pizza and sit in fold-down chairs. Chavez, who co-chairs the meeting, cracks the gavel precisely at noon.

“Welcome,” he says. “I got rid of my hepatitis C here eight years ago, but I realized I had a lot more work to do.”

Chavez was elected to chair these meetings because, like Sylvestre, he is that rare type of person that speaks both science and street. Sylvestre thinks if she or another doctor directed the meeting, newcomers would be turned off.

Introductions circle the room, sounding names, short histories, or states of mind. Today, four people mention are mid-treatment, and indicate they don’t feel like saying or doing much of anything. Others in the rooms nod knowingly.

A light-skinned black man in a fedora introduces himself as R.C. Carrier, a quiet, 65 year-old Vietnam vet and OASIS regular. His girlfriend goes next.

“Name’s Charlene. I don’t have hep C, but I do suffer from a lot of the symptoms that go with hep C. So, with that, I’m out.”

“I was told twenty years ago I’d probably never need treatment,” says Victor, a round black-haired man in his mid-fifties. “I’m in stage five fibrosis now.”

The OASIS crowd is familiar with the stages of liver fibrosis. Stage five is on the cusp of cirrhosis, wherein the scarring becomes irreversible and usually leads to liver failure. “I had a
hard time staying away from alcohol,” Victor continued. “I had three years at Christmas and then drank. Now I’m back on the wagon, so I don’t know. With that, I’m out.”

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When everyone has checked in, Sylvestre takes the stage in her usual outfit of black cotton top and grey denims.

“So,” yells Sylvestre, “they came out this interesting study in the Annals of Internal Medicine, a fancy journal.”

She walks to the dry-erase board and starts drawing arrows. “They tested three strategies for patients with diabetes lowering their blood sugar.”

Sylvestre finds good fodder in medical journals; she tries to have something new every week so the veterans don’t get bored.

“One,” she says, “is regular doctor appointments. Follow the doctor’s advice.” The second strategy was to pay people $300 if they reduced their blood sugar to a certain level, and the third was to hold diabetes patient peer groups.

“Which group do you think was most successful,” says Sylvestre, “in lowering their blood sugar?”

The group yelled a combination of “cash” and “peer groups.”

Pointing to the first arrow, Sylvestre said, “What about number one, going to the doctor?” At the unified “no” resounding, Sylvestre tiptoed sheepishly behind the dry erase board. “So, what we’ve been doing here works,” she says. “Which is why we do it.”

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The second floor of the clinic had to be torn up, and Sylvestre got a good deal on carpet tiles. She’s an amateur carpenter and electrician, and is usually doing manual labor somewhere if she’s not with a patient or at group. When the patients have all left, Sylvestre tends to side projects upstairs.

“The whole system we have for drug treatment sets people up for failure,” Sylvestre sighs, and drops a box of tiles at her feet. “By the time I see people, their self-esteem is shot. They’ve gone through this thing we call treatment, which is just sooo not treatment, and failed. So they think the failure is themselves.”
Two parrots, African Grays, mutter in a side room, and two yellow Labradors, who Sylvestre trained as seeing-eye dogs and then kept, surge occasionally across the room.

“Unfortunately, addiction doesn’t have a cure,” says Sylvestre, “But neither does diabetes or hypertension. But you apply treatments—you take medications and you put yourself in environments that aren’t asthmagenic. You get rid of your cats and other triggers, and guess what? You do better. It’s the same thing with addiction. Applying these medical models doesn’t take a lot of brain power, but because we don’t like these guys, we fail to see the correlations.”

“She does not ask them to change before she’ll help them,” says Dr. Anthony Albanese, a gastroenterologist who directs the drug treatment program at a California VA hospital. By engaging patients with chronic diseases despite their stage of recovery, Albanese says Sylvestre bridges a gap that keeps most addicts away from health care. She turns much of the health decision-making over to patients who have rarely been invited into the medical process.

“The first thing we do in medicine is we’ll say ‘I want you to stop drinking and stop using drugs,’ when often they’re seeking care for something else they’re concerned with. So, if they’re here because they’re worried about their hep C, we are putting up an artificial barrier to treatment.”

Working her way across the clinic’s second floor, Sylvestre is talking about the pros and cons of modern medical specialization.

“People say to me, ‘Do you have your patients see an ophthalmologist before they get started on hep C treatment?’ I say, ‘Huh uh, no.’ Would I like to? Sure. If I could have a team of doctors come here and do all this stuff, that would be just hunky dory. I would absolutely love it. It would be the best for the patients to see the highest level of sub-specialists. But these folks have a lot of different things going on! They may not have transportation, may not have the mental abilities or structural aspects in their lives that allow them to show up to a lot of appointments.”

Sylvestre removes her work gloves, peels off her long-sleeved thermal top, puts the gloves back on, and smoothes the row of tiles she set.

“Then you say, ‘You need hep C treatment? Sure, I’ll do it. First you have to see a psychiatrist, you have to see a cardiologist, you have to see an ophthalmologist, and you get all those taken care of and then we can treat your hepatitis C.’ Huh. Uh uh, ain’t gonna happen.”

Sylvestre is always working. Seeing patients is just a fraction of her interest in the world. She grows exotic herbs for an Italian restaurant in San Francisco, and keeps bees on the roof of the clinic.
It would seem to follow that the Sylvestre brand of primary care is extensive; she has learned to handle a range of issues in a single patient. She’s become expert in fields of medicine in which she didn’t train. She surprised herself by becoming so familiar with psychiatric medications. Her unique versatility summons a certain anticipation around her work. When she is gone, who will carry this on?

But Sylvestre insists that the vital aspects of the OASIS model are transferrable, if primary care givers had more leeway, and were properly reimbursed.

“It's kind of like putting down this floor,” says Sylvestre. “I’m not a flooring expert, but the floor is coming out fine. And if it doesn't, fine, then I can call in an expert. Same thing with the patients.”

While Sylvestre distances herself from the doctor class, she persistently refers to what scientific evidence says about treatment approaches.

“It's a medical illness,” Sylvestre says, reminding her patients that all chronic illnesses have periods of remission and periods of irritation. She uses medical language to reinforce this: if relapse is defined as a re-emergence of symptoms after medication is discontinued, diabetics and asthmatics relapse as frequently as people who are addicted to substances.

“We all have stuff we should do less of and stuff we should do more of,” she says.

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There are clear signs that OASIS meetings have a political edge that pushes them beyond personal discovery. Posters hang on the walls, kept from marches and demonstrations.

“HEP C CAN BE TREATED"
“WHAT ARE WE, CHOPPED LIVER?”
“ADDICTION IS A MEDICAL ILLNESS: SPREAD THE WORD.”

For the medical profession, the basic controversy over addiction dates back to at least the early 1900s, when opium and morphine addiction became widespread in the United States. In 1914, five years before Prohibition, Congress passed the Harrison Narcotic Act, the crux of which remains in effect to this day.

The Act made it a crime for doctors to provide maintenance supplies of narcotics to people who were addicted to them. It allowed narcotic distribution, however, for a discrete window of time, during which doctors could use it to wean a patient off the drug.

“Detox has never worked, in any epoch, in any place, ever,” says Mary Jean Kreek, who heads the Laboratory of the Biology of Addictive Diseases at Rockefeller University. Kreek is the
surviving scientist from the New York City trio that pioneered the first medication-assisted treatment for heroin addiction.

Vincent Dole and Marie Nyswander, the husband-and-wife doctors who engineered the original methadone trials in the mid-1960s, laid the scientific basis for long-term treatment of addiction. Their research of the partial-opioid methadone challenged the “psychogenic” view of addiction, axiomatic for a hundred years prior. The psychogenic theory held that addicts are psychopaths, which explained the character defects—lying, stealing, manipulating—people associated with it.

But Dole thought that opiate addiction was not the result, but the cause of the antisocial behavior. He hypothesized that opiate drugs altered the brain chemistry, which made them uniquely difficult to abstain from long-term. Addiction to opiates, he wrote, is more of a metabolic process than psychological disorder. Dr. Kreek later helped prove that genes also play a significant role in determining who becomes addicted and who does not, reinforcing the biological basis of addiction.

Methadone creeps into the bloodstream, instead of rushing, effecting a slower, more muted release than heroin or other fast-acting painkillers like morphine or hydro- and oxy-codone. The drug acts to prevent craving by attaching to the same receptors that have grown used to the flood of dopamine produced by other drugs. It can mute powerful cravings by essentially substituting a flood with a steady stream.

Until there’s a cure, declared Dole, methadone should be considered for intractable cases, as a safe and effective management of heroin addiction and protection against dangerous relapse.

Widespread disapproval of methadone persists, says Joan Zweben, the UCSF psychologist, among lay people, medical professionals, and even addiction specialists and 12-step programs. “Methadone has been the gold standard [of addiction treatment] for decades,” she says. “And yet the stigma lives on.” Zweben thinks that a vague definition of addiction maintains confusion where science has shed light. “Many people, doctors included, confuse addiction with dependence,” she says. “But addiction is really continued use despite adverse consequences.”

Zweben, who has worked in methadone clinics since the 1970, says the anti-medication bias in the recovery world is deeply destructive. Addicts still hear doctors spurn methadone maintenance as ‘substituting one addiction for another.’

This is slowly getting better. In fact, the newly released Diagnostic and Statistical Manual V replaces “substance dependence disorder” with “addiction,” marking recognition among psychiatry leaders that addiction merits its own diagnosis. Where dependence connotes a child-like state, suggestive of self-destructive habits often displayed by teenagers, addiction is a pathological inability to refrain from use. And some addictions can be successfully managed with the help of medication.
“People are ashamed of methadone because they’ve internalized the stigma,” says Zweben. “Diana gets that and doesn’t try to push them off.”

“She says, ‘If you don’t relapse, you’re not an addict,’” says Mike Baldwin, a 55 year-old former heroin addict, and a patient of Sylvestre.

Everyone knows it’s bad for diabetics to eat fatty food and drink soda, she says, but there’s a reason people rarely succeed in cutting them from their diets. Every addictive substance has its own lure for the brain. Alcohol and cocaine addiction often go together, as so cigarettes and coffee.

But opiates, such as heroin, morphine, and vicodin, produce a profound addiction that makes it the most intractable. Sylvestre seems to understand this in a way most people don’t unless they’ve had firsthand experience, Baldwin says.

“Addiction just plain makes sense,” Sylvestre says. “If you don't feel good most of the time and something makes you feel good, wouldn't you want to take it again?”

“A junkie is always thinking about quitting,” says Baldwin. “I tried everything. I even left the state, went to Spokane. I was clean in Spokane for six years, but every day of those six years I felt hollow inside.”

Baldwin says her approach has even rubbed off on him; whereas before he was fixated on getting off methadone, to “prove I can be normal,” he doesn’t feel any shame about needing the medication now.

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The clinic as it is stands on shaky economic ground. Sylvestre and her husband bought the building wherein OASIS currently lives, and Sylvestre doesn’t receive a salary. A grant from a pharmaceutical company covered start-up resources. Getting Medicaid, which insures most of her patients, to pay for hep C treatment is a big struggle.

Sylvestre has been able to adapt to these realities, but admits OASIS does not function as part of a highly specialized, for-profit health care system. At OASIS, at least, she can call the shots.

“I’d slit my wrists if I had to work in a big HMO,” says Sylvestre.

It’s hard for Sylvestre to understand why more medical centers don’t just use the peer group model. It’s been shown to be the most effective way of getting marginalized patients invested in
their health. The peer groups, probably the simplest part of OASIS, are essential in getting the attention of people who mistrust doctors.

It comes like a sigh after a long workday when Sylvestre admits that maybe it’s not that doctors can’t work with addicts—it’s that they won’t.

“It may be a case of I-can’t-stand-the-look-of-you-with-your-drug-ravaged-body,” she says. “We are not all liking our patients. And if we don't like them, we don't want to treat them, we don't want them in our practice, we don't enjoy seeing them.”

“We can convey that in so many ways, so that the patient doesn't come back. It may be a message like, ‘Well, come back in six months when you stop using.’”

Sylvestre drops another box of carpet tiles on the floor, and mentions that her clients have done most of the physical labor in building this clinic. Like peer group meetings, employment, she says, is a good incentive to show up.

“You should hear the stories I get about how they are treated by doctors,” says Sylvestre. “When they are perhaps drug users or drug seekers or whatever. It really kind of makes me ashamed sometimes.”

Doctor and patient are sitting in the OASIS office, after group on a recent Tuesday.

“Jesus, Orlando, you have had so many medical problems,” Sylvestre says, marveling at 14 years of hand-written notes about her patient. Chavez sits across from her, grinning healthfully.

For his part, Chavez can’t say exactly how Sylvestre helped him with addiction.

“She is very subtle with her stuff, and it took me a while to get how she operates,” says Chavez. “She works with you at your appropriate stage of change. She knows if you try to force something on someone you get resistance. So her intervention is based on the changes you make.”

In the eight years since Chavez cleared his hep C at OASIS, he has won awards for health education and outreach, and grants to do rapid testing for HCV in the Berkeley Free Clinic’s mobile van. He days recently are a flurry of hepatic activism. His own work with street populations, he says, takes a lot from Sylvestre’s mode of health care.

But her intervention didn’t quite come in time.

Soon after Chavez spoke on the radio, he was flown out to New York City to carouse with Greg Allman at a benefit concert for World Hepatitis Day, an awareness initiative spearheaded by Allman and the singer Natalie Cole, both of whom were treated for hep C.
Backstage after the concert, the rock singer put his arm around Chavez and said, “Where are you on the list?”

“I’m working my way up to it,” said Chavez.

Chavez seems happier, and more active, than you’d expect from someone who has “decompensated” cirrhosis—more commonly called end stage liver disease. It’s ironic that after eluding death so for so long, Chavez knows he will die soon unless he gets a liver transplant.

That decision will be made by a liver transplant panel, a group of people unknown to him and consisting of various specialists, including a psychiatrist. In the last year, Chavez has tapered off methadone completely—he knows it still turns people off, and he doesn’t want to give the panel any reason to reject him a priori.

Chavez faces fierce competition. In large part due to hepatitis C, the waiting list for new livers peaked in 2001, reaching 15,000 people. He can only hope that a fact of his past—that he used to use drugs—won’t count against him.

“My name’s Orlando - I don’t think I’d be alive right now if it weren’t for this place, and the doc.” Chavez is starting off a Tuesday meeting. He seems nervous, and is bobbing his hand around at his side. He pauses for a long time before saying: “I do have end stage liver disease now. I remember how scared I was [when I first came]. I sat in the back. You don’t have to be alone.”

After the meeting, Chavez said he thought he might have found a live donor. “I met someone,” he said, suggesting more than a liver might be at play. The nervous shaking, he said, was a physiological reaction to an onset of hope, entirely unexpected.
“Most physicians who care for HCV-infected drug users withhold antiviral treatment until drug use has stopped.” Stephenson J. Former addicts face barriers to treatment for HCV. JAMA 2001;285:1003-5.

Since it was formally identified in 1989, hep C’s projected impact on the health care system has gone up every year. In 1998, costs associated with work-loss and health costs were over $600 million. “For the 10-year period from 2010 to 2019, the direct medical cost of chronic HCV infection is projected to exceed $10.7 billion, the societal cost of premature mortality attributed to HCV infection is projected to be $54.2 billion, and the cost of morbidity from disability associated with HCV infection is projected to be $21.3 billion (2).” (CDC MMWR 9/5/10; “Evaluation of Acute Hepatitis C Surveillance – 2008”)

Fact check – last I checked, numbers screened and treated in 2004 were definitely—though new trials might exceed (but they are still not individual doctors)

The end-of-treatment response rate as measured by undetectable virus at the completion of treatment is similar to that of other studies in non-opioid-dependent populations, 54 versus 51%. Clearly, arguments that HCV treatment should not be undertaken in this population because of poor adherence, psychiatric disease, or altered immune status need to be reexamined in light of these results.

“Successfully treat more challenging HCV patients, including those with active drug use, mental illness, and psychosocial instability.”

Those motivated enough to return weekly to the clinic attended peer group meetings with other patients. These meetings doubled as information sessions about hep C; sometimes, they centered on strategies for sticking with the treatment without going completely off the rails. In the afternoon, people saw the doctor for their next round of medicine, usually a shot producing a couple of days of fog and nausea. Besides drinking lots of water and taking your psych meds, returning to group the next week was the main piece of advice they left with.