"Who Is the Rest of Them?"

A Piece of My Mind

The curtain around Bed 12 gives the illusion of privacy. The doctors present confidently, unaware their words carry clearly to the woman they are reducing to pathology. "Thirty-three-year-old female with sickle cell disease, splenectomy, chronic opioid use. Sixth crisis in eight months. Patient appears comfortable on her phone..."

I've overheard presentations like this countless times—efficient, necessary, complete.

I also know what's missing.

Behind that curtain, Franny—a producer, mother, wife—is listening to herself distilled into diagnoses. Months later, as part of our humanistic charting study, she told me about that night: tucking her children into bed with a smile shielding her pain; her husband's eyes, love barely concealing terror; her mother staying behind—the same mother who buried Franny's father to this disease.

What haunts me most was what she said next:

"I actually had a doctor say to me, 'I help you because I know you're real. You're not here for the drugs, I know you're not like the rest of them.'"

She paused, eyes fierce despite exhaustion.

"Who is the rest of them? Because if you're talking about the sickle cell community, I am the rest of them."

The Weight of Invisibility

I understood her pain differently than most physicians might. Not just because I've cared for hundreds of people with sickle cell disease, but because I've been invisible too.

Over a decade ago, I was a semi-professional soccer player in Germany. On November 28, 2013: I scored my most memorable goal—chipped the keeper from 25 yards out, the ball floating in slow motion before dropping just under the bar. My captain Benni grabbed me before I could run toward the coach who'd benched me, knowing I might say something I'd regret. Teammates piled on. Pure joy.

Two days later, I had a tonic-clonic seizure.

For eighteen months before that, I'd been having "episodes": sudden pauses mid-conversation; loss of bladder control, once, driving onto a sidewalk because I couldn't move for several seconds. After my epilepsy diagnosis, the neurologist in Germany told me those smaller episodes weren't seizures—they were"likely psychiatric." What else was I left to think? That word—"psychiatric"—left me questioning my reality.

Back in the U.S., MRI in hand (read as "normal"), another neurologist listened—really listened—beyond what they expected to hear. They revised my medications; the episodes stopped. Then, looking at that same "normal" MRI with fresh eyes, they found what had been there all along: part of my brain pushing through a hole in my skull.

The difference wasn't the technology—it was being heard.

The Child Who Loved Transformers

My brain surgery was July 25, 2014. But it wasn't until I started medical school in 2018 that I began to see invisibility from the other side – how easily we make patients unseen despite our best intentions.

During my rotations, our team cared for a 20-year-old with Duchenne muscular dystrophy. His body frail, on a ventilator and pressors, we managed every organ system meticulously. His family thanked me—not for my knowledge (I was just a student) but for the love and support, the simple hugs that said they weren't alone.

They invited me to his funeral.

At the funeral, I learned he loved Transformers.

For months, we'd ensured his ventilator settings were perfect, his cardiac output optimized. But we never once changed the TV from news to something he enjoyed. He'd lost his eye-tracking communication device and wheelchair control three years earlier due to insurance. His undocumented, Spanish-speaking family was so thankful for everything being done, they never asked for more.

I broke down. We had become so good at managing his organs that we forgot about the child lying there, conscious, aware, invisible.

The 95% Truth

That realization drove me to conduct an academic study, interviewing 38 patients across NYC Health + Hospitals. I asked how they saw themselves, then whether their healthcare providers saw them the same way.

Thirty-six said no.

A 72-year-old Black physician: "It wouldn't matter what my accomplishments were. I would be a Black woman to be disdained and disrespected and talked down to."

A jazz pianist with bipolar disorder: "Once they know my diagnosis, my personhood falls off a bit."

A mother with pancreatitis: "Please take care of me. Think of my children."

Ninety-five percent invisible.

Building Visibility Into the System

We're taught to ask open-ended questions but aren’t given the time to hear the answers. Even if we did, where would those stories live in systems designed for billing codes, not human narratives?

Providers now spend 27% of their time with patients and 49% on documentation.[1] As waiting times in EDs rise—facilities over capacity, not enough doctors or hospitals anymore—those long minutes patients wait could become something more.

The gap inspired the Humanistic Charting Tool (HCT). While patients wait, they respond to prompts: Who are you? What does health mean to you? How do you prefer to receive care? What should we know about your life?

Their answers appear on a single page, front and center in the chart. 30 seconds for a provider to read, but it changes everything.

In our pilot at UCSF's Emergency Department—where patients filled out the tool and paper was handed to providers before visits—we saw:

- The largest gain: patients' rating of "my clinician knew important information about my life" rose from 3.3 to 4.7 of 5 ($p<0.05$)
- "Spent enough time with me" rose from 3.9 to 4.8; overall visit rating from 8.3 to 9.3 of 10 ($p=0.013$)
- Net Promoter Scores: 52 (patients), 83 (providers)
- Every measured care-experience metric significantly improved[2]

One emergency medicine veteran said: "It humanized the way I saw patients…everyone is burned out and this reminded me why I like medicine…by humanizing them."
This isn't about blame. As Paul Batalden said, "Every system is perfectly designed to get the results it gets."[3] This is about mutual growth, so that Franny never has to prove she's "real," that a child with DMD can watch Transformers, that the next person with atypical seizures is believed.

Two portraits of the same person

How Franny sees herself
How healthcare sees Franny
"I am a daughter, an active family and community member, a wife and a mother. I am a producer and on-air personality, and I just so happen to be wrapped in sickle-ly goodness all around."
"33 y/o female with PMHx of SCD, splenectomy, chronic opioid use… 6th pain crisis in last 8 months"
Who Is the Rest of Them?

The night before my surgery, I wasn't afraid to die. I was afraid of what I'd leave behind—especially my sister. But in those 25 phone calls to everyone I loved, I felt something overwhelming. Not fear, but love—the love that had always surrounded me, the strength of human connection I only truly felt when facing its potential loss. I saw the immensity of what I was leaving behind, and I believed they could take care of her, that she would be okay. That knowledge gave me the comfort to walk into that surgery with confidence.

This is what I want every patient to feel in their moment of vulnerability—in the ED with chest pain, with abdominal pain. The healing that comes from being truly seen, the comfort of human connection. This is

why I dedicate my life to ensuring everyone in healthcare receives and provides that recognition and connection.

We've built extraordinary capabilities to treat disease while systematically engineering out our capacity to see the humans who carry it. We raise physicians in greenhouses of objective clinical reasoning, the person hidden behind the screen, behind the diagnosis, behind the assumption.

In a future where HCT is standard, Franny's chart would begin: "Mother of two beautiful girls. Television producer. Sickle cell warrior who refuses to let disease define her limits."

The physician who reads that sees differently. The conversation changes. The pain is still 10/10, but now it's a mother's pain, a professional's pain, a human's pain. The same medications might be prescribed, but they're given to a person, not a diagnosis.

Who is the rest of them?

The soccer player whose story didn't fit the textbook. The child with DMD who loved Transformers. The mother with sickle cell disease who is more than her crises. The 95% who feel unseen.

We all are.

The question isn't whether we can afford to weave humanity back into healthcare. It's whether we can afford not to. Behind every curtain, in every bed, is someone's Franny—fully human, irreducibly complex, and worthy of being seen.

Christopher Montgomery, MD, MPH, is an emergency medicine resident at UCLA whose journey from patient to physician drives his work to reintegrate humanity into healthcare systems.

References:

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