PERSPECTIVE PRIVACY AND ALL THAT

## **Privacy and All That**

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As I flick through the scans, I exhale. The patient's disease is stable. I know that has little to do with me and much to do with his biology and indefatigable spirit, yet it feels good to have thumbed our noses at his cancer again.

We can usually extend survival in patients with metastatic colon cancer to about 2 years, but this patient passed that "finish line," as he calls it, last year. True, his health took a dive at the time, his vitality depleted by chemotherapy. Diarrhea made his weight plummet and his spirits sag; disheartened, he remarked that after all, he'd reached the finish line. But we stopped chemotherapy, he bounced back, and soon he was on a better-tolerated treatment. Then scan after scan showed liver metastases stilled in their march. We treated the news cautiously until he decided that a 6-month honeymoon qualified as a response. Three months later, even I agreed.

Now we measure his well-being by his ability to mow the lawn or paint the neighbor's house. He feels robust but says he doesn't sleep for a week before seeing me: "I know one day you will have bad news."

So I share this news joyfully: "Fergus, the pictures look good. Everything is as it was 3 months ago."

"That's wonderful. Really, I'm so grateful," he says. But his affect doesn't match his words, and after some hesitation, he says, "Doc, I didn't see Ahmed today."

My mind races. I could say, "No idea, Fergus," "Ask the nurs-

es," or "He might be late." I could quietly usher him to the door, signaling that our time is up. But that would be wrong.

Ahmed and Fergus: outliers in a clinic where grim predictions prove accurate for nearly everyone. Ahmed young, Fergus old; Ahmed whose appendicitis turned out to be a bowel obstruction caused by cancer, Fergus who had a colonoscopy to silence his nagging wife and had to admit she'd been right.

They'd sat in neighboring chemotherapy chairs, swapping stories. Wasn't the FOLFOX something? Not that FOLFIRI was any better, with hours spent in the bathroom. Lucky they both benefited from Avastin. From antiemetics to the best cafeteria choice, from childhoods in Ireland and Bangladesh to blistered feet, they always found something to chat about as clinicians prodded and examined them. Once, while reviewing their blood work, I overheard a reassuring discussion about Islam and Catholicism, each man giving his take on a good life. Noting a falling platelet count in one and diminished hemoglobin in the other, I hoped that neither would die.

"Doc, it's fine, you don't have to tell me," Fergus says now, looking crestfallen and apologetic.

"Fergus, he died. Ahmed died last week."

"I'm sorry. It's good of you to tell me, Doc. I know you have to watch privacy and all that, but . . . ."

My relief at having broken the news is replaced by panic. What if he calls Ahmed's shy wife, who avoids talking to men? What if he posts a death notice or sends her flowers? I visited Ahmed in his last days. Although he told his wife he wasn't in pain, she knew otherwise. When she whispered for him to slip away, he said he wasn't sure what lay across the finish line. But he looked weary, gaunt, out of place. Though we'd hoped it would never come to this, we were ultimately thankful for death's reprieve.

The normally jovial Fergus regards me through tears. "Can you tell me this much?" he asks. "Did he go peacefully?"

What should I say? Fear is written all over his face. Both men had the same disease, a similar pattern of spread, similar experiences with many treatments. In the end, Ahmed had an infection that wouldn't heal, a festering abscess. After multiple setbacks, he just wanted it covered up. Fergus had kept him occupied while nurses dressed his wound.

Was it a peaceful death, with that malodorous abscess on his abdominal wall? Was it a good death if he lingered long enough to become a shadow of the self who was once a lauded soccer player?

"Did you want to know something in particular?" I ask Fergus. Despite my sympathy for his plight, I hesitate to disobey a cardinal rule: Physicians don't discuss one patient with another. Fergus says, "I was just hoping that he didn't die in pain."

Clearly, knowing what happened to Ahmed is not a matter of curiosity for Fergus but something far more important. For in PERSPECTIVE PRIVACY AND ALL THAT

Ahmed's journey, he recognizes his own. "You hear all kinds of ways people die; the Irish love to talk," he says, sheepishly. But what he's really saying is, "Tell me I won't die in pain."

"Ahmed died peacefully," I say carefully. "We were able to give him adequate medication to control his pain. I talked to him, and although he was drowsy, he recognized me and smiled."

"I'm happy for his wife," says Fergus. "My wife said the strain was really showing in her face the past few weeks." Perhaps it takes a caregiver to recognize another caregiver's ordeal. "Doctor, if you speak to his wife," says Fergus, "tell her I'll miss Ahmed. It will never be the same again."

Visibly relaxed, Fergus smiles wanly. "I didn't mean to put you in an uncomfortable spot," he says, "but I feel better knowing this."

Still wondering whether I breached some protocol or upheld a covenant of trust, I go on with my day.

A few weeks later, Ahmed's wife calls to thank me. I'm bowled over when she asks, "How is Fergus?"

"Ah, OK," I stammer, thinking that any elaboration might be insensitive.

"Ahmed missed him a lot," she says. Then, overcoming her shyness, she says, "Fergus calmed my husband's fear of death. Please tell him I will never forget his kindness."

Having unintentionally become the messenger, I'm left pondering the way patients brought together by serious illness connect with each other's journey. While doctors provide medical explanations, patients engage with each other on a different and more practical level. They discuss wigs, disabled-parking spots, benefits eligibility, health insurance. They talk about their children and pets. They also talk about their disease, their drugs, what works and what doesn't. Though they're not conventional friends, seldom maintaining contact outside medical facilities, they're connected by the experience of illness. It's not surprising, then, that when a patient dies, the effect on other patients can be profound. Yet we never discuss this openly. A new patient takes up the chemotherapy chair, others share whispered questions about its former occupant, and things keep moving.

There's no protocol for sharing information with patients about their fellow travelers. We offer them anonymous anecdotes about patients who had a good response or similar side effects, but we're seldom called upon to tell patients about the death of someone with whom they'd grown close. There's an unspoken rule at a cancer clinic: If you don't talk about

others' deaths, perhaps you can stall your own.

But what of patients who are not merely curious about how someone died but also seek answers, reassurance, validation? We know there's a gulf between the sort of conversations we have about death and dying and the kind we should have. What if patients think the best guide to their futures is what happened to the woman in the next bed? We assure them that every case is different. That may be true of disease biology, but end-of-life worries can probably be captured in universal questions. How and when will I die? Will I be in pain? Will my doctors stand by me? Will my family suffer? Even if we answer well, our patients may look to their fellow patients for truth. A few, like Fergus, will brave asking their doctor. Like all sensitive conversations, this one can be therapeutic, letting us use our knowledge to assist patients at a difficult time.

I don't know how I'll answer another similar patient; I do, after all, worry about "privacy and all that." But I can't help thinking that Ahmed would be glad to know that Fergus feels better.

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DOI: 10.1056/NEJMp1307152
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