The quietly defiant patient

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It is 11:30 pm on a chilly fall night. I am in the emergency department, barely a quarter of the way through my internship.

I face a fatigued, bespectacled 50-something-year-old man who has waited a gruelling six and a half hours for this moment. I harbour serious doubts that my skills are worthy of such a wait but am not about to share this. The man is wearing a tie and dress shoes after a day's work. He explains that a few months ago he was told that he has esophageal cancer. He has come to the emergency department after clearing his throat and bringing up a small amount of blood. He has worked his normal day today, has eaten his usual spice-free meals, has neither smoked nor drunk any alcohol and has even gone for a walk that evening with his partner. He has come to the emergency department unaccompanied.

Seeing small amounts of such bleeding is not new to him, he explains. But such bleeding was alarming to his partner, who insisted he go to the emergency department. The long wait is behind him, and yet his expression seems to convey two conflicting urges: One is to run away from the hospital's moans and smells; the other is to remain and to learn what his medical prospects are now that he has experienced bleeding.

I avoid the man's gaze and pretend not to notice his careful scrutiny. I sense helplessness, both his and mine. I feel like an actor who has yet to learn her lines and yet must appear on stage before a discerning audience. I obtain his history and learn that he is otherwise healthy. I perform a physical examination — healthy.

I later try to convey a sense of confidence while examining his blood test results.

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I hear myself explaining that his blood counts are normal, consistent with his history of a small amount of bleeding. Playing the part of the reassuring clinician is a comfortable role to an intern like me.

He cautiously asks whether we might consult the surgeon who previously saw him. I agree that this would be helpful and telephone his surgeon. While doing so, I note that the patient worriedly watches, searching for clues that my expression may divulge.

The surgeon answers directly. The confidence in the surgeon's voice provides a much-needed sense of security in this tense moment. I turn the speakerphone on. The patient's six and a half hour wait is now to be rewarded.

"Tell him he's making a mistake in not having the tumour removed from his esophagus," the surgeon's voice orders.

The man's eyes appear to glaze. Is he crying? I pick up the receiver, cutting off the speakerphone.

"Tell him that once it spreads, it's game over," the surgeon persists. "He has to make a decision and it's dangerous for him to delay."

"What exactly needs to be done?" I ask. "What should I tell him?"

"He knows," the surgeon replies. "I've explained the surgery to him already. We need to remove the affected part of his esophagus and then sew the 2 remaining ends back together. This will involve pulling his stomach upward into his chest."

I turn my back to the patient to face the wall as I learn of the potentially life-saving standard of care for esophageal cancers. The patient's surgeon spares few technical details: the expected length of hospital stay and the known

complications, including severe breathing difficulties, pneumonia, heartburn, heart attack, stroke and death, among others. The conversation leaves little doubt of the gruelling and difficult nature of such a surgery. Yet the alternative is metastatic disease and death. The need for surgery before the cancer spreads is imperative, the surgeon explains.

The telephone call comes to an end, and I now turn to face the man.

"Your surgeon tells me that he has reviewed your treatment options with you," I tentatively say.

"I've heard what he has to say. I want to live my life as I did before my diagnosis. I want to live a normal life for as long as possible."

Having nothing else to offer, I listen. He has a lot to say. I learn that he is clear in his understanding, both of his diagnosis and of his prognosis with and without surgical intervention.

"Your bleeding has stopped," I hear myself saying. "Your surgeon will see you when you feel ready."

The man gazes at me for a moment longer. I see a tear roll down his cheek as he considers his options.

"Thank you for listening."

The man then stands up from his hospital chair and leaves.

Two days later, the hospital administrator telephones the ward to which I'm assigned. I am congratulated for helping this man and providing "great care," which perplexingly had been the very limited care of an intern. It feels to me a bit like cheating. Caught early in its course, esophageal cancer is a potentially curable disease. Should it metastasize, the prognosis worsens considerably. I dread what the surgeon may have to say about such "great care."

This event took place 25 years ago. I never learned what happened to this man after our encounter. The moral dilemma that this represented never made it into a medical journal, nor was it even presented at the hospital's surgical rounds. At the time, physicians did not view such encounters as opportunities for improving medical education. If a patient didn't accept the suggested treatment, it was simply felt to be their own fault. They were deemed noncompliant or misguided. The physician's perspective was a hard and fixed truth and not to be questioned.

Looking back, there are many urgent questions that I had not even remotely considered. How had this patient come to the decision to carry on with his routine in the face of his diagnosis? Why had he come to the emergency department alone? What were his fears? What were his personal goals in his care? Was he in need of counselling?

Had his physicians played a role in arriving at this decision? This patient had been but one of several emergency consultations that evening. Could time pressure have been a factor in our interaction? There had been a need to prove myself by seeing more patients that night. Providing simple responses to difficult questions lessened waiting times, but perhaps the quick pace came at the cost of missing out on his true medical needs.

Asking just a few of these questions 25 years ago may have led this conversation in a very different direction and provided very different conclusions. Twenty-five years ago, he had waited six and a half hours to obtain the care of an inexperienced intern who'd known enough to listen, but not enough to ask.

And now, 25 years later, this same but older physician better understands the meaning of this patient's quiet defiance: Listen more and talk less before insisting on a clinical path. His defiance had been an olive branch that if understood, could have helped in guiding his care. It had been our own defiance in not recognizing this that had failed him. He had expressed a need to be more fully understood, and his quiet defiance had gone unrecognized in its potential: a cry to be helped on his own terms.

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This is a true story, although it happened many years ago. Pertinent details have been changed so that the patient cannot be identified.

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