

GOMER

The truth is in the definition.

BY DAVID MULLER

THIN AND FRAIL, MR. HORN WAS BREATHING with pursed lips from advanced lung disease due to a lifetime of smoking. A bit too animated, neat to a fault, charming, and justifiably anxious—he had emphysema. He looked like a red-cheeked, short-of-breath Fred Astaire.

We first met in his Upper East Side apartment, where I came to see him for an initial home visit. He was referred to our Visiting Doctors Program by his equally anxious daughter, who'd noticed that for months his breathing difficulties had kept him from getting to the doctor for anything other than emergencies.

Mr. Horn was well informed when it came to his health. He regularly received newsletters with medical updates on emphysema, he was familiar with research on the subject, and he had an interest in complementary therapies. He knew that his lung disease was incurable and that he could expect to be more and more short of breath as time passed. He was also hard of hearing, so that I had to lean close, my lips almost touching his ear, and speak slowly and clearly.

Like many physicians, I'd spent a good deal of my residency training in Veterans Affairs hospitals, and, as a result, when I interview men of a certain age, I always include questions about military service. Elderly veterans such as Mr. Horn predictably become animated, no matter how sick, when asked about "The War." It is a matter of great pride; it helps them hark back to their youths and feelings of strength, and if you have a healthy respect for history, it helps make your patients more than human, it makes them heroes. Mr. Horn told me that he'd served in the CBI Theater ("China, Burma, India! Didn't you know?") as a sergeant in the Medical Corps. He had lots of stories to tell in our first encounter, but I would have to savor them another time.

Mr. Horn had an extensive smoking history and had lost his wife to lung cancer (she had never smoked). He and his children had watched her die a "bad" death despite inpatient hospice care, and this experience would color many of their end-of-life decisions. While reluctant to discuss the details of her final days, they made it clear that she had suffered unnecessarily and that the family's expectations for a "good" death had not been met. I wouldn't understand the true meaning of that disappointment until I experienced it firsthand more than a year later.

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David Muller (David.muller@mssm.edu) is dean for medical education at the Mount Sinai School of Medicine in New York City, where he works in Mount Sinai's Visiting Doctors Program. The name of the patient in the essay has been changed.

Mr. Horn's son lived with him in an impeccably neat two-bedroom apartment, and his daughter (who lived nearby) and son shared the responsibility of caring for him. Despite emphysema, Mr. Horn was independent around the apartment, but he couldn't walk more than a few yards outdoors because of the synergistic effects of low oxygen levels and anxiety. These problems fed off each other, sometimes to the point that he became debilitated just anticipating exertion. And yet he made his bed every morning, exercised on a stationary bicycle when he could, always dressed neatly, and made sure to preserve all of his wife's womanly touches around their home, from doilies to framed needlepoint landscapes.

When I first saw him, Mr. Horn had had a persistent cough for several months, despite seeing an internist, a pulmonologist, and an otolaryngologist for the problem. The cough kept him up at night, and he had lost about ten pounds. The thought on everyone's mind, including mine, was lung cancer.

Mr. Horn had his own ideas. He was appropriately concerned about his condition, but he felt that he was in no shape to undergo any kind of evaluation, much less any treatment, other than what we could do at home. He was also clear that he did not want to be taken to the emergency room or to be hospitalized under any circumstances. He understood that his emphysema was an illness that could not be cured. He had seen his wife die in a hospital inpatient setting and wanted more than anything else to be home when his time came. He clearly had given these issues lots of thought, and he was able to express his wishes to me succinctly and in a matter-of-fact manner. He confided that his real concern was how his son would get along once he was dead.

Caring For The Homebound Patient

MY FIRST IMPORTANT DECISION AS HIS DOCTOR was to stop his ACE inhibitor, a blood pressure medicine that can cause persistent cough. His cough disappeared in less than a week, he started eating, and my reputation was made. After that, he always told students who accompanied me on home visits how I had solved a problem that had stymied so many other doctors.

During the ensuing months, I saw Mr. Horn at home every six to eight weeks. I worked hard to get him on a regimen of minimally sedating medication for his anxiety; there was no longer any way to improve his lung function. For about a year Mr. Horn did quite well. But on a routine visit one morning, I discovered a lower-than-usual oxygen level and worsening forgetfulness. At the next visit he was a bit worse, so I asked his son and daughter for a family meeting. One week later, the four of us sat around the coffee table in Mr. Horn's living room for an hour and a half and talked about his condition. I explained that his lungs were deteriorating, making him weaker, more forgetful, and more breathless. I suggested home hospice care, and we spoke quite openly about his life-limiting illness and the benefits hospice would provide: nursing, an aide, supplemental oxygen, medica-

tion, and medical supplies, all for free. During this discussion Mr. Horn was alert, but he seemed unable to focus, and he was a bit disheveled. I had to repeat simple statements several times before he acknowledged that he understood. His children were hesitant to accept home hospice, and it took me some time to realize that this was related to their previous experiences with their mom being in inpatient hospice. I assured them that we could stop the hospice care if they ever felt that their needs weren't being met and that I would remain intimately involved in Mr. Horn's care. They ultimately agreed.

Mr. Horn declined rapidly over the next few weeks, and as he became more confused, his children began to worry that there were things we should be doing to evaluate the changes. Both the hospice nurse and I tried to reassure them that this was part of his dying process and that our focus should continue to be his physical comfort. At his children's insistence, however, we did some basic blood tests and found him to have a new and significant anemia. My impression was that this new finding was part of his inexorable decline, but there was no denying that anemia could be contributing to his shortness of breath and confusion. I shared these thoughts with Mr. Horn's children, but when they insisted, I was able to convince the hospice staff that two units of blood might give him some comfort and improve his quality of life.

The blood did nothing to improve his condition. In fact, five days later, he had a sudden decline at home. Despite his clearly expressed wishes and our extensive discussions, his daughter called 911, and he was brought to our emergency room.

Interrupting The Dying Process

THE FOLLOWING MORNING I WENT TO MR. HORN'S HOSPITAL ROOM and met the medical student assigned to cover him. We looked at his admission labs and discovered that his sudden deterioration was probably a result of dangerously high carbon dioxide levels in his blood. This typically happens when someone with his type of lung disease is given too much oxygen. In fact, it turned out, his family had kept him on high concentrations of oxygen at home, despite careful instruction from the hospice nurse and from me. And he had been given the same high concentration while en route to the hospital, in the ER, and in his hospital room.

When the student and I went to the bedside, Mr. Horn was still sleepy, difficult to rouse, confused, and disoriented. We turned his oxygen down to a safer level and hoped for the best. When the family arrived a few hours later, the student was at the bedside. Mr. Horn still looked as if he was in a deep sleep, but as soon as the student squeezed his hand, his eyes opened and he greeted his children, much to their amazement and delight.

Still, during his hospital stay his decline continued, compounded by delirium from the unnatural hospital routine. It was clear to the medical team that Mr.

Horn was terminally ill and would not survive the hospitalization. The family seemed to have come to terms with that during the first few days of his hospital stay, but then began to ask about life-supporting interventions. Did they really think he was going to recover and return home? Did they no longer realize he was going to die?

We arranged a family meeting. On the appointed day, the resident, student, and I entered Mr. Horn's room. He was sitting upright in bed struggling to breath, his disheveled hair plastered to his sweaty forehead, the respiratory mask askew on

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his face, his eyes wide open and searching. His children were at the foot of his bed. We greeted them and then spent time trying to communicate with Mr. Horn. He seemed to recognize me but didn't know my name. He didn't have his hearing aids, so we resorted to writing messages on a pad of paper. Despite being able to read the notes, he was unable to concentrate, and he kept calling for someone “in the other room.” When we took off his mask to ease communication,

his oxygen saturation slipped from the needed 90 percent to less than 70 percent, and we had to quickly replace it.

His children asked about his condition. We explained that he was doing very poorly, that he continued to worsen despite all of our interventions, and that there was no reversible cause for his decline. This wasn't an infection that was going to resolve or a medication error that we had yet to discover. He was dying from his emphysema. We thought that it was important to focus on his comfort at this stage and suggested that small doses of morphine might significantly relieve his distress and his shortness of breath.

That's when it happened. His daughter turned to me and angrily said, “I know he's just another GOMER to you! That's why you won't do anything for him!”

Now, GOMER is a funny word. It's an acronym that was first coined in an irreverent 1970s book about medical training by Samuel Shem titled *House of God*. GOMER stands for “Get Out of My Emergency Room,” and the book suggests that it is the general sentiment of doctors toward patients they would rather not take care of—sometimes because the patients are homeless and smell bad, sometimes because they're old and have no hope of meaningful recovery, and sometimes because the doctors are too tired to care.

I hadn't used the term GOMER since my internship fifteen years ago, and here was this woman accusing me of treating her father like just another case—just another emphysematous lung to get onto the launching pad for discharge as soon as humanly possible. What happened to all those check-ups at his dining-room table; the careful study of his bathroom to figure out why he panicked whenever he needed a shower; all those phone calls and prescriptions and fights with his man-

aged care plan? Here I was at this man's bedside, at his deathbed, with trainees in tow, and a very angry family member to contend with. How—and why—did his daughter manage to dredge up this offensive term?

Living With The Consequences

WE'RE TAUGHT THAT PATIENT AUTONOMY IS THE sine qua non of ethical patient care and that clarifying a patient's wishes in the presence of caregivers is an indispensable way to ensure that their wishes are respected. After ten years of making home visits and helping patients die at home, I believe that there is a corollary to this rule. A patient's wishes are important, but after the patient dies, family members have to live with the consequences of the decisions they made in those last days. Their experience with death includes unanswered questions after every conversation with the doctor, second-guessing every change in medication, and obsessing over every teaspoonful of pureed food. While I would never countenance overturning a patient's stated wishes, I have been known to tweak a plan of care to help alleviate a family's misgivings.

Mr. Horn's children had asked for a blood test, and I had complied. At the time, it seemed a harmless intervention that would help them feel that they weren't neglecting him in his time of need. Unfortunately, it led down the path to transfusion. The physician can easily and inadvertently feed the family's belief that medical intervention makes sense.

Add to the mix that a family member is often the medical proxy (the legally designated person to make decisions) once a patient is no longer able to make decisions for him- or herself. For any given patient, a doctor might have to take into account different opinions, different personalities, and a lifetime of complicated family dynamics. This requires skills that aren't taught in medical school and the ability to work seamlessly with others who are expert at this, such as nurses and social workers. Doctors can play a crucial role in orchestrating a "good" death, but they can also—despite the best of intentions—be a party to a miserable one.

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Mr. Horn languished in the hospital for more than a month after that bedside family meeting. His daughter apologized immediately after her GOMER comment, but neither she nor her brother ever agreed that his care should be strictly palliative. He was delirious every minute of every day, hungry for air, bedbound, incontinent, and often restrained. He finally died when there was nothing left of him.

I wish he had never come to our emergency room.