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# The Goses

**By Gerard Spiniello**

Several years ago I began moonlighting one night a week at a long-term care facility (LTAC) here in Boston. This unit was a place where sick patients were sent usually after a prolonged stay in an acute hospital for some horrendous illness. Most of them came from the big downtown hospitals. These were the patients who had been at death's door but didn't quite make it through. They had suffered complication after complication and spent weeks or even months languishing in the hospital. After receiving this acute hospital care, they still required skilled in-patient medical treatment. Some were on ventilators, still unable to breath on their own. Others required prolonged courses of intravenous antibiotics for deep-seated infections such as endocarditis and osteomyelitis. There were patients who had surgical complications and leaked unidentified fluids from partially healed incisions. Many had permanent changes in their mental states from strokes and intracranial hemorrhage, leaving them non-**c**ommunicative or in a vegetative state. Not all of them were elderly. Some patients were in their forties or fifties and even younger.

The MACU (medical acute care unit) consisted of two long corridors with private and semiprivate rooms. It occupied an entire floor of a large in-patient geriatric facility building. When the place was full, the census was about forty patients. Despite the brightly painted walls and curtains, it was a dismal place, a museum of medial failures. Patients who could get out of bed were propped up in wheelchairs or "Geri" chairs and placed in the halls along with their multiple IV pumps and tube feedings. I would come to learn in time that the MACU was also something else: It was a testament to the resiliency of the human spirit. No matter how sick and disabled some of the patients were, they continued to fight and wanted to stay alive no matter what.

There sometimes comes a point in the course of a patient's illness when treatment becomes futile. Just because we can do it does not mean we should do it. It is not always appropriate to offer some treatments to patients if it may prolong their life but not maintain or improve its quality. The goal of medicine has always been simple: relieve suffering, first and foremost, and in the process do no harm. But as a byproduct of our tremendous advances in medical treatment we have, in some cases, not cured disease but only prolonged suffering. Some of the patients I cared for on Monday nights were stuck in a cycle of low grade, chronic instability. They were in limbo. Some had no hope of meaningful recovery but were kept alive with expensive, invasive and aggressive medical interventions. Pacemakers kept their hearts beating, respirators kept them breathing, and they were fed through tubes inserted directly into their stomachs. They were, in my view, the living dead. It hurt my heart to care for my Monday night patients. I had never seen so many people in one place so close to death.

Mr. Kinsey was a 90-year-old gentleman who was dying of metastatic disease. His bone scan lit up like a Christmas tree. He was suffering from a long illness and not the usual

transfer from a downtown hospital. He apparently was presented to his primary care doctor in this advanced stage, and there was nothing much to do for him except radiate some of his painful bony lesions. The goals of care with a patient like this are geared towards palliation of symptoms and a peaceful death. Interventions such as intubation and artificial ventilation would be futile and would only prolong his suffering. There was only one problem: Mr. Kinsky was an Orthodox Jew.

At the beginning of my usual Monday overnight shift I would get a "sign-out" from the doc going off duty. I was told Mr. Kinsky's condition was deteriorating and that he was a "full code." I always cringed when I heard that little tacked-on message, "Oh, by the way, he's a full code." This inferred that the patient shouldn't be a full code, but because there was not a formal DNR (do not resuscitate) order, everything had to be done medically in the event of a cardiac or respiratory arrest. I thought to myself, "It would not be pretty if I had to stick a tube down this guy's throat and pump on his chest. I would probably break a bunch of ribs with the first compression. This wouldn't be a code; it would be assault and battery."

The patient's son Mendel had been given the option earlier in the day to make his father a DNR/DNI (do not resuscitate/ do not intubate). He was apparently struggling with the decision. At the beginning of my shift I usually visited those patients with active issues. I went to Mr. Kinsky's bedside to see how he was doing. The patient was an elderly cachectic man lying in bed with his eyes closed and arms at his side. His black yarmulke contrasted sharply with his pale white skin and his full long white beard. His respirations were labored. He sat almost upright in the bed with the head raised 45 degrees to help him breathe. His lips were slightly cyanotic, and I could see a few beads of perspiration on his forehead. His son was seated at his bedside and bolted to attention when I entered the room. He was dressed all in black and wore a traditional wide brimmed hat. His beard was long and dark and reached to the middle of his chest. He had heavy eyebrows and wild untrimmed nasal hair. I couldn't help but stare at it. I extended a handshake but the son simply looked down, avoiding eye contact, and practically pushed me out of the room into the hall. He mumbled something that sounded like, "Let's talk out here." It was apparent he did not want his father to hear any of our conversation.

Out in the hallway I could see this man was anxious and in acute distress, his eyes darting from me to the floor to the paper he held in his left hand. He said, "They want me to sign this paper that says I don't want my father to be resuscitated."

I asked, "Do you know what that means?"

He said, "Yes," and then there was a long pause. "But it's not that simple."

I thought to myself, well, it's pretty simple to me. Your father is dying and has no hope of recovering, so we should make him as comfortable as possible, and let him go. I did not formally examine the patient before his son hustled me out of the room, but just at a glance I could tell he was slipping into respiratory failure. He would need to be tubed and put on a vent if he was not made DNR/DNI. I explained this to his son.

He asked, "Would putting him on a ventilator make him live longer?"

"Yes, temporarily."

"Would he suffer?"

I said, "We could sedate him: give him narcotics and sedatives to help him relax and let the machine control his breathing."

"Have you done this before?"

"Yes, many times."

The patient's son had a pained look on his face throughout the course of our conversation, and I could tell he was struggling here.

He then asked, "Would the medication you give make him die quicker?"

I didn't quite know how to answer this or where this line of questioning was going. I was confused. Did he want me to keep his father alive by tubing him and putting him on a vent or hasten his demise with intravenous narcotics and sedatives? Families sometimes tend to speak in code when under stress and faced with difficult treatment decisions involving loved ones. I took the liberty of calling the patient's son by his first name, "Mendel, isn't the important thing that your father not suffer?"

He looked me right in the eyes now and with a genuine expression of sadness and in a soft, barely audible voice again said, "It's not that simple." He then asked, "If we do nothing, how long will he live?"

I said, "Only God knows that."

A slight smile broke through his despair.

"My father has led a good life and has always obeyed the law, the Code of Jewish Law: Shulchan Aruch, and done the right thing. Not the easy thing, but the right thing. Now I have to be sure, very sure, I do the right thing for him at the end."

Mendel Kinsky leaned against the wall and was now stroking his long black beard with his right hand staring at the DO NOT RESUSCITATE order in his left hand. He looked like he was contemplating some deep dark mystery. He was. He was trying to determine if his father was a *goses*. According to Jewish Law, a patient before death may fall into this category. A *goses* is a person who it is estimated has less than three days to live. During this state no treatment can be instituted that will prolong the patient's life, and no measure can be withdrawn that will shorten it. The way I saw it, when God puts his hands on the patient, we medical people should take ours' off. So resuscitation of a *goses* is a tricky question. That's why Mendel wanted to know how long I thought his father would live. His other question made perfect sense. If placing him on a ventilator would extend his life by weeks or months, it would be worth doing. If he would die within hours or days of intubation then it would have no value and be forbidden. If the narcotics and sedatives I administered had hastened his father's death**,** this would not have been allowed. Anything and everything should be done to prolong life if there is an underlying reversible cause for the patient's demise, but if there is no hope of survival and the patient is expected to die within days, there can be no interference with the dying process. It was at this point that Mendel told me his father was a rabbi.

This was one of those times when I really questioned my career decision. I thought about friends and classmates who had gone to law school or into business with their expense accounts, two-hour lunches, luxury boxes at sporting events and the ever popular work-from-home option. The only time they got up at night was to go to the bathroom. Just then Rabbi Kinsky's daughter came rushing out of his room with a look of panic on her face, "Come quickly."

I rushed back into the patient's room and found him again sitting up in bed with labored breathing. I asked him how he was doing and pulled down his green plastic oxygen mask, so he could speak. He looked more alert and smiled at me as he spoke in short breathless sentences, not being able to get out more than a few words at a time. "What is it? What is the talk? All the talk? In the end—there should be….less talk... and more...feeling-thinking….and more remembering. More understanding….and more

forgiveness. God knows all...and will forgive...forgive no matter what we do. And the rules….the rules….all the rules...they don't matter that much—at the end—as long as…. you followed... the rules... at the beginning...and in the middle. Don't worry so much... about doing the wrong thing at the end."

It seemed as though the patient had heard every word of my conversation with his son. He spoke in a kind and reassuring way, as if I were the one to be comforted here. I got the sense he truly cared about what I was feeling and how I might be afraid of doing the wrong thing as I struggled with the details and decisions regarding his care. I sat in a chair at the bedside to his right. Without looking up he extended his arm and patted my shoulder. "Thank you." There was a sense of finality to his voice, and indeed, these were to be his last words. I thought he should be saying these things to his son, but clearly he wanted to say them to me. Why did he care so much about my feelings? I had never met this man before and was stepping into his life at literally its last moments. I had guessed it was because he was being true to himself right to the end. As a rabbi, he had always cared about people and what they thought, how they felt, and comforted those he thought were in need. Why should he stop now?

I went to see some other patients and returned to Rabbi Kinsky's bedside. Mendel could clearly see that his father had slipped into a coma and was actively dying with shallow, labored respirations. I felt a definite change in the tone and mood of the room. Mendel and his sister seemed more relaxed, more at peace and smiled when I again sat down at their father's bedside. Rabbi Kinsky had told me directly, and his family indirectly, not to worry so much, especially about making mistakes or breaking any rules. Without any further discussion, I ordered the patient to receive sedation. It didn't take long for him to be more comfortable. He actually seemed peaceful. I kept vigil with Mendel and his sister at the bedside for several hours. Rabbi Kinsky passed away peacefully as the sun came up, filtering into his room on a Tuesday October morning.

Medicine is imperfect. Clinical scenarios are never fully predictable, but listening to patients and their family, really listening to what is being said, and sometimes more importantly to what is not being said, will guide a doctor's clinical compass. I had listened. I heard the patient, I heard the family, and I had listened to my own inner clinical voice. My sense is that we all agreed.

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