

Pandora's box

Paul Rousseau

Palliative Care, Charleston, SC, USA

Correspondence to: Paul Rousseau, Palliative Care, Charleston, SC, USA. Email: palliativedoctor@aol.com.

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It's hard for physicians and patients to peer into the soul of death...when time is counted in hours and days (1).

"How'd your visit go with Mr. Jones?" I asked.

"As well as could be expected, I offered him treatment, he's going to let me know what he decides tomorrow."

"By treatment, you mean chemotherapy?"

"Yes."

"How long do you think he has to live?"

"Well, maybe two to three weeks, depending on how he responds to chemo—if we can even give him chemo. His performance status is so poor."

"Did you tell him that? How long he'll live, I mean?"

"No. He asked, but I told him maybe six months, perhaps longer if chemo worked. It's hard to tell people that they're...that they're..."

He paused, "Are you going to do a consult on him? He and his family really need palliative care. Maybe you can give him a better estimate of his prognosis; I just didn't have it in my heart to tell him."

Mr. Jones was a 72-year-old man with metastatic pancreatic cancer. Per his chart, he was extremely cachectic, weighing seventy-nine pounds—"skin and bones" was how one nurse described him—and was barely able to lift his head from the pillow. When I reviewed his chart, there were no notes that suggested, at least to me, that chemotherapy would even be an option. It sounded like he would die in hours to days.

When I entered his room, Mr. Jones' wife and three adult children sat bedside. Various catheters snaked from his bruised and bony arms carrying saline, antibiotics, morphine, and total parenteral nutrition. His face was covered by a fogged oxygen mask that muted his gurgled breaths; his eyes gazed upward, as if being pulled by a magnet. The room was quiet save the hiss of oxygen and the erratic beep of the heart monitor.

"He just had a bolus of morphine," his wife said, "Normally he would be more awake."

"I understand, it's more important right now to get his pain controlled. Why don't you and I speak?"

We stepped outside the room to a waiting area. I sat and talked to Mrs. Jones and her children for the next hour. They knew Mr. Jones was dying, and they knew chemotherapy would likely be futile; his tumor burden was just too great. In fact, they worried it might kill him. Still, they said it was his choice. To him, chemotherapy was his "last hope".

I told them that they were right, that no matter what we did, his time was limited, but if we could reframe hope to living as long as possible, surrounded by family and friends, and with symptoms controlled—but without chemotherapy—perhaps we could help him, and them, heal. What I didn't want for Mr. Jones was unnecessary suffering; what I didn't want for his family was a grief burdened by "could haves and should haves" and missed opportunities for time together.

"Dr. Rousseau, we've gone along with what my husband wants. It's his cancer, and it's been his decisions what to do. We've supported him one-hundred percent. But it's been like a big Pandora's box that he prefers remaining closed, for if opened..." Her voice trailed off.

After a few moments, she spoke again, "He just doesn't want to die. One doctor said it's denial. But in his heart, I think he knows what's inside the box." She looked at the floor. "Why did the cancer doctor even offer chemotherapy?"

My mind searched for words; the physician-patient relationship is a precious human bond, and I didn't want to destroy that bond.

"I know this may sound strange, but his cancer doctor cares about him, in fact, he cares so much, he can't tell Mr.

Jones 'no' when it comes to chemotherapy, nor can he tell him how long he'll really live."

"I understand Dr. Rousseau, but it just doesn't seem right."

I had to agree with her. Lamentably, many physicians are uncomfortable sitting in the midst of suffering—they don't know what to say, they find silence difficult, and they feel uneasy responding to emotions. After all, doctors tend to be talkers and doers—we radiate, we operate, and we intubate, but we don't always alleviate. We try to fix suffering by doing what we've always done, treating the disease, not the person. We're experts in physical distress, but novices in spiritual and emotional distress, especially when someone is dying. We're inclined, by our training and by our experience, and yes, by our love for our patients, to treatment and interventions. So that's what we do: we treat the disease—with chemotherapy, with radiotherapy, with surgery, with whatever we think will help.

However, some argue that medicine is the culprit—that it has changed. And it has. It's become a distant and impersonal environment that values volume, numbers and data over caring for the person. In fact, it's evolved into a commercial transaction that has only served to further distance the physician from the patient. Government regulations, insurance mandates, quality metrics, productivity quotas, economic 'incentives', electronic medical records, and time constraints have increasingly pushed physicians into a clinical environment of paperwork and pencils rather than patients and presence. Still, I believe truth and healing are possible within such an onerous

environment, for the words of truth and the balm of healing need minutes, not hours.

I told Mrs. Jones, I would return in a couple of hours, and hopefully Mr. Jones would be more awake. But as I walked down the hall, I wondered how our concern for self-preservation—for that's what it is when we're not truthful—had somehow supplanted the importance of the patient and healing. To be healed—to accept that death is near, and that family, comfort, and peace are most important—is essential, not only to patients, but to their families. Healing makes the person whole, and restores their personhood and their worth as a valued human being. But it requires truthfulness and a willingness to experience suffering: both ours and the patient's. There's no other way, and hard as it may be, that means sitting with the patient and attending to the messy emotions of life—and death. It means opening Pandora's box, for then, and only then, can we truly heal.

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Footnote

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References

1. Rousseau P. Presence. *J Clin Oncol* 2010;28:3668-9.

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