Dying to Talk

Ranjana Srivastava

JAMA. 2009;301(8):807-808 (doi:10.1001/jama.2009.207)

http://jama.ama-assn.org/cgi/content/full/301/8/807

Dying to Talk

In a selfish way, I am relieved that he has outlived other atrocities to prepare him for this final one. Mr V has survived war, then a brush with cancer that was supposed to have ended his life. Ten years ago, an aggressive stomach cancer required a gastrectomy and chemotherapy. He was given a bleak prognosis, but when he passed the three-year mark, things looked optimistic. At five years, he relaxed, and at ten years, he was pronounced a survivor.

A month later, he began experiencing abdominal pain and was found to have recurrent cancer. The disease had returned with a vengeance, dotted throughout his abdomen, causing his bowel loops to become matted in a dysfunctional mass. The bowel telescoped into the esophagus, making it extremely painful for him to swallow.

His disease is inoperable. A nasojejunal tube worsens his pain and has to be removed. A jejunostomy in a heavily cancerous abdominal cavity is considered too dangerous to attempt. I am asked to see him, more out of wishful thinking than necessity. The referral note reflects the intern's perturbation—she asks for my opinion on palliative chemotherapy, but it is the plea in the last line that catches my attention: "We are concerned about our growing inability to feed or hydrate him and would be grateful for your input."

I walk into his room to find him nodding off. Saline drips into his arm, which lies awkwardly positioned in the narrow bed.

"I am the cancer doctor."

"I was expecting you," he responds weakly. I look around for his wife but he tells me she has stepped out for lunch.

"She is always here, the poor dear. Let her have a break." His voice is gentle and affectionate.

I ask him how he feels. He is pale and thin, with pronounced, dark brown eyes framing an expressive face. His spacious forehead contains many furrowed lines, as if he has needed each one to ponder the challenges life has thrown him in his 50 years. His black hair is sparse now, but he would have cut a handsome figure in his youth. His limbs are long, the movements of his fingers fluid.

"My biggest problem is pain. I can't even swallow my saliva. The doctors say, 'Try to eat,' but they don't listen." His face contorts with pain.

"I can see. Does the morphine help?"

"Nothing helps, Doctor." I cut to the chase.

"Your surgeons can't insert a feeding tube. They have asked about chemotherapy, but I am more concerned about your nourishment."

"Basically, there is no way to feed me," he states flatly.

I shake my head regretfully. "I can talk to your doctors again."

He holds up his hand in surrender. "They have all come by and said there is nothing."

Despite no oral intake for days, he projects a clear mind. Adjusting his posture in bed, he says simply, "It seems that I will die of starvation before cancer."

He has breathed words into my fear. I scan his face, calm and pensive.

"I don't want chemo and I don't mind dying, but it would be nice to eat and drink."

"I understand," I respond somberly, wondering how to deliver the undeliverable.

It becomes apparent that his predicament has been discussed extensively. When I return to his bedside, his wife springs from her seat. I quickly tell her that I have nothing new to offer. Her face droops but he replies sagely,

"This time it won't let me escape, but it's good of you to try." Involuntarily, he reaches out for one of many drinks arranged on the table. One sip later, he realizes his mistake. Her eyes flick from him to me in silent accusation.

As the days pass, I experience much moral distress. I wish he would protest or show some anger or resentment, anything to allow an opening to counsel him. But he is resolutely calm.

It is hard to believe that in this modern age, when there are seemingly inexhaustible ways of achieving a given outcome, we all draw a blank at Mr V. So many times, I have bemoaned my profession's collective inability to say no. But today, I long for a reprieve, hoping someone will agree to take up his case, giving us something to feel better about, if only temporarily.

His wife calls me. "He hasn't eaten for days. They say the IV can't stay in forever."

"I understand."

"Then he will die!" she says, bewildered at our inability to stem her husband's inexorable decline.

"I am sorry." What an inadequate expression to encompass my feelings.

"You must know experts. Can they help?"

"Would you like a second opinion?" I bite my tongue even as I make the offer.

"Yes! Yes! That's what we should do!" Her enthusiasm is infectious and for a moment, I too let myself imagine that some invisible force will help her husband. She immediately embraces me as her ally. I feel guilty at the thought of playing for time.

A Piece of My Mind Section Editor: Roxanne K. Young, Associate Senior Editor.

I find myself persistently musing over the situation, unusual even for one faced with tragedy and death on a routine basis. Discovering my own helplessness mirrored in the patient's, I realize that I am angry at having no one to be angry at. It seems absurd that in an era when the wonders of medicine seem too many to count, we cannot fulfil an urge as primal as hunger and thirst.

"What can I do to make him eat?" his wife enquires after watching him go without food and water for another week.

"You can't," I counsel.

"But how can he live like this?"

We both know the answer.

He grows weaker. His occasional excursions to the bathroom with his walking frame stop. One afternoon, I find him alone again. His response to my perfunctory questions about his pain, thirst, and hunger are predictably gracious. But there is something unspoken: our relationship has evolved and I don't feel like his treating physician because I have never done anything therapeutic for him.

Eager to find something positive about his circumstances, I remark on how he seems at peace.

"You are a good man. This is very unfair."

"Even good men die," he responds quietly, revealing his own sadness. "I have known many of them."

"Are you afraid of dying?"

"No. But I find the starvation hard." This is the first time that he has expressed this sentiment; it is confronting to hear him say it.

"It seems like a personal failure to me that we aren't able to help you."

"That's the most one can ask of a doctor. That means I have been in good hands."

Breathing heavily, he drags his body up the bed. The sliding covers reveal wasted muscles, parched skin. "I have something I must ask you. I want you to tell me how I will die." Perhaps he catches a flicker of hesitation on my face for he adds, "I have asked a few doctors, but no one wants to."

Expectant eyes fill his face. Although I feel disinclined to dwell openly on his death, I also feel relieved to do something within my capacity. He starts before I demur.

He has seen his father die of respiratory failure—can I ensure he avoids air hunger? His friend suffered from uncontrolled pain—does the hospital ever run out of pain killers? Does the body adapt to slow starvation, making it harder to die? Does unconsciousness hurt? Could he surface from this deterioration and be forced to live again? What will I write as the cause of his death?

Outside, the daily business of the hospital continues. A panicky voice trembles as it announces a code blue; an intern cajoles a nurse to insert a catheter; a demented man wanders off the ward again.

I feel uncomfortable that I, who cannot help him live, am readily entertaining his death. I keep one eye on the door, as if to avoid getting caught for discussing death when my duty is to save lives. But gradually, as our conversation unfolds, he relaxes and I feel at ease. I am persuaded that this is therapeutic, indeed cathartic, for us both.

Physicians are partial to terms such as *fix*, *cure*, and *conquer*. The medical student counts a successful rotation as one with procedures; the resident is triumphant when he clinches the diagnosis; the attending likes nothing more than an efficient ward round of patients whose medical and social issues are "sorted." Absent from this narrative of professional development is a cohesive way in which to deal with the disappointment, frustration, and plethora of emotions that accompany our perceived failure at conquering disease and suffering.

Had Mr V needed consent for a procedure, many physicians would have been willing, but when it came to talking about his inevitable death, the reluctance was all too real. Part of the reluctance stems from the perceived lack of expertise in having such conversations. However, physicians are also poor at accommodating the notion of not being in control.

I was surprised at how long I continued to search for an answer to Mr V's problem when I knew there wasn't one. But what I found hardest of all was casting aside my own reluctance to discuss his dying. How ironic, that we, witnesses to life in all its glory and ruin, have yet to come full circle and talk easily about death.

I hope that we can invest more resources into teaching physicians to engage with their patients about death and dying. As the population ages, there will be a preponderance of patients with complex chronic illnesses. Many will seek guidance and counseling about end-of-life issues and place their trust in their physician to discuss matters that may be considered anathema by others. But this is a skill that also does not come naturally to most physicians, who would rather enthuse about a new therapy than entertain morbid thoughts about death.

Discussing the broad issues surrounding dying does not necessarily have to be the domain of one expert or even the hospice team, especially because the majority of deaths do not occur in hospice. A key focus of education and training across all specialties should be to teach ways of dealing humanely with questions about the end of life and recognizing when to summon assistance.

In the end, just like our other conversations, the one about death and dying requires us to set aside our own judgments and present an open mind and a ready ear to patients. Even if we will not deserve their praise for a cure, we will have earned their gratitude for easing the process of death.

Ranjana Srivastava, MBBS(Hon), FRACP
Melbourne, Victoria, Australia
docranjana@gmail.com

Postscript: Mr V elected to go home without taking up the offer of subcutaneous fluids. He spent a few good days at home with his extended family. He subsequently asked to be readmitted to hospice to avoid his wife's distress at his inability to drink. He died within a short time thereafter.