

DOCTOR AND PATIENT

Talking Often, and Calmly, About Dying

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This past week, as end-of-life care discussions joined the political conversation, I thought a lot about a patient I'll call John.



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John was the son of Polish immigrants and a man still grieving over the death of his lifelong partner a few years earlier. Over the course of caring for him, I heard about his wife, her final gift of a gold crucifix necklace so heavy his head seemed bent down in permanent supplication, and his regret over not having died first to help his bride adjust to life “beyond those Pearly Gates.”

Despite all those conversations about the death of his beloved wife, I never asked John how he might have wanted to die.

Recently diagnosed with inoperable lung [cancer](#), John had been admitted to the hospital with intractable [shortness of breath](#); he was drowning in the fluid produced by his [tumor](#). His cancer doctors, hoping to give John a few weeks' time with the latest [chemotherapy](#) regimen, asked me to place a tube the size of a small garden hose in John's chest as an indwelling drain. Even with plenty of local anesthetic, I knew that it was an uncomfortable bedside procedure that verged on painful.

But other than a single cry of pain, John did not complain when I inserted the chest tube. And he hardly protested or asked questions a few days later when that tube became clogged and I had to place another. Soon afterwards, the gurgling sounds of his breathing increasingly audible, John required a third chest tube.

John's health deteriorated despite our best efforts. His sentences became one-word gasps. His eyes became glassy. He began wearing a humidified oxygen mask, and the head of his bed became enveloped in a moist plastic scent so sharp I gagged from the taste every time I leaned over his bed to listen closely to him. Never alone in a room shared with three other male patients, John endured the fearful stares of their visitors; he was too tangled up in tubing to get out of bed and draw the flimsy polyester drapes that would afford some privacy.

Three days before he died, just as a doctor was about to insert a breathing tube down his throat, John asked to be left alone. He signed a "Do Not Resuscitate" order. He set the oxygen mask aside. He disentangled himself from the long tubes that connected his chest tubes to suction. And he received enough morphine to ease his shortness of breath and to relieve him of that constant sense of drowning.

In retrospect, I don't know if John wanted all that we did to him because we never had that conversation. John's admission to the hospital had set the health care train rolling; and neither I nor the other physicians had the time, support or courage to think about putting the brakes on long enough to find out what John wanted. We were too afraid of taking away John's hope and believed that if we mentioned death, he would believe we had given up.

I thought about John, and patients like him, as debate about end-of-life care continued to heat up. What started out as legislative proposals to finance optional end-of-life care consultations between doctors and patients morphed into governmental bodies (so-called "death panels") that would decide which dying patients would and would not receive care based on cost-cutting measures. False assertions and rumors resulted in debates

so ferocious that even well seasoned health care advocates were taken aback.

As someone who has written an entire book about the difficulties of caring well for the dying, I find all the fury aimed at halting support of end-of-life care discussions more than a little ironic. Why? Because the truth is that most of us need all the help we can get to start these difficult conversations. The truth is that we never talk or even want to think about talking about dying because we are afraid of dashing our loved one's or our patient's hopes. The truth is that we fear — even abhor — these discussions because we believe that by talking about dying we are giving up.

Yet all of those imagined fears could not be farther from the reality of end-of-life care discussions. At least according to some of the best research on the impact of those conversations on patients and their loved ones.

I spoke recently with Holly G. Prigerson, director of the Center for Psycho-Oncology and Palliative Care Research at the Dana-Farber Cancer Institute in Boston and a nationally recognized leader in research on end-of-life care discussions. While health care providers and family members may worry about dashing hope, Dr. Prigerson and her colleagues have found that most patients were in fact relieved when the topic was broached. “We expected patients who were told they were terminally ill to be more upset,” Dr. Prigerson said. “But they weren't significantly more anxious, overwhelmed, distraught or hopeless. In fact, people were more afraid of the unknown than they were of bad news; and having the conversation and having people acknowledge that they were dying seemed to come as a relief.”

[In a study published last year in The Journal of the American Medical Association](#), Dr. Alexi Wright, a medical oncologist from Dr. Prigerson's research group, and co-investigators found that patients are not the only ones who benefit. Discussions about end-of-life care can be beneficial for survivors, especially after their loved one's death. “These conversations affect how patients die; and the way patients die affects how their family members adjust to loss,” Dr. Prigerson noted. “End-of-life care

conversations are not just acute, time-limited events. They should be repeated and they appear to have enduring consequences.”

Even for patients who want to pursue every possible avenue of treatment, end-of-life care conversations remain important as they serve to remind physicians and health care providers of each patient’s particular preferences and background. [Dr. Prigerson and her colleagues recently studied women with advanced cancer](#) who also had young dependent children. Not surprisingly, these women were more likely to seek treatment that focused on extending life rather than relieving discomfort or pain. Unfortunately, [like patients in other studies](#) who opted for more aggressive care, these women had higher levels of [anxiety](#) and significantly poorer quality of life. But, as Dr. Prigerson observed, “No one is saying that they shouldn’t get the aggressive care that they want. These women were having the conversations that allowed them to say what they wanted and to get more aggressive treatment.”

While the timing and appropriateness of these discussions should be considered in each individual case, talking about end-of-life care “doesn’t inhibit or prohibit patient choices. Instead patients will be more likely to make better informed decisions and to get the kind of care they want. And physicians will have an idea of their patients’ preferences, regardless of what those preferences are.”

“At this point,” Dr. Prigerson reflected, “the studies show that patients and families benefit. Even if they are not told, patients who are dying probably suspect that something isn’t right. They appreciate the honesty of these conversations, which in turn enhances their trust in and the therapeutic alliance with their doctors.

“If patients remain silent, their voices won’t be heard. And the effect on patients and surviving family members can be significant and enduring.”