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Misunderstanding Chemo

By
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Let's start with a simple medical fact: Chemotherapy doesn't cure people who have very advanced Stage 4 lung or colon cancer.

Chemo can be quite effective at earlier stages. Even in late-stage disease, it may relieve symptoms for a while; it might help someone with tumors in his lungs breathe more easily, for example. Chemo can extend life for weeks or months.

It can also make the recipient feel nauseated, wiped out and generally lousy, and require him to spend more time in clinics and hospitals than a dying person might choose to. But it can't banish cancer. Many aspects of medical prognosis and treatment are uncertain. Not this one.

Such patients' doctors have almost certainly told them their cancer is incurable. Those who opted for chemotherapy anyway had to sign consent forms spelling out the potential side effects. Yet Dr. Jane Weeks, a research oncologist at Dana-Farber Cancer Institute in Boston, knew from previous studies that cancer patients can develop unrealistic ideas about their odds of survival.

So as she and her co-authors began analyzing results from the first representative national study of patients with advanced cancer, all undergoing chemotherapy, to see what they thought about its effects, Dr. Weeks expected many — perhaps a third of them — to get it wrong.

She was staggered to see how mistaken she was.

Nearly 1,200 patients or their surrogates were interviewed within months of a diagnosis of Stage 4 colon or lung cancer. They answered a number of questions during these telephone interviews, but the key one was: "After talking with your doctors, how likely did you think it was that chemotherapy would cure your cancer?" The only correct answer: "Not at all likely."

But a great majority chose one of the other responses indicating some likelihood of cure or else said they didn't know. The study, just published in The New England Journal of Medicine, found that 69 percent of lung cancer patients and 81 percent of those with colon cancer misunderstood the purpose of the very treatment they'd been undergoing.

The misperception was significantly higher among African-Americans, Asians and Hispanics than among whites — but not because of education levels, the usual variable in studies of health knowledge. "It suggests that this reflects cultural differences," Dr. Weeks said.

Strangely, the patients who responded inaccurately also were more likely to highly rate their communications with doctors. Those who grasped that chemo wasn't curative were, in effect, penalizing the doctors who helped them reach that understanding.

In a way, Dr. Weeks said, this makes sense. It reflects what researchers call optimism bias — or what Dr. Douglas White, a University of Pittsburgh bioethicist, has called "the powerful desire not to be dead."

These were not very elderly people. The bulk were ages 55 to 69. Only about a quarter of colon cancer patients and about a third of those with lung cancer were over age 70.

"It's completely understandable that patients want to believe the chemo will cure them," Dr. Weeks said. "And it's understandable that physicians hesitate to take away that false hope."

But this confusion can have unhappy consequences. For patients to make truly informed decisions, "they need to

understand the outcomes," Dr. Weeks said. "If they're missing this critical fact, that can't happen."

People often hit rough times during weeks of chemotherapy. Common side effects include nausea and vomiting, diarrhea and fatigue; there are many trips to hospitals for IV drugs, X-rays and blood tests. "They'll soldier on if they think it will cure them," Dr. Weeks said. "Any of us would."

But if these patients might respond differently if they understand that chemo is meant to make them feel better but may have the opposite effect, or that it may buy them another 10 to 12 weeks (a reasonable average for lung cancer) or maybe a year (for colon cancer) but won't prevent their deaths.

Moreover, "if patients think chemo has a chance of curing them, they'll be less likely to have end-of-life discussions early on," Dr. Weeks said. "And they pay a price for that later" — if they enter hospice care much too late or die in hospitals instead of at home, as many prefer.

Possibly, at the time of the initial discussions, these patients recognized that chemo didn't equal cure, she hypothesized. Then, they and their doctors began to focus on doing something, and they stopped seeing their cancer as incurable.

But realism — as palliative care doctors know — doesn't have to mean despair. "A really good physician can communicate effectively and still maintain patient trust and confidence," Dr. Weeks said.

"We have the tools to help patients make these difficult decisions," two Johns Hopkins physicians, Dr. Thomas J. Smith and Dr. Dan Longo, wrote in an editorial published with the study. "We just need the gumption and incentives to use them."

Paula Span is the author of "When the Time Comes: Families With Aging Parents Share Their Struggles and Solutions."