

Doctors' Delicate Balance in Keeping Hope Alive

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Being a Patient

Dr. Joseph Sacco's young patient lay gasping for breath; she had advanced AIDS and now she was failing.

Assessing her, Dr. Sacco knew her medical options amounted to a question of the lesser of two evils: either the more aggressive ventilator, on which she would probably die, or the more passive morphine, from which she would probably slip into death. But there was also a slender chance that either treatment might help her rally.

He also knew that how he presented her options would affect her decision, the feather that would tip the balance of her hope scale.

As Dr. Sacco, a palliative care specialist at Bronx-Lebanon Hospital Center, spoke to the woman on that chilly morning earlier this month, her eyes widened with terror: no intubation. He ordered morphine.

He agonized about his approach. "She's only 23," he said later that day. "Maybe I was too grim. Maybe I was conveying false hopelessness to her. Maybe I just should have said, 'Let's put you on the ventilator.' I may have spun it wrong."

The language of hope -- whether, when and how to invoke it -- has become an excruciatingly difficult issue in the modern relationship between doctor and patient.

For centuries, doctors followed Hippocrates' injunction to hold out hope to patients, even when it meant withholding the truth. But that canon has been blasted apart by modern patients' demands for honesty and more involvement in their care. Now, patients may be told more than they need or want to know. Yet they still also need and want hope.

In response, some doctors are beginning to think about hope in new ways. In certain cases, that means tempering a too-bleak prognosis. In others, it means resisting the allure of cutting-edge treatments with questionable benefits.

Already vulnerable when they learn they have a life-threatening disease or chronic illness, patients can feel bewildered, trapped between reality and possibility. They, as well as doctors, are discovering that in the modern medical world, hope itself cannot be monolithic. It can be defined in many ways, depending on the patient's medical condition and station in life. A dying woman can find hope by selecting wedding gifts for her toddlers. An infertile couple moves on toward adoption.

The power of a doctor's pronouncements is profound. When a doctor takes a blunt-is-best approach, enumerating side effects and dim statistics, in essence offering a hopeless prognosis, patients experience despair.

A radiation oncologist told Minna Immerman's husband, who had brain cancer, that he had less than two years to live. "That information was paralyzing," Mrs. Immerman said. "It wasn't helpful."

But when a doctor suggests that an exhausted patient try yet another therapy, in the hope that it may extend survival by weeks, the cost is also considerable - financially, physically and emotionally.

"We have to find a less toxic way to manage their hope," said Dr. Nicholas A. Christakis, an internist and Harvard professor who is writing a textbook about prognosis.

Efforts are being made across the medical community to grapple with the language and ethics of hope. Some medical schools pair students with end-stage disease patients so students can learn about anguish and compassion.

Numerous studies have examined what doctors say versus what patients hear and the role of optimism in the care of the critically ill. Patient advocates have been teaching doctors how patients can be devastated or braced by a turn of phrase.

A consensus is emerging that all patients need hope, and that doctors are obligated to offer it, in some form.

To Dr. Sacco's boundless relief, his patient rallied. He began counseling her to take her AIDS medications, to find an apartment, a job.

He wrote in an e-mail message: "We prognosticate because people ask us to and trust our judgment. They do not know the depth of our uncertainty or that no matter how good or experienced we are, we are often wrong. That is why choosing where to put the feather is so damn hard."

False Hopelessness

Robert Immerman, a 56-year-old Manhattan architect, knew that his brain cancer - a glioblastoma, Grade 4 - meant terrible news. After the tumor was removed, he asked the radiation oncologist his prognosis.

"The doctor was pleasant," Minna Immerman recalled, "as if he was telling you that hamburger was \$2.99 a pound. He just said the likely survival rate with this tumor was, on the outside, 18 months.

"Bob purposely forgot it," she said. "I couldn't."

After radiation, Mr. Immerman began chemotherapy. But after one treatment, his white blood cell count dropped so precipitously that it was no longer an option.

"The medical oncologist said, 'The chances of survival with or without chemo are very, very slight,' " said Mrs. Immerman, a special-education teacher. "I think she was trying to make us feel better. What I heard was: 'With or without chemo, this won't end well, so don't feel so bad.' "

Mr. Immerman got scans every two months. Mrs. Immerman watched the calendar obsessively. Twelve months left. Six months. "As time passed, instead of feeling better, I felt like it was a death sentence and it was winding down," she said.

She sweated the small stuff: should they renew their opera subscription?

Mr. Immerman turned out to be one of those rare people who reside at the lucky tail end of a statistical curve. In February, it will be 10 years since he learned his prognosis. He is well. For years, Mrs. Immerman was shadowed by fear and depression about his illness, before she finally allowed herself to breathe out with gratitude.

Candid exchanges about diagnosis and prognosis, especially when the answers are grim, are a relatively recent phenomenon. Hippocrates taught that physicians should "comfort with solicitude and attention, revealing nothing of the patient's present or future condition." A dose of reality, doctors believed, could poison a patient's hope, the will to live.

Until the 1960's, that approach was largely embraced by physicians. Dr. Eric Cassell, who lectured about hope in November to doctors in the Boston area, recalled the days when a woman would wake from surgery, asking if she had cancer:

" 'No,' we'd say, 'you had suspicious cells so we took the breast, so you wouldn't get cancer.' We were all liars." Treatments were very limited. "Now when we're truthful," Dr. Cassell added, "it's in an era in which we believe we can do something."

Doctors in many third world countries and modernized nations, including Italy and Japan, still believe in withholding a bad prognosis. But the United States, Britain and other countries were revolutionized in the late 60's by the patients' rights movement, which established that patients had a legal right to be fully informed about their medical condition and treatment options.

Now, whether a patient comes in complaining of a backache, a rash or a lump in the armpit, many doctors interpret informed consent as the obligation to rattle off all possibilities, from best-case to worst-case situations. Honesty is imperative. But what benefit is served by Dr. Dour?

"There are doctors who paint a bleaker picture than necessary so they can turn out to be heroes if things turn out well," said Dr. David Spiegel, a psychiatrist at Stanford medical school, "and it also relieves doctors of responsibility if bad things happen."

The fear of malpractice litigation after a bad outcome, he said, also drives doctors to be stunningly explicit from the outset.

The medical community has nicknames for this bluntness: truth-dumping, terminal candor, hanging crepe. But some social workers call it false hopelessness.

Given a time-tied prognosis, many patients become withdrawn and depressed, said Roz Kleban, a supervising social worker with Memorial Sloan-Kettering Cancer Center. "Telling someone they have two years to live isn't useful knowledge," she said. "It's noise. Whether or not that prediction is true, they lose their ability to live well in the present."

Health care providers debate the wisdom of giving patients a precise prognosis: "There's an ethical obligation to tell people their prognosis," said Dr. Barron Lerner, an internist and bioethicist at Columbia University medical school, "but no reason to pound it into their heads."

Others say that doctors should make sure they can explain the numbers in context, with the pluses and minuses of treatment options, including the implications of choosing not to have treatment.

Though many patients ask how long they have to live, thinking that amid the chaos of bad news, a number offers something concrete, studies show that they do not understand statistical nuances and tend to misconstrue them. Moreover, though statistics may be indicative, they are inherently imperfect.

Many doctors prefer not to give a prognosis. And, studies show, their prognoses are often wrong, one way or the other.

Where does this leave the frightened patient?

Meg Gaines, director of the Center for Patient Partnerships, a patient advocacy program at the University of Wisconsin, Madison, thinks false hopelessness is more debilitating than false hope.

"I tell people to ask the doctor, 'Have you ever known anyone with this disease who has gotten better?' If the answer is yes, just say, 'So let's quit talking about death and talk about what we can try!'"

Some patients do triumph against grotesque statistical odds; others succumb even when the odds are piled in their favor.

But willful ignorance, she cautioned, can be dangerous.

"People should know about prognosis to the extent that it's necessary to make good decisions about monitoring your health care," she said. "You can't be an ostrich in the sand. When the stampeding rhinoceri are coming, you have to be able to get out of the way."

False Hope

Perhaps just as harmful as false hopelessness, many experts believe, is false hope. "If one patient in a thousand will live with pancreatic cancer for 10 years," said Dr. Christakis of Harvard, and doctors hold out that patient as a realistic example, "we have harmed 999 patients." False hopelessness, in the name of reality, dwells on the dark view of a patient's condition, prematurely foreclosing possibility and a spirited fight. False hope sidesteps reality, leaving patients and family members unprepared for tragedy.

When Anna Kyle was in labor, the umbilical cord dropped ahead of the baby, who was deprived of oxygen for critical moments. Mrs. Kyle had an emergency Caesarean section. The baby had to be resuscitated.

The nurses in the neonatal intensive care unit told Mrs. Kyle, of Lonoke, Ark., that her son was a "good baby," because he didn't cry or fuss. Later, when he had developmental delays, her hopes were at war with her nagging fears. But doctors kept saying the child might outgrow them.

Her son, now 5, received a formal diagnosis last year. "Nobody wanted to say, 'Your kid has autism, your kid is mentally retarded, your kid will be in diapers most of his life,'" said Mrs. Kyle, whose husband earns \$10 an hour as a truck driver. "It hurts, it's nasty, ugly stuff, but it has to be said, so kids can get the therapy they need as early as possible."

Because patients hunger for good news, experts say that doctors should choose their words carefully: "If you get into the language of hope, you run the risk of over-promising things," said Dr. Lerner of Columbia.

The more useful discussion for patients, he added, is, "what hopeful things can I do?"

In his November lecture on hope, Dr. Cassell said that patients do not need "false hope that is personified in useless therapy with nontherapeutic effect."

False hope is both a hangover from the centuries-old belief that doctors should withhold bad news, and a practice newly infused by the explosion of so many medical treatments and the tenuous promise held out by clinical trials.

Consider the cost of false hope, experts note: not only the physical and emotional agony of dying patients who try last-ditch, occasionally unproven treatments, but also the depletion, financially and psychologically, of the patients' survivors.

"The battle cry of our culture is, 'Don't just stand there - do something!' " said Dr. Richard Deyo, a Seattle internist and professor at the University of Washington who writes about the high cost of false hope.

He added, "Physicians have a natural bias for action, whereas it may be more honest to say, 'Whether I do something or not, the result is likely to be the same.' "

A 1994 study showed that Americans have greater faith in medical advances than people in many other countries. Thirty-four percent of Americans believed that modern medicine "can cure almost any illness for people who have access to the most advanced technology and treatment." By contrast, only 11 percent of Germans held the same belief.

Accompanying the medical advances, however, are an increasing number of physician subspecialties. One downside is that patients hear from a variety of voices, and they can become inadvertently misled.

Pat Murphy, a nurse and grief counselor who heads the family support team at University Hospital in Newark, said that, for example, when a patient has a critical stroke, a cardiologist, among others, will be called in for an evaluation: "The doctor might say, 'This is a strong heart' and then he leaves," she said. "The patient will probably never regain consciousness. But the 'parts people' talk to the family out of context, and the family thinks they're hearing good news."

Another result of this medical renaissance is thousands of clinical trials. Phase 1 trials often try out doses of an unapproved drug; perhaps only 5 percent of volunteers may derive any benefit. "Most people think they don't want to be an experiment," said George J. Annas, author of "The Rights of Patients." But, he said, when desperately ill patients learn about a trial, "all of a sudden there's no difference in their minds between research and treatment."

A 2003 study of advanced-stage cancer patients who volunteered for Phase I trials showed that at least three-quarters of them were convinced they had a 50 percent chance or greater of being helped by the drug.

Because patients listen selectively, it can be difficult to tease out who owns responsibility for false hope: Patricia Mendell, a New York psychotherapist who works with fertility patients, noted: "A doctor can tell a patient she has a 95 percent chance of an I.V.F. cycle not working. But the patient will feel it's her right to try for that 5 percent. "

Indeed, false hope can represent a complex entwining between terrified patient and well-intended doctor: both want the best outcome, sometimes so intensely that what emerges is a collective denial about the patient's condition.

Hope

Elissa J. Levy was a winter sports jock, with a buoyant social circle and a power job on Wall Street. But in January 2002, she received a diagnosis of secondary progressive multiple sclerosis, a less common version of the disease, for which there are few treatments and no known cures.

Soon, Ms. Levy needed a cane, and could scarcely walk a block. Pain and fatigue dogged her. Her quick brain grew foggy, her right hand floppy. She cut back her new job as a deputy director of a Bronx charter school to three days a week. In the mornings, her mother had to help dress her.

But though her body sagged, her neurologist helped prop up her spirits. "Often I would come in crying," Ms. Levy said, "and he would hold my hand and say, 'We'll figure this out together.' Or 'We can hope that this treatment works.' "

Given the gravity of her disease, was it appropriate for the doctor to stoke her hope?

"Hope," wrote Emily Dickinson, "is the thing with feathers/That perches in the soul."

Imprecise and evanescent, hope is almost universally considered essential to the business of being human.

Few can define hope: Self-delusion? Optimism? Expectation? Faith?

And that, say experts from across a wide spectrum, is the point: hope means different things to different people. When someone's medical condition changes, that person's definition of hope changes. A hope for a cure can morph into a hope that a relationship can be mended. Or that one's organs will be eligible for donation.

For so many, hope and faith are inextricably linked. "Truly spiritual people are amazing," said Ms. Murphy of University Hospital. "Until the moment of death, families pray for a miracle and then at the moment of the death, they say, 'This is God's will' and 'God will get us through this.'"

As health care providers struggle with whether, how and when doctors should speak of hope, a consensus is building on at least two fronts: that what fundamentally matters is that a doctor tells the truth with kindness, and that a doctor should never just say, "I have nothing more to offer you."

More doctors are embracing palliative care specialists as partners who work with critically ill patients and their families to help them redefine their hopes, from the improbable to the possible. Many doctors, whose specialties range from neurosurgery to infertility, retain therapists to counsel patients.

"Hope lives inside a patient and the physician's behavior can either bring it out or suppress it," said Dr. Susan D. Block, a palliative care leader at Harvard. "When a patient has goals, it's impossible to be hopeless. And when a physician can help a patient define them, you feel like a healer, even when the patient is dying."

Dr. Spiegel, the Stanford psychiatrist, recalled a woman who knew her death from cancer was imminent: "She had 15-minute appointments scheduled all day with relatives, to set them straight on how to live their lives. Then she was going to die. This was a hopeful woman."

Harvard's medical school matches first-year students with critically ill patients -- in essence, the patients become the teachers. One patient, Dr. Block recalled, was a high school teacher dying from lymphoma, who agreed with alacrity to participate. When her husband came into her room, the patient said, with tears in her eyes, "Honey, I have one last teaching gig."

Last April, Ms. Levy's doctor started her on a drug that is still in clinical trials, but has long been available in Europe. Shortly after she began taking the daily pill, she went for a checkup and lay down on his examining table.

He asked her to lift her leg.

Normally, Ms. Levy struggled to budge her leg. But having taken the drug, she flung her leg into a 90-degree angle. She gasped.

Usually, when her doctor pressed one finger against her leg, it collapsed. Now he pushed with his open hand. She held steady. Both she and her doctor grew teary-eyed.

Finally, she walked down the hall without her cane. Both patient and doctor wept openly.

The drug does not cure her disease; it treats symptoms. But Ms. Levy, 37, now walks 20 blocks at a clip, works four days a week, goes to the gym. She is dating. A recent test showed that her disease has not progressed.

In a sense, Ms. Levy's relationship with her doctor combined the best of the old and new worlds. He was hopeful but also candid. And he could offer her promising treatments, including one that, at least temporarily, seems to help.

"And if I start feeling bad again?" Ms. Levy said. "I have hope that I'll feel good again."

Getting Answers In the Right Dose

The doctor is about to say something and it does not look good. How can patients elicit information and encouragement?

Experts advise patients to ask questions that are specific rather than unanswerable ("How long will I live?"): What is the likelihood of remission? What are the long-term impacts of treatment? Is this medication likely to work and what if it does not?

What studies evaluate the success of the operation? How similar are patients in those studies to me? How many procedures have you done?

Can you connect me with an organization of people who have lived with this disease for a long time?

Many patients think they want to know everything. But then they hear it, and they feel crushed.

"In the way we dose our drugs, we need to dose our information," said Dr. Lidia Schapira, a Boston oncologist who studies doctor-patient communication. "Finding that dose needs to be explored with each patient. It's about what the patient needs to know, not what the physician is comfortable saying."

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