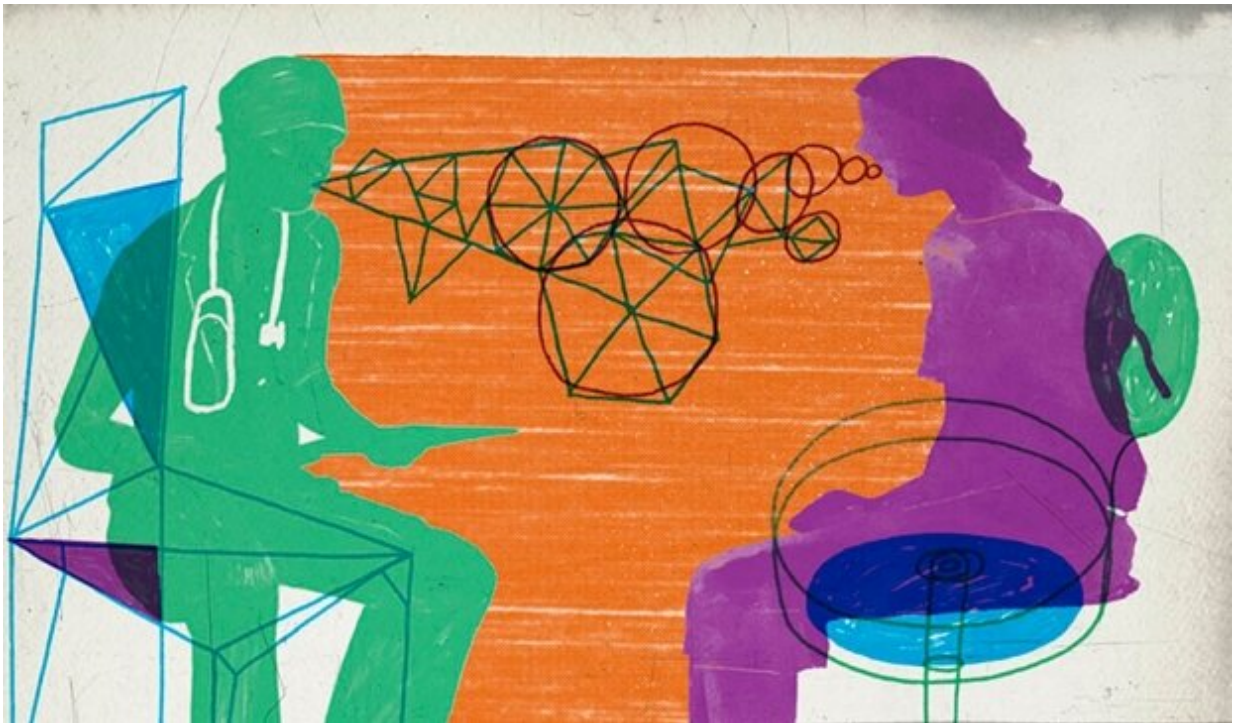


Clarity, honesty matter most in critical care talks with patients

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Credit: Jeffrey Decoster

High-stakes conversations with patients and families about critical issues call for doctors to consider how their words are interpreted, Stanford researchers and experts say.

As a doctor in the cardiovascular intensive care unit at Lucile Packard

Children's Hospital Stanford, Loren Sacks, MD, sometimes has to give parents awful news about their child's health. It's always heart-wrenching, but especially so when the child is dying.

"Part of what I love about working here is that we're able and willing to try things that may actually let a kid live," said Sacks, clinical assistant professor of pediatric cardiology at the Stanford School of Medicine. "But hand-in-hand with that is the acknowledgment that some of the things we do are not going to work."

It's difficult to tell parents there's nothing more to be done to save their child, but Sacks takes to heart the responsibility of lifting "some minuscule amount of burden off of a mother and father." That includes ensuring that the whole care team knows how to help that family navigate through the worst experience of their lives.

"The way we communicate, the words we choose, the tone we use and the emotion we're able to get across can completely shape the family's perspective and their experience," said Marcos Mills, MD, a pediatric cardiology fellow who works with Sacks. "That is, to me, as powerful as anything else we do, because this is an event, a time in this patient's life, that's going to be remembered forever."

Stanford clinicians whose specialties sometimes enfold them into the lives of dying people share that philosophy. But they're also acutely aware that mishandled conversations with clinicians who aren't skilled in end-of-life care could keep patients and their families from fully understanding the severity of their illnesses or care options.

In new research using linguistic theory to examine the root causes of doctor-patient miscues, Stanford biomedical ethicists raise alarms about whether a patient who is unclear about a prognosis, or about the implications of treatments being offered, can truly give doctors consent

to treat them.

David Magnus, Ph.D., is studying why common words physicians use to explain challenging medical concepts—such as "treatable" or "comfort care"—often mean different things to patients than they do to doctors. The director of the Stanford Center for Biomedical Ethics, Magnus said he recognizes the challenge of delivering bad news, and of delivering it clearly and honestly.

"It's really hard emotionally and psychologically. It's hard to do, and it's really hard to do it well," he said. "Our research shows that even when physicians seem to be doing a good job, there is the potential for miscommunication."

"Depending on the words"

But communication is a clinician's best tool, especially in the care of critically ill patients, said psychologist Barbara Sourkes, Ph.D., the director of the Pediatric Palliative Care Program at Packard Children's. It starts with the power of words, which "can be an invaluable bridge to form an alliance, to form a therapeutic relationship, with patients and their families," she said.

"People are depending on the words we use to know whether they can trust what's being said. But the words do not exist in a vacuum," Sourkes said. "They are woven into a clinical interaction or a relationship. People are sometimes faced with massive amounts of information that might bear life-and-death implications. It's an overwhelming challenge to take it all in."

Under severe emotional stress, she said, patients' families are unlikely to absorb everything, even if they are well-versed in medical concepts and terminology. "Sometimes there's simply too much, and you see that they

cannot track every detail of what they're hearing. Often, people just want to know, "What does this mean for me today and tomorrow?" Beyond that, the future looks too far from the immediacy of the present."

In research published in the July issue of the [*Cambridge Quarterly of Healthcare Ethics*](#), Magnus, lead author and Stanford Medicine resident Jason Neil Batten, MD, Stanford medical student Bonnie Wong and William Hanks, Ph.D., professor of sociocultural anthropology at UC-Berkeley, stressed the gap between patient and physician experience and culture may lead to misunderstandings, even when physicians try to be clear and avoid using medical terminology.

And that means knowing the meanings nonphysicians assign to words commonly used in clinical conversations.

For example, in research published in March in [*Critical Care Medicine*](#), the same research team found that when doctors say something is "treatable," patients think they are being given good news, such as that there's a potential cure. Doctors, however, might use the word to relay what they can offer, such as slightly prolonging life, or slightly improving an organ system, even if it is not a cure.

The role of context

In the Cambridge Quarterly issue, the researchers applied the linguistic theory of pragmatics—or the role of context in the meaning of language—to understand why doctors and patients often interpret words differently.

Contextual differences between doctors and patients can vary widely beyond the differences in their medical expertise, and include coming from different cultures, or speaking different languages, Batten said in an interview about his research. But the differences don't stop there.

The Rev. Diana Brady, MDiv, BCC, director of Spiritual Care and Chaplaincy Services at Packard Children's, said multiple layers of social dynamics must be considered to understand how patients receive information. For example, while more value is now placed on empowering patients as partners in their care, some patients remain more comfortable with a traditionally expertise-centered model of deferring to their doctors to make the decisions.

"It's never a one-size-fits-all," said Marina Persoglia Bell, interpreter services manager for the children's hospital. When more than one language is involved, providers, she said, want to partner with language interpreters to assess, "Where is this family on a given tenet of their culture?"

Persoglia Bell said clinicians also want to guard against only using seemingly common, yet technical, language that may not clearly convey the gravity of a situation for the family. If a doctor describes a terminal cancer diagnosis by using only medical terms—such as melanoma, carcinoma or sarcoma—a family might miss the most important point.

Brady said there is a real struggle to find the right words under those circumstances. "It kind of brings up our own fear as the care provider, our own vulnerability that what we want to do is be able to cure," she said. "We struggle to find our different ways to say that we can't, that we're limited. And that's tremendously difficult."

It's especially difficult in urgent situations, when decisions must be made and consent must be acquired quickly, Sourkes said: "It's extraordinarily complicated. It's complicated enough when there is time to be thoughtful about it."

Different expectations

Confusion can also result when seriously ill patients and their doctors have different expectations of meetings to discuss updates on prognoses and treatment options. Batten's research found that patients typically expect either good news or bad news during update meetings, which is why, Magnus said, physicians need to start such conversations by saying which it is.

Still, even people with terminal illnesses tend to dwell on positive aspects of what they hear and might leave a discussion about their palliative care believing they have new reason for hope—that their lives can be improved, extended or saved—though that might not be what doctors intended to convey.

Sometimes, Batten said, the use of medical lingo is the reason patients don't apprehend the bad news. He recognizes the practicality of physicians using medical terms in their day-to-day work. For one thing, it quickly gets the whole care team in sync. While it's already known that patients can end up confused by terms they've never heard, his research points to the confusion over doctors using ordinary words that take on wholly different meanings in a medical context.

Doctors understand, for example, that declaring an intensive care patient "stable" doesn't mean the patient's condition is no longer dire, he said. But a family member could hear this word and feel relieved.

Sourkes said that the perspectives of clinicians and patients can be poles apart, so it's crucial to be conscious of "ruptures in understanding" by asking patients what they actually heard.

"I have seen some conversations in which the physician has presented a plan, and possibly even prognostic details, and what the patient or family repeats back can differ dramatically from what was said," Sourkes said. "Asking for a playback is an important safety check. When you hear

disparities, misunderstandings and omissions, you can slow down and say, "Yes, I did say that part ... and it's also really important that you understand ...' and then deal with the part they didn't grasp."

"Skills that need to be learned'

Magnus, who holds the Thomas A. Raffin Professorship of Medicine and Biomedical Ethics, said it can be tough in high-stakes conversations to recognize when a patient's understanding is breaking down.

"Even people who are naturals at it can still be better. Our research shows that not only are these skills that need to be learned, but actually there are mistakes that you won't anticipate," he said. "And the nature of your training—to look at the world as a physician—almost makes it impossible for you to see the way in which patient understanding goes off the rails."

He said that viewing situations through the lens of pragmatics has given him a clearer picture of how and why misunderstandings occur, even when doctors say all the right things.

Fourth-year medical student Jacob Blythe, who is researching the implications of the term "you're not a candidate" in reference to a particular treatment or surgery, such as an organ transplant, said the study of how language shapes what we understand and imagine helps raise awareness among physicians about communication challenges.

The research, he said, has solidified his desire to keep the patient's perspective in mind as his training progresses, and as he begins to view the world as a physician rather than a patient.

"I think all of my classmates are going to be very technically competent doctors, but they're still going to be subject to the challenges of human

language when they're doing that competent work," he said. "An implication of this work is how do you better educate clinicians to recognize the types of miscommunication and misunderstanding that result from human language, as a thing that we all share and something that we must use."

Sacks said poorly managed conversations can intensify already difficult situations, and the weight of getting it right is heavy. An early mentor guided him through talking to parents about ending treatment and allowing their child to die by advising, "If you can't do anything for their child, other than give them a peaceful passing, one thing you can do is give that family a good, or at least a supported, memory for when their child is gone."

He still carries that lesson into his work and into his role as an instructor as he looks for new ways clinicians can learn to better manage tough conversations, especially because opportunities to learn this skill in medical school are traditionally limited.

"The vast majority of what people learn is from watching an attending or a supervisor do it, or being pushed to just do it themselves and figure it out," he said.

Programs to help communication

Several programs at Stanford are helping to change that, he said, including various communications workshops and access to tools from VitalTalk, a nonprofit organization that teaches communication skills to medical professionals.

Sacks and Mills are adding to the options, working on a team that is developing virtual reality training so doctors are comfortable with what to say and how to say it during difficult conversations.

Though simulated training with actors standing in as [patients](#) is the gold standard, Sacks said, it's costly and challenging to fit into a busy med student's schedule.

So in 2017, a team that includes Sacks, Mills and Anne Dubin, MD, professor of pediatric electrophysiology, began working with STRIVR, a Menlo Park company with expertise in creating novel VR platforms, to develop a virtual reality training program.

In the training, which Sacks said is immersive and allows for real-time feedback, learners strap on a virtual reality headset to practice conversations with parent avatars. As scenarios play out, background information and tips are displayed within the trainees' sight line—case backgrounds, the parents' names, what the next part of the conversation should include, or suggested responses to questions or concerns.

A trainee might be reminded to start with an open-ended query: "Tell me how you think your baby is doing?" Another reminder might be to alert a parent that difficult things need to be discussed, or to use direct, clear language and avoid medical jargon.

The three scenarios so far involve telling a parent their child won't survive a terrible injury; telling a parent it's time to disconnect an artificial heart pump that is keeping a child alive; and telling family members that a transplant team has decided their child isn't a candidate for a heart transplant.

The goal is to guide trainees in sensitively addressing parents' responses, such as, "Isn't there something else to do?" Or "We've done all these things; can't we keep doing those things for more time?"

During a pilot, 20 pediatric cardiology trainees tested the program: 95 percent of them said the simulation generated emotional stress similar to

what they'd expect in a real patient encounter, and 98 percent said they'd be willing to try the program again.

Sacks hopes the program can help doctors in supporting families as they grieve, something Brady said families value.

"It's important to parents that it mattered to health care providers that they were going through a difficult time," Brady said. Even if the outcome was their child's death, parents have reported that the sensitivity shown by care teams meant "their hope wasn't ripped away."

Provided by Stanford University Medical Center

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