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We need to talk: How doctors and nurses learn the harrowing task of delivering bad news to patients

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The woman was facing death. Terminally ill with cancer, she'd just started hospice, the pain management and spiritual care given to those beyond the reach of any cure.

"Do you think I will see my husband in heaven?" the woman asked her chaplain.

Julie Lepianka begins her "Spiritual Health" class at Cardinal Stritch University by telling this true story to her nursing students. Before revealing the chaplain's answer, she asks students how they would respond.

Most say they would tell the woman, "I'm sure you will see your husband," because that's what they would want to hear. Lepianka tells them that as a new nurse she would have done the same.

The chaplain, however, chose a different response.

"I don't know," he told the woman. "What do you think?"

"I hope to God not," the woman answered. "He beat the hell out of me every day of our marriage."

In the three years Lepianka has taught the class, she has always begun with this anecdote, and each time the room has gone quiet at the end. The assistant professor uses the story to illustrate the complexity of one of the most sensitive tasks in medicine, and a primary focus of her class: breaking bad news.

"You cannot put your story into the patient's story," she tells her students. "You can never fully understand what a patient is going through. You always need to ask."

A few months later, Lepianka would put her 30 nurses-to-be to the test.

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At some point in their careers, virtually all doctors and nurses face the duty of telling patients something they don't want to hear.

Bad news comes in many forms, from telling parents their child has a manageable illness such as diabetes or asthma, to informing patients that their disease has entered the final stage. Some conditions, such as pregnancy, may be good news to one woman, bad news to another.

The American Medical Association recognized the importance of conveying painful information back in 1847, noting in its first code of ethics:

The physician should be the minister of hope and comfort to the sick; that, by such cordials to the drooping spirit, he may smooth the bed of death, revive expiring life... The life of a sick person can be shortened not only by the acts, but also by the words or the manner of a physician.

Yet for years, medical and nursing schools offered their students relatively little to prepare them for the first moment they look into the eyes of a nervous patient, knowing they are about to upend the person's life.

Gene Beresin, a professor of psychiatry at Harvard Medical School, remembers the preparation he received.

"Let me put it this way," he said, "almost none.

"I was fortunate that we had training electives in patient-doctor communications and this topic would come up. But formal training in this particular area is extremely rare, and it's one of the most important areas."

Early in their training, Harvard students take a tutorial: "Giving Bad News." Instructors watch each student evaluate someone playing the role of patient. The ungraded exercise is used to determine whether a student's approach needs improvement.

Another Harvard professor has her students practice by talking with actual cancer survivors, said Beresin, who also serves as executive director of The Clay Center for Young Healthy Minds at Massachusetts General Hospital.

For previous generations of doctors and nurses, such training was scarce, if it could be found at all.

COURSE OF THEIR LIVES: Gross anatomy lab: Hallmark of first year at medical school (<http://archive.jsonline.com/news/health/The-Course-of-Their-Lives-Medical-College-of-Wisconsin-students-gross-anatomy-class-225058322.html#!/the-first-cut/>)

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Julie Rish, a clinical psychologist who teaches communication skills to medical students at Cleveland Clinic, said, "I hear from our own faculty, 'I wish I'd had this course back when I was in medical school.' "

Few studies have measured how patients' health is affected by the way in which they are told bad news.

However, a 2004 paper in The Lancet medical journal reported, "Doctors frequently censor information they give to patients about outlook on the grounds that what someone doesn't know cannot harm them."

In fact, a U.S. study found that "even if patients requested survival estimates, physicians said they would provide frank disclosure only around 37% of the time, favoring instead either no disclosure, or a conscious overestimate," The Lancet noted.

A 2014 Chilean study found that the health repercussions of conveying bad news flow both ways. When done poorly, the task "can lead to stress or even an increase in anxiety and depression in the patient."

On the other hand, some medics experience feelings of shame and responsibility for the discouraging news they must deliver. Often they fear they are about to destroy a patient's optimism.

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Julie Lepianka, a nursing professor at Cardinal Stritch University, teaches a course to nursing students on how to deliver bad news to patients. Lepianka stands in the nursing lab at the university. (Photo: Michael Sears / Milwaukee Journal Sentinel)

The mission could hardly be more important to Lepianka.

"This fills my soul," she says. "I ended up where I am supposed to be."

She is 48 and married with two children.

When going through nursing school in the early 1990s, Lepianka received no specific training on the subject she now teaches.

In a sense, though, her training had begun long before she took her seat in a nursing classroom.

When Lepianka was a junior in high school, her best friend, Becky, was diagnosed with cancer.

She remembers arriving at Howard Young Medical Center in Minocqua to the sight of Becky sitting there, her normally pretty hair now matted in clumps.

"She asked me to cut her hair. It was an extremely vulnerable thing to do. She was too afraid," Lepianka says.

"I cut her hair and something shifted inside me in that moment. As sad and awful as it was to be present when someone is at her most vulnerable, it is also the greatest privilege. It is a gift."

Lepianka was 17. Her best friend died two weeks before their graduation.

In college, Lepianka pursued a degree in cellular biology, planning to teach high school biology. However, T. Michael Bolger, her godfather and the president of the Medical College of Wisconsin, persuaded her to consider health care. He had a hunch she would make an excellent healer.

In December 1994, she received a bachelor of science degree in nursing.

It wasn't long before she learned a crucial lesson. The patient was a woman in her early 40s whose cervical cancer had metastasized.

Lepianka went to the woman's house to perform an assessment. After introducing herself, she said, "So I see that your cervical cancer has spread."

"It did?" the woman asked.

The two words stunned Lepianka. After realizing that she'd made an assumption about how much her patient knew, the nurse apologized profusely. The rest of the visit passed in a blur.

"I did a horrible job with it," she recalls. "That was at least 20 years ago and I have never forgotten."

Her most vivid memory: The shame she felt as she left the woman's home.

* * *

Lepianka learned quickly.

In almost 20 years as a nurse for Aurora Health Care, she developed an instinct for what to say when it seemed as if no words were adequate.

Sometimes a patient facing palliative care would respond: "You're giving up on me?" The word "palliative" can sound scary, she would acknowledge. She would make sure the patient understood what it means.

Palliative care is given to patients with a serious illness that will not improve; hospice is reserved for those with a prognosis of six months or less to live.

She would say: Help me understand what you mean by "giving up on you."

Then she would reframe the situation: Up until now we have focused on your disease. Now it's time that we focus 100% on you and what really matters to you. We are going to be with you to support you. You are not alone.

Lepianka learned to navigate through the emotions that patients and families go through. Once, when she came to talk to a man dying of liver failure, the man's wife ordered her and the palliative care doctor to leave the room. Before exiting, Lepianka asked if there would be a better time to talk. She explained that she and the doctor only wanted to make sure the family understood the man's options.

Within an hour, they were invited back into the room. She remembers discussing how the hospice team could provide the man with the best quality of life for the days that remained.

Another time Lepianka had to tell a woman that her father's cancer had spread and he was dying. The woman was engaged to be married a year later. She had planned to have her father walk her down the aisle.

"We talked about time being limited," Lepianka recalls. "The daughter moved up her wedding. I told her on a Sunday and we moved her father over to a hospice center that evening."

"He walked her down the aisle on Wednesday. On Thursday he died."

* * *

Over the years medicine has developed its share of protocols for delivering bad news, most reduced to memorable names or acronyms: SPIKES, ABCDE, BREAKS.

BREAKS, for example, stands for "Background, Rapport, Exploring, Announce, Kindling, Summarize".

While the protocols differ, many of the ideas are the same. Make sure patients understand their condition. Acknowledge their emotions and respond with empathy. Listen. Explain options. Summarize what to expect going forward.

Beyond the training and protocols, however, doctors and nurses speak of a more fundamental need, "to be present with families." That's something no checklist can accomplish. Many feel it is a calling.

Steven R. Leuthner, a neonatologist at Children's Hospital of Wisconsin, remembers an early experience when he was a third-year resident in the neonatal intensive care unit at a children's hospital in Evanston, Illinois. A pregnant woman was brought in experiencing seizures. Her baby entered the world with no heartbeat.

Leuthner was able to resuscitate the child, but the mother died. Then Leuthner turned to the dad. Did he want to see his baby?

"Here's this new father. It's supposed to be the most glorious moment in his life and he doesn't know what to think," he recalls. "His baby may be severely disabled. His wife has died.

"I remember asking myself: 'Why do I love this so much? Why do I want to be here with this man to help him through this terrible time?'"

Looking back, he says, "I would not say there is a lot of structured organized teaching of how to give bad news. Basically, I relied on being a human being with empathy."

Like many in the field, Leuthner acknowledges that the traumas he witnesses can take an emotional toll on health care professionals.

"I always bring it back to one point," he says. "This isn't about me."

The way he sees it: He is there for a moment; the family lives with its loss for a lifetime.

* * *

"Here's what motivates me," Lepianka says, shifting into another patient's story, one that happened 15 years ago.

A woman lay in a hospital bed awaiting a maternal exam. It was the end of her first trimester and she felt anxious.

She had required fertility medications to deliver her 2-year-old daughter; that child had been born roughly two months premature.

The length of her ultrasound that morning also worried her. The technician spent a long time waving the scanner over her abdomen, then said the doctor would be in to talk with her.

The mother believed this baby was special. She had stopped taking fertility medications, and, wouldn't you know it, she was pregnant. She was beyond joy.

The woman's husband was with her when the doctor breezed into the room. As she lay in bed, the doctor said something about having checked her results. The fetus wasn't "viable," he said. Then he left.

Having been through nursing school, the woman understood what the doctor meant by not viable. The fetus was incapable of growing into a baby. In her mind, the doctor's words reduced her child to little more than a collection of cells.

She walked into the bathroom and wept. She had believed the life inside her was a miracle. Now, she believed, God had taken away her baby.

Her husband was confused. From the doctor's casual tone and body language he'd thought everything was fine.

When his wife returned from the bathroom she could not stop crying. The ultrasound technician sat with her briefly. Then the woman dressed and she and her husband went home.

A week later, she returned to the hospital for a procedure to remove the fetus. This time she prayed with the hospital's chaplain beforehand and felt comforted.

Several months later the hospital held a ceremony for parents who had experienced miscarriages. The woman attended, feeling that someone understood she'd been mourning much more than the loss of a mass of cells.

Parents were allowed to take home an object that remind them of their child

She picked a rock painted blue and inscribed with the word "serenity."

* * *

In mid-May, Lepianka's students face their test. Actors from Cardinal Stritch's theater department are set to play the patients. She does not say as much, but Lepianka hopes the experience will lodge in each student's memory.

"This is a workshop," she says. "Nobody is going to be perfect."

She offers one last piece of advice: "People will cut you a lot of slack when they feel that you care."

The first scenario involves a 35-year-old married woman, a smoker who has recently suffered a stroke causing her speech to become muddled. She has a 7-year-old child.

The second scenario involves a pharmaceutical salesman who has just had a polyp removed and has learned it is cancerous.

Students gently probe, asking the patients questions that elicit additional facts affecting their physical and mental health.

Before suffering her stroke, the woman in the first scenario had learned that her husband had been having an affair and intended to divorce her.

Students ask the salesman in the second scenario what he understands about his condition and what it means. "My father had colon cancer," the patient explains. "My dad had a (colostomy) bag. I don't want to go to the bathroom in a bag for the rest of my life. I'm 32 years old. Who's going to love me if I go to the bathroom in a bag?"

Becky Blando, a 23-year-old junior, asks the pharmaceutical salesman to take a step back. "Us getting this biopsy, this is giving us a head start," she says. "Because we're getting it early on hopefully that won't be the case." With a little luck, he will not need a colostomy bag.

The third scenario involves the same pregnant woman who has just learned her fetus is not viable. The woman is 31 and has a 2-year-old daughter at home. The actress playing her begins to cry.

Students explain that the doctor cannot find a heartbeat for the baby. They ask the mother if she feels ready to talk about options.

Despite her tears, the woman says she is ready to listen.

The first option is a procedure to remove the baby, which takes about 30 minutes and involves anesthesia. The second is a natural miscarriage, in which the woman waits until her body is ready to deliver, knowing the baby will not survive.

"I know this is a completely hard decision," explains Alex Dewey, a 25-year-old junior, "and I know you are completely blindsided by this."

"I don't want to think about it right now," says the actress playing the woman.

"That's completely natural," Dewey says.

"Is there anyone you would like us to call?" asks Mackie Cavanaugh, a 25-year-old senior.

The whole room is quiet. All of the other students watch this final drama unfold, some with tears in their eyes.

When the scenario finishes, Lepianka addresses the students and the actress: "Thank you for your courage."

Now that the exercise is over she has one last thing to tell them about the cases they have worked on.

"That first patient was a friend of mine. The second patient was a patient of mine.

"The third patient was me."



Mark Johnson has written in-depth stories about health, science and research for the Journal Sentinel since 2000. He is a three-time Pulitzer Prize finalist and, in addition, was part of a team that won the 2011 Pulitzer Prize in Explanatory Reporting for a series of reports on the groundbreaking use of genetic technology to save a 4-year-old boy.

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