

Critical Communication

*Using Plain Language
to Reduce Medical Errors*



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By Ilene Corina and Laura D'Angelo

Executive Summary

Critical Communication: Using Plain Language to Reduce Medical Errors has been written to reflect the community-building work of PULSE of New York, a non-profit organization dedicated to reducing medical errors. Critical Communication takes the world-wide health literacy movement in new directions. It sees health literacy as a two-way street that requires patients to speak up when they don't understand their health care information, and encourages doctors and hospitals to provide that information in clear ways. Critical Communication seeks to improve the ways patients, their families and health care providers relate to one another in speech, in writing and through non-verbal behavior. Critical Communications empowers patients to ask for information, while putting the onus on health care providers to make the information understandable.

PULSE has developed Critical Communication programs for patients, their families and health care providers. PULSE is working with community organizations and literacy groups to empower people to ask specific questions of their doctors. And PULSE is teaching compassionate communication to patients and health care providers, in the hopes of sharpening listening skills and inspiring compassion on both sides of the stethoscope. Improving Critical Communication in the doctor-patient relationship will reduce health care costs, improve outcomes, help to ease suffering following an unplanned outcome, and most importantly will save lives.

Introduction

Toni Cordell, a 32-year-old mother of three, arrived at her gynecologist's office for a check-up several weeks after surgery. Entering with a clipboard, the nurse greeted her: "How are you doing today after your hysterectomy?"

Toni was shocked. She had no idea that the surgeon had removed her uterus. "I felt totally humiliated. Someone had taken a part of my body from me, and I didn't know about it," she said. "But I wasn't about to let the nurse know any of this."

An attractive woman with an engaging smile, Toni exudes confidence. But her inability to read beyond a fifth-grade level so mortified her that she had become adept at hiding it. Written words were not all that blocked her understanding. Toni's doctor had neither explained the diagnosis nor the treatment, she said.

Toni had consulted the doctor because something painful had begun protruding from her vagina. "It looked more male than female," Toni said. It was so freaky that she felt relieved when her doctor said: "It's an easy repair." "When I heard him say that he could fix it, all I wanted to know was when and where," she said. Toni, now 66, did not ask for an explanation. "My generation sees doctors as godlike. Many of us were raised not to question doctors."

Toni later learned that her uterus had collapsed into her vaginal canal. The "hysterectomy" was intended to repair the "prolapsed uterus." Those words were never spoken to Toni. No doubt the terms appeared in the stack of papers that the hospital admissions clerk handed to Toni – papers Toni could not read. "The bottom line was that I knew in order to have surgery, the papers needed to be signed, so I signed them," she said.

Toni's shocking story is more common than one would think. Nearly one-half of the U.S. adult population - 90 million Americans – are unable to read, understand or act on basic information regarding their own health care, according to a 2003 report from the National Assessment of Adult Literacy. Eleven million adults in the United States are not literate in English, and eight million seniors lack basic literacy skills. Yet hospital staff routinely give patients thick packets of written material hoping patients will absorb the information - even during a medical crisis.

The disconnect – a wealth of written material in the hands of patients who will not understand it - is symbolic of an alarming gap in health care, according to PULSE of NY, a non-profit organization working to reduce medical errors.

“Poor communication between patients and their health care providers is a hidden health care crisis,” said Ilene Corina, president of PULSE of NY. Poor communication results in untold suffering and in some cases, death. And the cost to the health care system is enormous - an estimated \$58 billion a year, according to a 2001 report from the Center for Health Care Strategies.

The solution is simple, Corina said: “We need to empower patients to speak up, and to help doctors create shame-free environments where questions are welcomed and answered in plain language.”

Research shows that the skills needed to understand and use health care-related information far exceed the abilities of the average person, according to The Joint Commission report, *What Did the Doctor Say? Improving Health Literacy to Protect Patient Safety*. This well-documented link between poor communication and poor health has sparked widespread interest in health literacy. The Institute of Medicine (IOM) defined health literacy as the degree to which individuals have the capacity to obtain, process, and understand basic decisions about health care (2004). IOM ranked health literacy as one of the top 20 areas where improvement could transform health care in America (2003).

Critical Communication: Taking Health Literacy Further

But the health literacy movement does not go far enough in addressing the dynamic on both sides of the stethoscope. Corina said: “It’s not just about what the patient can understand. We need to focus on how health care providers can better communicate with their patients, both verbally and nonverbally.” PULSE puts health literacy under the larger umbrella of “Critical Communication.” Critical Communication empowers patients and families to ask questions, but maintains that health care providers are responsible for making information clear. “No other profession expects its customers to understand its jargon,” Corina said. “Every day doctors go into post offices and ask about the difference between certified and registered mail. There is no shame in that. Clerks do their jobs and explain it to them. No one says ‘Those poor doctors have low postal literacy.’ So why isn’t that same courtesy extended to the sick?”

When communication is clear everyone benefits. Patients are more likely to take the steps they need to recover and are more satisfied with their health care. Doctors and hospitals win the confidence of the public and don’t have to spend resources correcting mistakes and untangling complications. When

communication fails, patients suffer poorer health, are less likely to manage their treatment appropriately and have higher risks of hospitalization. (Baker, DW et al, 1997) (Nutbeam, D; Kickbusch, I, 2000). (Rudd, R et al, 1999). Further, people who don't understand their health care needs are more likely to end up in the emergency room. (Baker DW, Parker RM, et al., 1996).

Patient Safety Organizations Lead the Way

In 2000, the IOM issued a report that rocked the medical establishment and the public. *To Err Is Human: Building a Safer Health System*, found that between 44,000 and 98,000 Americans die each year from preventable medical errors in hospitals alone. That does not include people who die from medical errors after they leave the hospital or when they are at home. The number is huge – equal to the number of people who would die if a jumbo jet crashed every day, and every passenger died. In fact, medical errors cause more deaths annually than motor vehicle accidents, breast cancer and AIDS combined.

Most errors result from problems created by the complexity of the health care system. And when doctors and patients have problems communicating, errors can occur. A 2001 study, *Making Health Care Safer: A Critical Analysis of Patient Safety*, commissioned by the Agency for Healthcare Research and Quality (AHRQ) found that doctors often do not do enough to help their patients make informed decisions. Uninformed patients are less likely to accept the doctor's choice of treatment and do what it takes to make the treatment work.

To complicate matters, patients may hide their confusion for fear of taking up the doctor's time, or appearing difficult or stupid. Studies show that even when hospital patients sign consent forms saying that they understand the information presented to them, many do not. The statistics are startling:

- Sixty to 69 percent of patients do not understand or even read the information contained in the generic hospital informed consent forms (Parker, 2000).
- Forty-four percent do not know the exact nature of their operation (Byrne, et al., 1988)
- Between 18 and 45% are unable to recall the major risks associated with their surgeries (Graham, 2003; Saw, et al., 1994; Cassileth, et al., 1980);

- Many patients cannot answer basic questions about the services or procedures they agreed to receive (Wadey & Frank, 1997; Lavelle-Jones, et al., 1993).

Getting doctors and patients to speak to one another with clarity, respect and compassion has become a key focus for patient safety organizations. “The health literacy movement has been instrumental in getting us all to see that when a patient doesn’t understand something, it is not the fault of the patient,” said Diane C. Pinakiewicz, president of the National Patient Safety Foundation (NPSF). Communication is a two-way street. “Is the patient conversant enough in medical terminology to effectively understand the information? Should we ‘talk shop’ to someone who doesn’t belong to the shop?”

Gaps in Understanding: No One Is Immune

Corina bristles at the false assumption that low health literacy is the sole domain of the uneducated or the non-English speaking. Low health literacy afflicts people in all strata of society, including those who have trouble hearing, are unfamiliar with medical terms or are stressed out. Even former New York City Mayor Rudy Giuliani exhibited “low health literacy” the day he found out he had prostate cancer. His wife Judith Giuliani, a registered nurse, said he failed to understand the diagnosis when he received biopsy results in 2000. “From the moment a patient hears the word cancer ... your ears are hearing through a different filter,” she said. “Rudy, of course, as we all know, is one of the smartest guys around, but when he was first told that his diagnosis ... was positive, I watched his face as he said, ‘Oh, wow. Positive. Positive is good, right?’

“Even for someone as intelligent as my husband is, it took a few moments for him to filter through that process and realize that in this unfortunate case, positive was not good,” she said. (Ramer, 2007).

“Often, the ability to understand has nothing to do with literacy but with a person’s emotional state,” said James Conway, senior vice president of the Institute for Healthcare Improvement. A national leader in patient safety, Conway experienced how emotions can cloud understanding the day he received instructions on injecting himself with insulin to control his diabetes. Luckily, Conway did what he and other patient safety advocates advise: he brought his

wife to the doctor's office. "When (the nurse) was giving instruction, I wasn't able to pay close attention. I'm a guy and there were needles and I was worried. I was wondering if the needles would hurt and was thinking that it's easy to inject this orange, but it's going to be a lot harder injecting my stomach," he said. As predicted, his wife proved more able to reconstruct the instructions at home.

Conway sees health care as a team sport that's played within and beyond the walls of the hospitals. "I'm a diabetic, and the vast majority of care I receive will be in my bathroom or bedroom, not in a health care facility. We (health care professionals) need to understand that we are partners in care with patients whether they are hospitalized or laying in a bed that their family has set up in the dining room," he said.

Protecting Patients

"The single most important way we can help prevent errors is to be active participants of our health care," Corina said during a Legislative Symposium on Health Literacy sponsored in October 2008 on Long Island by Literacy Nassau and Literacy Suffolk. "When we are alone in the rooms with our health care providers, we need to know that it is OK to ask questions and to say to our doctors: 'Excuse me. I don't understand what you're talking about.' "

As part of "Critical Communication," PULSE trains people to advocate for themselves and for loved ones. "Someone who has been in a car accident, is in labor or has just had a heart attack is not in a position to start asking appropriate questions of their health care team. They need to be able to rely on friends or family members who have been trained to get information," Corina said.

During workshops around the country, PULSE uses the "Ask Me 3" program sponsored by the National Patient Safety Foundation (NPSF). Corina teaches people the three main questions to pose to their doctor, nurse or pharmacist:

- * What is my main problem?
- * What do I need to do?
- * Why is it important for me to do this?

"It's an easy tool that is elegant in its simplicity," Pinakiewicz said. "It's one of those things that when people learn about it they say: 'Wow. That makes so much

sense.’ The tool is as useful in an academic medical setting in the United States as it is in a refugee camp in Uganda.”

Hospitals around the country hang ASK ME 3 posters on the walls, or place brochures at bedsides and in waiting rooms. But Pinakiewicz said groups like PULSE are crucial in training people before they need to go to a hospital. “We can’t leave all the teaching to the acute care setting. That is where there is the least amount of time and the most pressing set of circumstances,” she said.

New York State Senator Kemp Hannon (R-Nassau County), chair of the Senate Health Committee, has worked with PULSE on patient-safety legislation. He said that PULSE brings the patient perspective to lawmakers who are charged with overseeing the entire health care system, from delivery of services to federal funding. “But the goal of the entire health care system is to make sure the individual is well served. PULSE takes the view of the individual in the system ... and helps us understand how we can change the system so it is more open toward the individual,” he said. “That’s valuable. There is no other group here that does that.”

Bringing it Home

Nassau County on Long Island is the home base for PULSE of NY. The 10th wealthiest area in the nation, the county has an estimated 240,000 adults who are functionally illiterate, according to Literacy Nassau, an organization that trains volunteers to teach basic literacy skills.

PULSE has joined forces with Literacy Nassau to teach people how to communicate with their doctors. Unbound by a set curriculum, the 300 tutors at Literacy Nassau help students achieve goals that students set. “Most of our students are busy surviving, but when a medical issue has a direct, significant and immediate impact on them or a family member it can become a focus in their literacy studies,” said Tina Sanacore, executive director of Literacy Nassau. Some 76 percent of the students are women. “Typically the women are the central force in their households who take care of everyone’s medical needs. If we can improve their health literacy skills, we will see a dramatic effect on Long Island.” In 2004, Sanacore tutored a woman from Jamaica who worked as a home health aid to an elderly man, taking him to doctor’s appointments and acting on his health care instruction. Ironically, one day on the way to a doctor’s office the van

the woman was driving was hit. Resulting knee problems jettisoned the woman into a health care system that she had trouble navigating. Sanacore was pressed into service, helping her student to understand medical instructions, complete health forms and prepare questions for her doctor. “At the time, I didn’t know about Ask Me 3,” Sanacore said. “I wish I had.”

Partnering with Doctors

“Ask Me 3” has been well received by health care professionals, said Pinakiewicz of NPSF. She credits the receptivity to changes brought about by patient safety groups and the consumer movement of the 1980s. “Before that, doctors weren’t used to being questioned, and some saw it as an affront to their authority. That attitude is still there, but less so. Many more doctors expect (questions) and welcome them....but on the other hand the time constraints that doctors are under are worse than they used to be.”

Doctors may act out of time pressure in ways that intimidate patients, Corina said. “It’s hard enough for people to feel entitled to ask questions. But it’s even harder when the doctor is looking at her watch, or talking into a tape-recorder, or has snapped his file shut on the way to the door,” she said. PULSE is working with advisors to adapt Marshall Rosenberg’s Nonviolent Communication program for the doctor-patient relationship. Rosenberg’s course offers tools to speak in ways that inspire compassion. NVC helps people to say how they feel and what they need and to make requests, not demands. And it sharpens listening skills.

“Teaching patients and doctors the language for connection could head off medical errors that stem from poor communication. Patients may feel more comfortable sharing important information or voicing their confusion,” said Anne Fleming, a compassionate communication trainer in Freeport and an advisor to the PULSE Critical Communication Project.

And it can change the way doctors practice, says Dr. Leslie Farrington-Griggs, a PULSE board member and OB/Gyn at the Women’s Comprehensive Health Center in Manhasset, N.Y. Farrington-Griggs always had a warm bedside manner, but compassionate communication training sharpened her skills. “Now in difficult situations, I feel more comfortable knowing what to do. Before I had to wing it. I knew something extra was required of me, but wasn’t always sure how to take action,” she said.

For example, Farrington-Griggs met a patient on rounds who was 21 weeks pregnant with twins. The woman's water had broken, leaving dangerously low amniotic fluid. Should an infection develop, the situation could be fatal. The only thing to do was wait. A specialist had explained this to the woman and her husband, before telling the couple to go home and watch for signs of infection. When Farrington-Griggs arrived in the room, the couple was furious. "They said the specialist had taken away hope," said Farrington-Griggs, who asked questions and listened for what lurked beneath the couple's anger. "I understood that they were losing hope and blaming us for it. They were feeling fear, hopelessness and abandonment," Farrington-Griggs said. When she reflected back those feelings to the couple, a shift happened. The husband became visibly relaxed and the couple was more open to hearing healthcare instructions.

"When we don't have this kind of communication, and we don't connect with the patient, he or she may not take the pills that were prescribed, or they won't feel comfortable saying 'I don't understand.' We want to connect with patients. We are caregivers not robots," she said.

Communication Models

For Toni Cordell, the trauma around the surprise hysterectomy changed her life. In her late 40s, Toni enrolled in a local literacy program and learned to read. She has become an outspoken advocate for clear communication between doctors and patients. Unfortunately, the surgery intended to repair her prolapsed uterus was not the end of the story: Toni underwent five more surgeries over the next three decades to rebuild her vaginal canal, her bladder and the urethra. The final surgeon, Dr. Niall Galloway of Emory University in Atlanta, restored her faith in doctors by treating her with empathy and respect. "Dr. Galloway came into the examination room while I was still clothed and spoke to me and gave me lots of information. Then he asked me to undress, came back in and did the examination," she said. The doctor left the room, allowing Toni to get dressed. When he returned, he explained that the vaginal passage was collapsing and how he intended to fix it and to reattach the bladder. On a piece of paper, he drew the vaginal passage and the bladder to illustrate the procedure. He invited her questions and answered them thoroughly. "He built a relationship based on mutual respect," she said. "It made all the difference in the world."

PULSE Objectives for Critical Communication

- Encourage early education and awareness of patient safety and quality health care through community workshops, one-on-one training, support groups and media ads.
- Teach family advocates to elicit clear information at all points in the health care system, from the initial doctor's office visit to hospital discharge.
- Train literacy volunteers to teach communication skills like "Ask Me 3." Raise awareness about patient safety by partnering with the leadership of disease specific organizations.
- Help doctors, hospitals and nursing homes create shame-free environments where questions are welcomed and answered in plain language, and where "teach-back" techniques are used to assess how well patients understand the information.
- Create models of understandable literature and information for all patients not just those with low literacy.

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