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Kevin Speaks

Commentary

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Ten years ago, Donald Berwick made an eloquent plea that we should listen to the words of those we serve—our patients and their families. He was right. None of us in health care would have work, do research, teach, or do all of the other things we love without them. Yet *serve* is probably not the right word. *Used* might be a better term for what patients and their families feel about how we care for and interact with them.

The Institute of Medicine has defined eight dimensions of patient-centered care in its report, *Crossing the Quality Chasm:* access to care, respect for patients' preferences, information and education, coordination of care, emotional support, physical comfort, involvement of family and friends, and transition and continuity. These are the most important aspects of care, according to patients and their families.

Has anything changed for patients in this regard since Donald Berwick first told us about the requests of a young patient named Kevin? A few things have improved, including the following:

- Open-access scheduling and improved flow of care in the hospital are providing better access to care.

- Shared decision making is becoming a practical technique for incorporating patients' preferences into the care process. Patients' values should be the principal drivers of their care.
- The Internet has opened up the world of health information and communication to both patients and clinicians. Web sites such as MyGroupHealth.com and PatientSite.com make the medical record, e-mail communication, and other credible health information available. New organizations such as the Center for Information Therapy in Washington, D.C., help clinicians provide evidence-based information to the right patient at the right time via print materials and the Internet.
- Over the last decade, almost fifty hospitals have implemented the model created by Planetree, a pioneer in personalizing, humanizing, and demystifying the health care experience for patients and their families. These hospitals' patients and their families are empowered through information and education and are encouraged to develop "healing partnerships" with caregivers.
- The widespread use of patient-controlled analgesia has perhaps done more to improve patients' physical comfort than any other medical intervention in recent decades.
- Many organizations now open their doors to families and friends in the emergency room, in the recovery room, and in the intensive care unit. Some are even changing their visitor signs to indicate that *providers*, not families, are the visitors in the patient's life.
- The spread of patient and family advisory councils is helping to build a strong foundation for patient- and family-centered care by providing a systematic way to incorporate patients' and families' perspectives into organizational policies and quality improvement priorities.

Sharing clinical pathways and guidelines with patients and their families begins to help with coordination of care, but true coordination is almost impossible to do well in the absence of a real health care *system*. Curiously, health care still has a lot to learn about providing emotional support and preparing people to manage their health problems after they are discharged from the hospital. We don't take advantage of what we know about coping styles, about adult and experiential learning, and about the help that families can provide to support care.

Kevin asked for help with the fundamental issues we all face when we feel vulnerable and need help: "Tell me what you know right away," he asked. "Comfort me, answer me, do not make me wait or waste my time. Try not to frighten me." And most important of all, "Help me, to the very best of your ability, to live and to grow." What is it about the culture of health care that makes it so hard for us to partner with our patients? The things that drive patients crazy also trouble our staff. The system of care for which we are striving will be possible only when we care for the staff, too. They need respect, manageable work, and managers who are accountable and who serve those who are caring for patients. They need time to heal and process difficult emotional encounters. They need information tools to meet patients' needs for information and decision-making support. They need well-designed systems that facilitate superb service, and they deserve reward and recognition for a job well done. Staff need a culture that acknowledges that the best care comes from people working as a team, not as "lone rangers" with sole responsibility for the success or failure of their actions. They desperately need new systems that make the environment safe for them and their patients, one that lets them admit mistakes so that better solutions can be designed for the future.

This new culture requires that the power and autonomy demanded by many who work in health care must go hand in hand with the *responsibility* to meet the needs of patients. A new culture would insist on new models of care that support partnerships with patients, while acknowledging the importance of professional knowledge and expertise. Perhaps someday one's status and pay will even increase commensurately with the healing and compassion one offers, rather than through intellectual intimidation or control over one's peers. Consumers tell us that the term *health care system* is an oxymoron, and we know they are right. We need a real system that supports those who work in it, as well as those who are served by it.

Health care also needs strong leaders who understand the experience of illness and what it is like to be on the front lines day in and day out. We need to recruit and train people who view healing as a vocation, a calling, if you will, at all levels of the system. People like this, working in a system that encourages and rewards their humanity, will instinctively understand how cruel it is to view Kevin's wishes as "unrealistic" and will never again use the excuse, "We're so busy. Doesn't he know he'll have to wait?"

In his book, *A Whole New Life*, Reynolds Price wrote, "It's often said by way of excuse that doctors are insufficiently trained for humane relations. For complex, long-range interactions with damaged creatures, they may well need a kind of training they never receive, but what I wanted and needed badly was the frank exchange of decent concern. When did such a basic transaction between two mammals require postgraduate instruction beyond our mother's breast?" What we all want and need from a new model of care is the same: a system that allows us to connect with our deepest human dignity and respect for one another, care that is relationship-centered at its core, and for it to be no longer *radical* to be kind to one another and especially to sick people. Together we can refuse to check our hearts at the door and find new ways to work together lovingly.

Further Reading

Price, R. *A Whole New Life: An Illness and a Healing*. New York: Atheneum, 1994.

Kevin Speaks

4^{th} Annual National Forum on Quality Improvement in Health Care

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How far we have come! A mere five or six years ago, the language of quality improvement, if not the ideas themselves, would have met with blank stares in most quarters of American health care. It is not that we did not believe that improvement was necessary, but rather that, simply put, we didn't have a plan.

Now we do—or at least we know what a plan should look like. We know that it must be driven by a constant purpose to be, in the future, something far better than we are today. We know we must change to do this. We know there are principles of customer focus, employee involvement, statistical thinking, project teams and improvement cycles, better reliance on intrinsic motivation, valuing interdependencies, and understanding the system as a whole—principles that are well worth mastering and using in our daily work, and that, properly used, can give us results in cost and quality that, under other sets of management principles, will be out of our reach.

We can now assemble as a group sixteen hundred strong, and many more besides, to explore and build that plan and to shore up our confidence that this is, after all, a plan worth staying with. I look around this room and take renewed energy in the task we have set. We are on a good and sound track, but it is a hard track—hard enough to test our commitment from time to time.

We have to find a constant source of renewed energy. Every now and then, as we feel our sense of safety and commitment tested,

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it is worthwhile for us to touch base with a fundamental question, from which, in the end, the energy to proceed really comes. That question is this: Why improve? What purpose is so important and compelling as to cause us to undertake willingly the dislocation of our systems, our priorities, and our beliefs? To make ourselves uncomfortable?

In the search for will, I always come back to those we serve.

Our purpose comes from those we serve. Continual reconnection to this basic purpose is the only durable source of energy for systemic improvement.

Let Kevin speak. Kevin is fifteen years old. When he was two, a catastrophic problem required the removal of a large portion of his small intestine—the part of the bowel that absorbs nutrition from food. Kevin now has "short gut syndrome"—too little bowel to sustain his growth and health—so for thirteen years he has been fed in part by special intravenous fluids through a plastic tube in a major vein. Nine times in thirteen years that plastic tube has gotten blocked or infected and has therefore had to be surgically replaced. When I spoke with Kevin last, he was in the hospital for yet another replacement of the tube—the tenth—and nobody—not Kevin or me or his surgeon—knew yet if a suitable vein could be found for a new tube. The stakes, obviously, were high.

My medical students had asked me to help them understand the life of a child with chronic illness, so we asked Kevin, the expert (and the customer), to help us. I asked him to write for us on a sheet of paper three things about the care he received that especially pleased him—what he would call "quality"—and three things in which we had failed him—our "defects." This is what he wrote:

Care is best when:

1. They tell you what's going on right away.
2. You get the same answer from everyone.
3. They don't make you scared.

Care is worst when:

1. They keep you waiting.
2. They don't listen to what you say, even when sometimes you know better.
3. They do everything twice instead of once.

In the storm of the health care crisis—the variations on "pay or play" or the "Canadian option" or "managed competition"; in the various debates about rationing and protocols and incentive compensation, and even about TQM—it is so easy—frighteningly easy—to forget why we trouble ourselves in the first place. It is so easy—frighteningly easy—to become trapped in the sterile thesis that our institutions must survive simply because they must survive, or that our true, deep purpose is to gain and preserve market share in a vacant terrain of others whose purpose is precisely the same. It is easy to believe that our habits of work are somehow valid and worth defending in isolation from the reason that work exists in the first place.

But the work is not there in the first place. The work is second. In the first place there is Kevin. "Tell me what you know right away," he asks. "Comfort me, answer me, do not make me wait or waste my time. Try not to frighten me," he asks. And unspoken, because he is so frightened, is the most important request of all: "To the very best of your ability, help me live and grow." We are not there to survive. We are there to help Kevin survive.

But we face a problem, because the more we look at Kevin's temperate, respectful, completely understandable requests, the harder they seem to satisfy. That, in fact, is what the medical residents thought when I showed them Kevin's paper. They called Kevin "unrealistic." "We're so busy. Doesn't he know he'll have to wait?" To his request that we give him consistent answers, the residents replied that medicine was too much an art, and at any rate that would require meetings among themselves and with consultants, for which there was no time.

We are trapped. Kevin's requests are reasonable—meeting them is our purpose—yet they are daunting. I asked Kevin to score us on a scale of 0 (meaning never adequate) to 100 (meaning perfect). This is how he scored us:

- They tell you what's going on right away: 35 percent
- You get the same answer from everyone: 30 percent
- They don't make you scared: 40 percent

It is our duty to help Kevin, yet we cannot help him without changing ourselves. There is a strong and inescapable line between the meeting of Kevin's needs, on the one hand, and the methods through which we manage ourselves, on the other. TQM, CQI, systems thinking, improvement—taken in the context of the needs of a frightened fifteen-year-old boy, these are not buzzwords; they are answers to the question, How can we help him better?

Kevin did not put it this way, but he might have: "Be a system," he required of us, "and once you're a system, improve, because I need you to."

Why does the request of a fifteen-year-old boy lead us to such remote corners of self-reflection as systems thinking, process control, and process improvement? It is because Kevin's requests are not requests of parts of us, but requests of the whole. It is inconceivable that any collection of fragments can reliably give this boy what he has every right to expect. Who can make it true that Kevin is not kept waiting, is treated consistently over time and place, and is reassured when and how he needs to be? Who can make it true that Kevin, in our collective hands, is safe—as absolutely safe as he can possibly be? How can we give Kevin the sense he needs that we are all there for him, all together? Whose job is that: The doctor's? The nurse's? The pharmacy's? The school's? The laboratory's? The computer people's? His parents'? His church's? None of those. No list of parts suffices.

Peter Senge describes the fallacies that come from thinking and acting in fragments. His MIT colleague Professor Fred Kofman calls the challenge "recovering the memory of the whole." If we wish to serve Kevin well, we must do it together; if we wish to improve how we serve him, then we must do that together as well. We will think in process terms and improve the processes of our work, or we will let him down. We will be whole, or we will fail.

What is true for Kevin as an individual is even truer for the communities we serve. The waste in health care, its excesses, the gaps in its coverage, and the errors in its services will not yield to conventional approaches. It does not matter all that much how the financing game is changed—under pay-or-play, global budgets, or managed competition. We who make care will still be faced with a choice: either to make that care better, safer, and less costly, or to get by.

They need us to change: the 35 million Americans who lack health insurance need us to change; the one out of four inner-city mothers who lack adequate prenatal care need us to change; the victims of adverse events in one out of every ten hospitalizations; the black citizens of America, whose infant mortality rate is twice that of whites and whose rate of violent death is three times that of whites; the victims of thoroughly preventable deaths from lung cancer, strokes, heart attacks, and premature birth; the elderly whose bed sores can be avoided; the children whose learning disabilities can be avoided; the teenagers who pregnancies can be avoided; the communities whose resources we continue to drain by double-digit rates of increase in health care costs, without any credible defense in the form of scientific proof of effectiveness. They all need us, as much as or more than Kevin does. They need us to be something in the future that we are not today.

When W. Edwards Deming urges us to constancy of purpose, or Joseph Juran instructs us to schedule improvements, or Tom Nolan inquires about what we wish to accomplish, or Peter Senge reminds us of our inescapable systemness, they are doing far more than asking us if we are satisfied with our bottom line. They are not just calling upon us to consider our own adaptive capacities so that we may survive. They are giving us the opportunity to reconnect with the reasons for our being here at all. TQM is worth little or nothing except in the context of fulfilling the aims of our organizations and, through our organizations, the aims of our lives. It is for these reasons that the learning taking place here is so important and, in the end, so thrilling to be a part of.

Kevin said it best when I asked him to tell me more about his simple request that, as he put it, we ask him the same question once, or maybe twice, but not over and over and over again as if we had no memories at all. “It worries me when different people repeat the same question,” said Kevin. “Don’t you ever talk to each other? Don’t you ever meet and agree on what to do? If you don’t talk to each other, you might forget me.”

Further Reading

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