Chapter 1

MY RIGHT KNEE

COMMENTARY

Gary S. Kaplan, MD

AT THE INSTITUTE for Healthcare Improvement (IHI) National Forum in 2003, then-President and CEO Don Berwick, MD, gave a keynote speech titled "My Right Knee." I always look forward to hearing Don speak, but I wasn't quite prepared to hear a speech that would provide a defining moment in my own leadership journey and quest for quality. His keynote was a mandate for transformational change in health care.

I have known Don for decades and, in addition to my service as chairman and CEO of Virginia Mason Health System in Seattle, I am proud to serve as the current chair of the IHI Board of Directors. In 2003, the team at Virginia Mason was in the very early stages of adopting the Toyota Production System as our management method. We were intrigued by this system because it is sharply focused on achieving perfect quality. Although zero defects is an admirable goal, many said it was impossible. After all, Virginia Mason is in the business of providing health care, not manufacturing cars.

It was Don's description of his own experience in search of high-quality, patient-focused care, and the disappointments and successes he experienced along the way, that gave me courage to stay the course in pursuit of the perfect patient experience.

Don's vision was that radical transformation was not possible until "we look at the people we want to help, and see ourselves; when we realize that their needs, out there, are our needs, in here." His insistence that we view health care through the eyes of our patients prompted my own thoughts of my parents, my wife, my children, and my future grandchildren. This was confirmation that zero defects is the only acceptable goal in health care.

A baseball fan (a gross understatement), Don tied the likelihood of whole-system transformation in health care to the chances of the Boston Red Sox winning the World Series.

So, what has happened in the decade since Don gave that pivotal speech? The Red Sox won the World Series—twice—in 2004 and again in 2007. What seemed like an unlikely accomplishment on the baseball field was a harbinger of things to come in health care.

IHI continued to drive improvement in health care quality and safety with its groundbreaking 100,000 Lives and 5 Million Lives Campaigns, motivating hospitals across America to significantly reduce morbidity, mortality, and errors in health care by adopting practices focused on patient safety.

For organizations faced with interpreting the Institute of Medicine's (IOM) landmark report, *Crossing the Quality Chasm: A New Health System for the 21st Century*, IHI created the clarity we needed in health care to engage in this work by reframing the IOM aims for improvement—care that is safe, effective, patient-centered, timely, efficient, and equitable—as "no needless pain, no needless death, and no needless waste." This mantra became the rallying cry for whole-system change in health care.

In addition to its work in the United States, IHI continued to expand its international reach. The Surviving Sepsis Campaign, in partnership with IHI, developed international guidelines for the management of severe sepsis and septic shock. Further, IHI's work with the World Health Organization (WHO) includes the promotion and spread of WHO's important surgical safety programs.

Throughout the country, we are now implementing the Patient Protection and Affordable Care Act, and with IHI providing successful models, we are seeing health

care–associated infections and hospital readmissions decrease. At the same time we are providing more preventive care with better coordination through increased use of electronic medical records.

A decade after Don's speech, organizations like Virginia Mason continue to experience what it means to be a learning organization. We do this by employing a management method, the Virginia Mason Production System, that insists on patient-focused alignment throughout our health system. This pursuit of the perfect patient experience requires transparency and a focus on respect for our patients as team members. As Don revealed, the only way we can achieve this is by walking in our patients' shoes.

"My Right Knee" was a personal turning point for me, and it raised the bar for the health care industry. Ten years later, are we where we need to be, ensuring no needless pain, no needless death, and no needless waste? Honestly, no. Yet the Red Sox did win the World Series, proving there is a cure for the curse of the Bambino. Similarly, I believe there is a cure for what ails health care.

MY RIGHT KNEE

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INSTITUTE FOR HEALTHCARE IMPROVEMENT
15TH ANNUAL NATIONAL FORUM ON QUALITY
IMPROVEMENT IN HEALTH CARE
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A DARK CLOUD hangs over IHI's home base, Boston, this year. It's the cloud of the Boston Red Sox. This is very painful for us, and especially for Maureen Bisognano, my closest colleague and IHI's brilliant executive vice president and COO. Maureen is as avid a Red Sox fan as she is a golfer. That's saying a lot, if you know about Maureen and golf. Just this fall, she phoned me after a weekend round of golf to say that it had been terrible. She was on the third tee when her golfing partner, Fred, dropped dead of a heart attack.

I said, "Maureen, that must have been so hard for you."

"You have no idea how hard it was," she said. "It took forever . . . hit the ball, drag Fred, hit the ball, drag Fred. . . ."

So, Maureen was a mess when, again, the Red Sox, her beloved team, got knocked out of the semi-final round—the American League Championship Series—by our archrivals, the New York Yankees, Satan's team. We came so close.

If you're not from the United States, let me explain. The Boston Red Sox suffer from a problem we call the "curse of the Bambino." "The Bambino" is Babe Ruth—it's his nickname—who was probably the great-

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est baseball player of all time. Babe Ruth started his professional career with the Red Sox, but in 1920, in search of filthy lucre, the owner of the Red Sox sold the Babe to the New York Yankees, Satan's team. With Babe Ruth on board, the Red Sox won the baseball championship, which we Americans humbly call the World Series, in 1918, but they haven't ever won it since. Meanwhile the Yankees have won the World Series twenty-six times. Bostonians know that the gods, themselves, have engineered this century of failure for the Red Sox—always a bridesmaid, never a bride—because of that treacherous trade; so they call it the "curse of the Bambino."

The Red Sox have fixed this problem lots of times, not by winning the World Series, but by firing people. In a famous instant in the 1986 World Series—Red Sox versus the New York Mets, Satan's other team—oh, it is seared in my sons' memories, and don't even *think* of mentioning it to Maureen—our first baseman, Bill Buckner, muffed an easy ground ball, and the Mets went on to beat us. Buckner was gone the next year. This year, in the seventh and final game of the American League playoffs, the Red Sox manager, Grady Little, left our worn-out star pitcher in one inning too long, and that let the Yankees come back from way behind to beat us. Grady Little is now the *former* manager of the Red Sox. That'll fix it!

This all has led to a common bet in Boston: people bet on which will happen first—"X" or the Red Sox winning the World Series. Graduate students' supervisors ask them if they'll finish their PhD theses before the Red Sox win the World Series. Their mothers ask them if they'll get married before the Red Sox win the World Series. I ask my kids if they'll please clean their rooms before the Red Sox win the World Series. I intend to empty my email inbox before the Red Sox win the World Series.

So, in that spirit, I ask you here: Which will happen first, the health care we ought to have, or the Red Sox winning the World Series? Being a health care improvement fan and a Boston Red Sox fan do have something in common: playoffs, but no Series. Until recently, I would have bet on the Red Sox.

But, now, I'm not so sure. It's been a good year for the quality movement . . . a very good year. I think a real turning point was actually almost exactly one year ago, when Sister Mary Jean Ryan and her colleagues at SSM Health Care earned and won the Malcolm Baldrige National Quality Award. They met world-class quality standards with the best assessment criteria we have on the same playing field as other industries! Now we have the news that two more places have followed

in SSM's steps: Baptist Hospital in Pensacola and St. Luke's in Kansas City just won the Baldrige, too.

The IHI had a good year. We launched our new IMPACT network—I call it "The Association for Change." A new project supported by the Robert Wood Johnson Foundation, called Transforming Care at the Bedside, is part of IHI's growing focus on helping the nursing profession—something we just have to tackle as a top priority in American health care.

Our Pursuing Perfection project, also funded by the Robert Wood Johnson Foundation, has begun to show major gains in all thirteen sites—seven US and six European. Maybe best of all, I am now clearly seeing a small but increasing number of American health care organizations finally aiming for whole system change—what we've been waiting for: improvement as the core strategy. For example, Randy Linton and his colleagues at Luther Midelfort; John Toussaint and Scott Decker at ThedaCare; George Kerwin and Pete Knox at Bellin Health System in Wisconsin; Gary Kaplan at Virginia Mason in Seattle; Sister Mary Jean and SSM throughout the country; Leo Brideau at Columbia St. Mary's in Milwaukee; Mayo Clinic at all of its sites; Bill Corley at Community Hospitals in Indianapolis; and Doug Eby and his colleagues at the South-central Foundation and the Alaska Native Medical Center in Anchorage; to name only a few.

And, the improvement movement is now absolutely global. Sweden, Norway, the UK, the Netherlands, Australia, and New Zealand are only some of the bright spots. The UK improvements are soaring with the help of such leaders and IHI friends as Sir Liam Donaldson, Sir Brian Jarman, David Fillingham, and Helen Bevan. John Oldham, longtime friend, associate, and senior faculty member of the IHI, was knighted this year—he is now Sir John Oldham, but he lets me call him, simply, "Sir"—because of what he's done to improve the UK's primary care services. The IHI is now working with the World Health Organization to figure out how to expand our efforts into the fight against AIDS.

Federal agencies are also doing tons. Take a look at Medicare, with some bold, new programs to reward exceptional quality of care, led by Steve Jencks, Sean Tunis, Barbara Paul, and Michael McMullin; the Bureau of Primary Health Care in HRSA, showing massive improvements in access and chronic disease care in community health centers under the leadership of Sam Shekar; and the Veterans Health Administration, setting the pace in patient safety.

Trying to keep up with this pace of change, IHI's management team and staff have been working this year on a big redesign of the IHI itself. We've decided that we're going to focus all of our energies—that we'll judge ourselves—on what we are actually achieving on the Institute of Medicine's [IOM] six aims for improvement: safety, effectiveness, patient-centeredness, timeliness, efficiency, and equity. We are going to make IHI more results oriented than ever before.

We have rephrased the IOM's aims a little. Here are the results we want to get, and we want to get them with you:

- No needless death
- No needless pain
- No helplessness
- No unwanted waiting
- No waste

And we want those results for all—for everyone; that's the sixth IOM dimension: equity. That's what IHI exists to accomplish. That's how we'll measure our progress and yours. This clarifies our priorities. We will work on what helps get there, and we will turn down chances to work on things that don't.

So, with all of this, I'm bullish on improvement. It's a tight playoff series, but quality is pulling ahead by a game or two. Maybe, just maybe, the curse of the chasm—the health care quality chasm—will fall before the curse of the Bambino does. The trick now, just like for the Red Sox, is to put it all together.

This year, the stakes on that race—the race to put it all together—are up for me. Pretty soon, for me, what's been a spectator sport is going to be a participant one. I'll explain in a minute.

But, first, let me tell you a story.

This is my favorite saying; it comes from Mahatma Gandhi: "You must be the change you wish to see in the world." My colleague, Manoj Jain, from Tennessee, told me the following story about Gandhi that makes the point clearer.

The story is about a ten-year-old boy, Anil. Anil had become obese and was showing early signs of diabetes. His mother was at the end of her rope, and so she took Anil to Gandhi and asked the great man to tell Anil to stop eating sweets—no cakes, no pies, no candy. It could save his life. But, Gandhi refused. He said, "I can't do that. You'll have to come back in fifteen days."

"But, why not, Gandhiji?" the confused mother asked.

Gandhi said again, "Come back in fifteen days." And so she left with Anil, disappointed.

She returned as Gandhi asked, with Anil, after fifteen days, and then Gandhi sat with the boy and talked quietly.

"But, why couldn't you have done that fifteen days ago, Gandhiji?" the mother asked.

"Because fifteen days ago," Gandhi said, "I, too, was eating cakes, and pies, and candy. Now I have stopped, and I can tell Anil that I won't start eating them again until he can."

Isn't that an interesting idea? Helping by joining. A little scary, though.

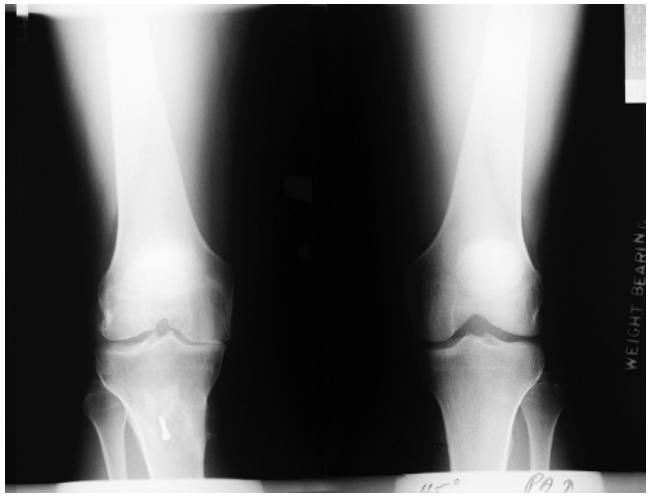
The problem we need to solve is this: despite the good news, no one seems yet to have put it all together for the total quality of care—like the Red Sox, real, transformation change is still a bridesmaid, not a bride. It must be very hard to get there—to total quality. It must take some different level of energy, insight, and courage than we've mustered so far. But, I think I have an idea about how we can do it, and that's what I want to talk with you about—where the courage is.

I propose this: if we are going to care enough to do it all—to win the series—really, really different care—we're going to have to change the way we see our patients' lives, not as movies, out there, but as mirrors, in here. We'll change when we look at the people we want to help, and see ourselves; when we realize that their needs, out there, are our needs, in here. When we realize that the white coat and the dark suit are disguises. I am toying with the idea that our next, big step is not just to serve people but to join them. Gandhi joined Anil.

Take a risk with me. Ask yourself what health care you or a loved one might need between now and when the Red Sox win the World Series. Don't do it hypothetically—ask it for real. Some of you know, but most of you don't. But you can guess. What need will you have? How might you suffer? What will you need?

You have the next two days here at IHI's National Forum to design exactly the care you're going to want. That's going to take courage—to drop your guard, to be a patient, to understand what you need. But, I hereby declare that, for the next two days, you have a right to demand the help you want, when you want it, the way you want it. And, I'm going to go first.

This is my right knee. It is on your left . . . my right (which already worries me).



Radiograph of the Author's Knees, Showing "Bone-on-Bone" Osteoarthritis of the Right Knee

I was born with two knees. Now, I have maybe 1.7 knees. It all started when I was in medical school. Playing soccer one day, my right kneecap "subluxed" or dislocated for an instant toward the outside of my knee, and then flipped back into place. That hurt. When it happened again, I went to see a surgeon. He said that my knee mechanics weren't lined up right, and that I needed an operation. I was a nerd in medical school—hard to believe, I know—and so I had read up on myself in advance, and asked him if he thought an operation that I think was called the McRae procedure would be a good one. He said, "Fine," and so I had the operation a few weeks later.

Oh, my goodness! I remember the pain when I woke up. It was so bad that, for a minute, I couldn't even feel it. It was like a big truck so close to my face that I couldn't tell at first that it was a truck. Then, the truck hit me—for about two days—pain absolutely nothing like the soreness of a subluxing kneecap. Not even on the same continent of pain.

But, I trusted medicine, and so I went through it with what I'd call "writhing optimism"—since at least my problem was now over. It sort of was over. My kneecap never again subluxed to the outside of my knee; a few weeks later, it subluxed to the inside of my knee.

So I went back to see the surgeon. He was apologetic; he said that he had apparently overcorrected the problem. I agreed politely. I asked him

if he had ever seen that before. He said, no, actually, because that was the first time he had ever done that particular operation, something he hadn't mentioned to me before it all started. "Maybe I should have told you," he said. I agreed politely. Within a few years, by the way, when it was finally subjected to a long-term follow-up study, the McRae procedure for my kind of problem was discredited—its complication rate was something like 30 percent.

So, I went to another surgeon at a different hospital—a community hospital near where I grew up. The surgeon there was happy to help. He suggested a simple repair job, which went pretty well, except for a couple of days of shaking chills and temperature of 104 degrees postoperatively. At least my knee never subluxed again.

That was that for twenty years. At age forty-five, I was playing basketball with my kids when my knee—the same one—suddenly gave way and exploded in pain. A bunch of tests followed—X-rays, MRIs, CAT scans—but no diagnosis. Everything looked okay, the local orthopedist said, except that I couldn't walk.

I was a little bit frustrated, so I went to a sports medicine clinic in another city, where I had seen some terrific improvement work, and saw a specialist I admired. He agreed that the tests didn't show anything, but his clinical impression was that I had torn a cartilage and needed arthroscopic surgery. He did it—no pain this time, by the way—found the cartilage tear, and trimmed it.

That did the trick, so well in fact that I increased my jogging and five years later, in 1998, I ran the Boston Marathon for the first and last time. My friend says that, given my knee history, this shows that I have the courage of a lion and the brain of a gerbil. I agreed politely. It was my only marathon because, during it, I blew out my cartilage again, and ended up on the arthroscopy table for the second time—my fourth knee operation—losing most of the damaged cartilage.

Now, eight years later, my knee has pretty much had it. The cushioning cartilage on the inside half of the joint is completely gone. I have, in the poetry of the orthopedic surgical literature, "bone on bone," which is a bad thing in a joint, where it's supposed to be "cartilage on cartilage."

Bone wears down; cartilage doesn't. I don't know when, but sometime, pretty soon, I am going to need a total knee replacement—maybe even to walk, but certainly to do the things I love to do outside, like hike and cross-country ski and climb. Frankly, I don't think I can hold out until the Red Sox win the World Series.

But here—long way around—is my problem: I'm scared. Actually, I'm terrified. That's not a rhetorical statement; it's a fact. I know that my

future function is going to depend on taking advantage of this amazing technology—total knee replacement—but I also know much too much, much more than I want to know, about what could go wrong.

I told you that the IHI is trying to focus on five goals for health care change in the world: no needless death, no needless pain, no helplessness, no unwanted waiting, and no waste. At a system level, these are a vision. At a personal level, that is, for my knee and me, they're more than a vision—they're a need.

So, I had a meeting with my knee, and we decided to issue an RFP—a Request for Proposals—like a foundation does when it wants some research done, or like a company does when it wants a contract. My knee and I want to get some bids. We'll set the specs, and then anyone who wants to can bid to get the job.

My specs are the same as the IHI's vision: the "No needless" list. But, since it's my own knee—or 0.7 of a knee—I'll need to adapt the RFP with a little more detail.

Specification Number One Is "No Needless Deaths"

My RFP says it this way: "Don't kill me." At first, I wrote, "*Please* don't kill me," but then I decided to be a little more assertive. What do you think?

Prospective applicants: I'm warning you that I don't take this deliverable for granted. When I give you the contract on my knee, it will, absolutely, be a little bit like what the mafia also calls "a contract"—on my life. You become 007, licensed to kill . . . me. You see, the minute I slip under your anesthetic and your knife, I will, without any doubt, be taking the greatest risk to my life, statistically, that I have ever taken—greater by at least one order of magnitude, maybe two. I have climbed Mt. Rainier, crevassed and with vicious weather, five times. On those five climbs combined, I was running a risk of dying, if you use historical figures, one-fiftieth as great as I will take in your operating room. Each airplane flight I take will be five thousand times less lethal than my flight through your operating room.

Here is how you can kill me. Actually, there are too many ways for me to list them all, but here are some of the ways you can kill me. You can give me an infection during my surgery. You can mix up a blood transfusion if I need blood. You can fail to prevent my pulmonary embolism. If I need a respirator for a while when I wake up, you can give me pneumonia. You can forget that I am allergic to hazelnuts and maybe to codeine. You can misplace a decimal point in the order for morphine.

You can place the endotracheal tube by mistake in my esophagus, and not realize it until it's too late.

Everything on that list, by the way, happens and can be prevented—not down to zero, but awfully close to zero—I'll call it "Mt. Rainier" close to zero. I'm not asking you to make me as safe in your care as I am in my home, just please make me as safe in your care as when I cross the crevassed glaciers of Mt. Rainier.

I can give you some hints about how to do this. You can bring my surgical site infection rate as low as Baptist DeSoto Hospital or LDS Hospital has. You can prevent deep vein thrombosis and ventilator-acquired pneumonia as completely as Dominican Santa Cruz and Baptist DeSoto. You can be as attentive to medication errors as OSF, and you can use the VA's approach to preventing esophageal intubations—which in America average 8 percent of all non-critical-care intubations.

Without my RFP, I'd be entering the lottery of safety that we now have in this country. Four years ago, I sat in a room with about thirty hospital CEOs as they were shown their complication rates for, of all things, total knee and total hip replacement in their own hospitals. The rate of complications ranged from 3 percent in the lowest hospital to 21 percent in the highest. Now—forget about the 21 percent—even 3 percent doesn't feel all that good to me, frankly. If I told you that you were about to do something that stood one chance in thirty of hurting you really badly, would you do it? But, beyond that, I have to tell you that, as far as I know, no member of the public had access to that information at the time, or since. In my RFP, I am going to ask you to please tell me how you are doing, and, if you don't tell me, then I have to assume that either you don't know or that maybe you have something to hide. I don't mean to be strident or rude, but I really don't think you have a right not to tell me your results and then expect me to give you my knee to work on.

Actually, I've been there, done that. That's sort of what that very nice first orthopedic surgeon tried with me. He did an operation he had never done before, and he couldn't possibly have known the chances it would help or hurt me, beyond a wild guess. If that's what was going on, he should have told me. He was very nice, but he should have told me.

You might kill me. I want you to promise me that you know that. And, I want you to promise me that you've done everything you possibly can to reduce that risk to its theoretical minimum. None of my children are married yet; I haven't met my first grandchild yet; my wife and I want to take a trip to Nunavit someday; and I want to hike in the Himalayas. Now that I think of it, I want to watch my son's faces—Ben's and Dan's faces—when the Red Sox win the World Series, and I want to go

to the party Maureen is going to throw that night. And, if you take that stuff away from me by killing me, I will be very, very upset with you.

Specification Number Two in the RFP Is "No Needless Pain"

Now, I have to explain this one, too, in my own terms. It means, "Assuming you don't kill me, don't hurt me either."

I know that's a little unrealistic, because, after all, surgery is itself a form of hurting. I accept that. I'm not asking for perfect; I am asking for the least possible harm. I want you to know what's the least possible harm, anywhere, and get it for me. Specification Number Two has three subparts, actually, which I call 2A, 2B, and 2C.

Specification 2A is "Don't do stuff to me that won't help me." I have a track record on this one. As it happens, I don't think that I ever needed surgery on my knee in the first place. I certainly didn't need the extensive, painful, since-discredited procedure that this guy tried on me for his first time. The subluxation problem I had was pretty minimal, and now I think that a brace and some exercises would have been enough. I think I fell into the very trap that Jack Wennberg has been trying to point out to us for over two decades: that, in health care, supply drives demand, without regard to the quality of outcomes of care. Wennberg's work, now beautifully extended by his protégé Elliott Fisher, shows that, at American levels of supply of specialty services, we can find no evidence at all that increasing supply produces better outcomes for patients at a population level—just more use and more cost.

Dr. Fisher's brilliant recent *Annals of Internal Medicine* paper shows that if you divide American hospital service areas into quintiles according to the intensity of their services—from the lowest quintile, the lowest 20 percent, to the highest one, the highest 20 percent—and then you study the quality of care in each area several different ways, such as finding out if people reliably get the care that can help them, here's what you find: quality doesn't change at all with quintile. More intensity doesn't get you any more quality of care until you reach the top quintile—the most cost, the most intensity—and there, for some important measures, quality *decreases*. More is not better. At the top level, outcomes are worse. This is a frightening finding, with imponderably large implications for American health care. In fact, nobody powerful in American health care seems to want to touch this one yet with a ten-foot pole.

It is scary for me to think about it, but if Wennberg and Fisher are right, the reason my first knee operation was done in the first place may

well have been not because my knee *problem* was there, but because the knee *surgeon* was there. In fact, the same surgeon examined my other knee at the same time, said it was "tracking poorly" and probably should be operated on sometime to prevent subluxing. Happily, we never got around to that, and my left knee is just fine. That makes me also believe that the first surgery probably had something to do with causing the later cartilage problems. Maybe not.

Do I believe for a minute that that kind surgeon secretly rubbed his hands together greedily and cackled, "Hee, hee, hee—another knee I can make money on—little does this poor medical student nerd know . . ."? Not on your life. Absolutely not. I'd bet my life—actually, I did bet my life, didn't I?—that that surgeon believed that he was going to do me good. I am sure of that.

But, the fact remains: now I know that I had useless surgery for a nonsurgical problem. My surgeon and I didn't know that then. I have a screw in my knee for no good reason at all. My knee got screwed unnecessarily.

Specification 2B is "Don't do that again." I don't want a single drug, test, visit, stitch, or exercise regime that doesn't help me. You hurt me when you do that. I want you to promise that you don't do unproven, unnecessary things to me. Act on evidence, not just on hope.

Specification 2C is "Reduce the suffering I have from my bad knee." It's the obverse of Spec 2A. Reduce the burden of disease. That's why I am coming to you in the first place. It's Job 2, just behind safety. This is a balance, I know; I can handle that. Maybe you could offer me a higher chance of great function with a new prosthesis that is a little less tested than the old standby, but slightly more promising. I can understand that sometimes risks and results are a trade-off. What I want you to do is to involve me in that trade-off decision. I can help you make it, but only if you let me help you make it.

Now, once we've decided on what to do, do it right, please. Don't add to my pain by a complication, and please do choose your approach to anesthesia, prosthetic implant, postoperative recovery, and so on based on science. Since my right knee is on your left, and vice versa, I want to make sure that you don't get your signals crossed on that while I am asleep. I will give you credit if your response to my RFP tells me how you make sure to execute this clinical plan absolutely reliably. I won't give you a lot of credit for telling me that you value autonomy for your nurses and doctors if that means you don't use scientific evidence reliably. I take off points for wide variations in your clinical protocols from doctor to doctor.

Here's a question I'd like you to answer. Suppose the doctor who was meant to operate on me Tuesday morning got the flu on Monday, and so a different doctor had to do the operation. Would you guarantee to me that the same high level of quality of care—the exact same, evidence-based care—will happen anyway? When I got on the airplane to fly here from Boston on Monday, I didn't need to know the name of the pilot to have confidence in the trip. I want it to be the same on your operating table.

This has a lot to do with your culture. Is it open and fair, and does it value input from anyone in the know? Let me tell you a little detour story. A year or two ago, trying to plan ahead for a better knee, I went to see a surgeon who several friends told me was a young up-and-comer—let's call him "Dr. Upandcomer"—who told me he could help by doing a semi-experimental procedure involving removing a wedge of bone from my tibia and fibula, inserting a metal plate, and sort of lining the bones up better to alter the stress patterns. Dr. Upandcomer did say, when I asked him, that no randomized trials had been done yet, but he was pretty sure it worked because he'd seen lots of patients do well.

I assume that Dr. McRae felt the same way about his operation thirty years ago; so I am a little fussy about evidence. Anyway, Dr. Upandcomer's plan didn't sound like a good idea to me, partly because the picture of all the hardware—screws, plates, and things—that that new procedure would leave in my knee seemed to me to make it potentially harder to put a new knee prosthesis into the knee when it came time for that later on. The wedge was just palliative—just temporizing. It was just a simple thought—all those screws seemed to me like they might get in the way. Anyway, I already had a screw.

A little while later, I went to see a different surgeon, who friends told me was sort of "Dr. Knee" in a particular city—a knee-man's knee-man. I wanted to know what he thought; if I should have that wedge operation, or what. So, I asked him. To get the picture, you need to see the set-up in your mind's eye—there was me sitting on a table, Dr. Knee facing me, and behind Dr. Knee, out of his line of sight, but in mine, was Dr. Knee's senior fellow, who, it happened, had actually trained with Dr. Upandcomer, the one who recommended the operation with the plates and screws.

Dr. Knee said that *he* thought that, if Dr. Upandcomer thought the new procedure would help me, I should have it.

I asked Dr. Knee, "Wouldn't the wedge surgery now make knee replacement later on much harder, with all those plates and screws in my knee?"

"Not at all," said Dr. Knee, shaking his head. But, just then I noticed that the senior fellow behind him was waving his arms at me trying to get my attention and silently mouthing the words, "Yes, it would," and nodding his head up and down. Dr. Knee turned around, and, like a scene on *Saturday Night Live*, the fellow suddenly stopped his waving and acted like he was just smoothing his hair down.

When you answer my RFP, please tell me why that wouldn't happen in your hospital. How do you make sure that, if the housekeeper or student nurse in my operating room sees something that could help me—maybe even save my life—he or she will speak up loudly, promptly, and directly and that the surgeon will praise that participation, not scowl. Explain to me how you make sure that the team really is a team, and that communication channels stay wide open, so that every patient—so that I—get the benefit of all the best information.

So, Spec 2A says "No needless pain—don't give me needless pain by doing things that don't help," and Spec 2B says, "Don't give me needless pain by the converse defect—failing to do things for me reliably and consistently that do help."

Spec 2C is a special case of the other two. It reads, "Relieve my pain." I'm stoic, but I'm not a Zen master. If it hurts, I want you to take the hurt away. That includes physical pain and emotional pain. I want you to relieve both.

Physical pain you can get right by using the science. I already know that from my own pain-free operations number three and number four. These were done with world-class pain control, and I'm going to tell you where, because you should know: Virginia Mason Clinic in Seattle, Washington, where I went for those procedures. Not a single moment of any pain at all, at any time. It wowed me.

And, it made me even more upset about the gaps our nation has in pain control. A few years ago, my hero, Joanne Lynn, led an IHI Collaborative on end-of-life care that focused on pain control. When we started, we found that cancer patients in a major hospital who were admitted explicitly to relieve their pain waited on average 110 minutes for their first dose of pain medicine.

Thanks to good science, we know how to relieve pain safely. I want you to promise me that you will use that knowledge, so that I do not suffer if I don't have to. No needless pain.

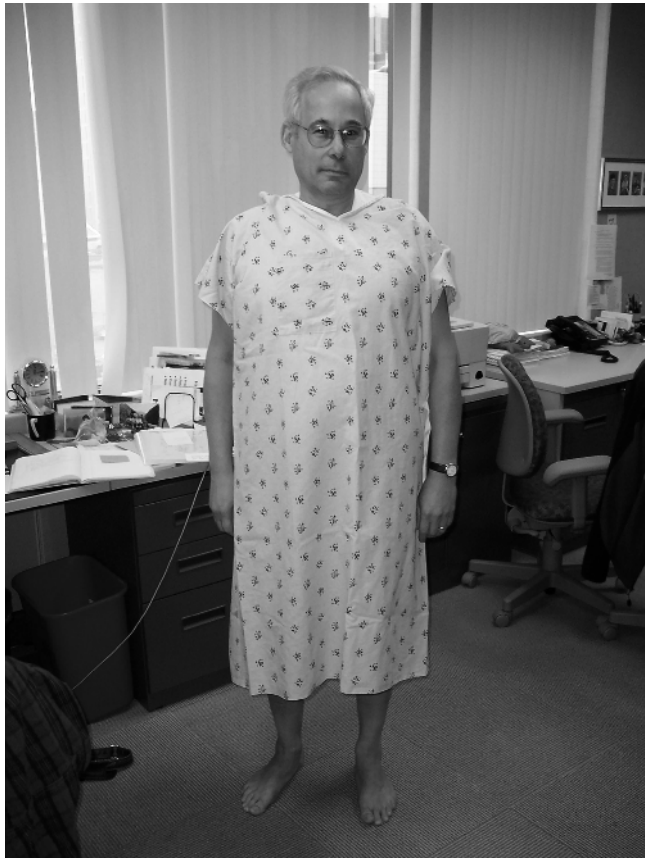
Emotional pain is more subtle. We all have our own version. My emotional pain gets worse when I'm alone, when I want to know something but no one will answer me, when I feel criticized or like someone thinks I'm stupid, when I'm frightened. So, your reply to my RFP will have to tell me how you plan to help me with that stuff. Will you promise

me that I won't be separated from the people who love me? I won't hire any place that doesn't let my wife and kids into the ICU, recovery room, or emergency department any time I want them there. Any time. Will you promise me straight answers to my questions, and will you stick with me until I finally understand your answers?

You can see how this works at Terry Clemmer's ICU at LDS Hospital, which has open visitation and the best approach to helping family members I have seen anywhere. You can study it now at Geisinger Clinic in Pennsylvania, where Karen McKinley has been leading her medical ICU, though not yet the surgical ICU, to fully open visiting hours.

Specification Number Three Is "No Helplessness"

I can maybe show you this one better than talking about it.



Berwick in a Hospital Gown

So you're laughing. Why are you laughing? Because I look ridiculous. It's a slippery slope from here to helplessness. I *do* look ridiculous —childlike, undignified, vulnerable. That's what I mean, partly, by helplessness. Look how much you can take away from me when I agree to become your patient. You can take away my clothes, my privacy, my right not to be naked. You can put things in my body orifices and veins. You can take away my pills, and give me yours. You can harm me with an error, and never tell me. You can read me your rules, but I cannot read you mine.

I'm looking for a place that won't let that happen. The two most important ways to prevent my helplessness are to share information with me and to give me choices. First, keep me posted. That'll begin with my medical record. No one can touch my knee who won't give me my medical record to read anytime I want it, no questions asked, and no delays. Better yet, let me keep my record with me, and I'll let you use it anytime you want.

To keep me from feeling helpless, you'll need to leave choices in my hands. You'll need to find out the way I want things, and adapt to me. You'll need to read my rules, and not just read me yours.

A close relative of mine was in a hospital this summer for a serious illness. She needed anticoagulation and blood tests every six hours. She also needed her blood chemistries monitored every six hours with a different blood test. Problem was, the orders were put in at separate times, and the six-hour intervals weren't synchronized. That meant my cousin had eight blood draws a day instead of four.

So, I asked on her behalf that they synchronize the blood drawing, but the IV nurse refused "because the doctor ordered it that way." So did the floor nurse, who looked pretty annoyed at me. They called the surgical resident, and he looked even more annoyed. He said that he refused to take responsibility for any risks that delaying one or the other of the blood tests would involve. My cousin was so scared that she cried. Moreover, he told us that this meant that at 2:00 a.m., he, not the IV nurse, would have to draw the blood.

That's what I mean about helplessness. Eight needle sticks when it could have been only four. Blaming the patient and her difficult relative for asking that a moronic scheduling defect be repaired. Shifting the burden to the patient. Treating an honest, logical request as a bother.

I'll tell you what I'd like. Tell me how you treat "patient's orders"—mine—as respectfully and carefully as you treat "doctor's orders," and maybe I'll let you get into my knee. If your feeling is that that makes me a "difficult patient," then save us both time and don't submit a proposal.

I guess I'd like an appendix to your application that tells me how you make sure that all of your staff understand that—that you hire people who have the attitude "The patient is the boss," and that you give them the tools to make it so.

If I'm not going to feel helpless, then I need to be able to reach you later on—after I go home—maybe months later, maybe even years later—with questions and suggestions. You make me helpless when you leave me confused with no way to get unconfused. I'd really appreciate 24/7 answers, if you can arrange that. Email access to the doctor would work just fine for me. Who knows when I might feel worried? If you tend to view discharge as "out of sight, out of mind," I don't think you can get the job. My knee—or the metal one you put into me—is hopefully going to be around for quite a while—twenty years, maybe, so I want you to remember me . . . that long.

It is interesting to me, and sad, that the surgeon who first did the wrong operation never, ever, called me or followed up on me in any way at all to see how I was doing, which has at least a little to do with how he is doing. How can he learn about the long run? Did he think I was done with my knee when he was? I'll give you extra points if you have a total knee registry, and use it a lot. Even more points if you follow up patients regularly for years, to understand the effects of your work on them over time.

Specification Number Four Is "No Unwanted Waiting"

This is sort of obvious. I want you to tell me how you prevent delays of all types. I am really busy, just like you are, and for most things, the best wait for me is no wait at all. In your clinics, I'd appreciate your using the Advanced Access model of Mark Murray and Catherine Tantau, like the Alaska Native Medical Center, and Luther Midelfort, and ThedaCare do, or like Everett Clinic or the Veterans Health Administration, so I can get an appointment any day I want it. In your hospital, I'd appreciate it if you'd use the brilliant work of Professor Eugene Litvak on how to smooth flow through your system. Maybe you could participate in IHI's Flow Collaboratives. That way, you won't leave me alone on gurneys in your hallway. You'll start my surgical case when you say you will. If you do a test, you'll store and retrieve it on demand, and if someone else already did the same test, you'll use that test instead of repeating it. You'll schedule my discharge in advance to the half-hour, and I won't have to wait around for a missing doctor's signature or because my medications haven't arrived.

I am already helping you with this one. In my bedroom closet, behind the sweaters, is my X-ray file. It contains almost all of the X-rays, MRIs, and CAT scans taken of my right knee in the past decade. Some are copies. Most are stolen. It's a complete file. It's probably also a felony.

Why am I a felon? Well, let's review the history. Since 1991, I have received surgery, care, or opinions for my knee in seven different locations—six in New England and one on the West Coast—from eleven physicians and surgeons, four physical therapists, and a masseur. I have had eight different X-ray, MRI, and CAT scan sessions in five different facilities. On no occasion at all did anyone who saw me have anyone else's X-rays or images to look at—only their own—except when I, myself, physically transported them. This required me to take time, over and over again, traveling to hospital file rooms, filling out forms, and waiting while they searched. On two occasions, when I tried to borrow films to transport them, the facility told me they were lost.

So, I figured, why not lose them to me? They're no more lost than they were before, except now at least one person knows exactly where they are lost to.

Since I became a felon, every single clinician I have seen about my knee has had every single image that was ever done in the past ten years. The Berwick right knee imaging retrieval system has become 100 percent reliable. And, the delays waiting for people to find or fetch films have fallen quite low—to zero, as a matter of fact. Well, my closet is a little messy, so it can take me a few seconds.

Just a warning: to the young people in the audience, I am not advising you to steal your own X-rays and medical records so as to improve reliability, decrease helplessness, and drive delays to zero while also saving hospitals and clinics the costs and delays of retrieval and tracking down lost items. That would not make any sense, would it?

Do you know that in the Military Health Command, patients can store and carry their own medical records?

Specification Number Five Is "No Waste"

Now, do I really care about that one? After all, my health insurance is pretty good, and, if you want to raise your costs by creating scrap or wasting materials or duplicating efforts, isn't that your problem, not mine?

Of course, the good citizen in me wants you to reduce your costs by reducing your waste. European health care systems, after all, tick away at one-half the cost of ours. Here are some recent figures: the OECD

[Organisation for Economic Co-operation and Development] nations provide comprehensive, universal health care at $2,000 per person per year, while we spend $4,800 in the United States. I am astounded by the myths chiseled into concrete in the minds of Americans about these differences. The myth that people flock to us for care they cannot get in Canada or England. The myth that these other systems are disciplined by rationing that we don't accept.

The myths are wrong, and it is one of the greatest frustrations I have as a student of improvement that I cannot seem ever to win the attention or curiosity of American health care leaders to study and harvest bold, new ideas from these non-US systems. The answers we need for America's health care do not lie in our normal experience. They lie outside our normal experience. The knee surgery outcomes in Sweden are good. I think they're better than ours. I know that their postoperative care is more integrated than ours. I know that they have a national knee arthroplasty registry with over seventy thousand entries in it. In your response to my RFP, maybe you'd like to tell me how you are learning from other nations about how to make better care with less money. If you answer that question, you may be the only one who does.

But, actually, my knee and I have a more selfish reason to ask you about waste. It relates to something Paul O'Neill first told me: the importance of what he calls "a habit of excellence." He thinks, and I agree, that excellence in a system, to be reliable, can't be divisible. You can't say, "Be excellent here, but it's okay to be sloppy there."

Waste is a symptom of a defective process. It is non-excellence. I want my knee in the hands of people and a place who are intolerant of the disorder, duplication, unpredictability, and inattention to detail that lie at the root of waste, because then I can predict with more confidence that my care may be orderly, coordinated, anticipatory, and attentive. I want my care from a place where a habit of excellence creates a sheen and leanness, a sensitivity in real time, a calmness and steadiness that no glutton seeks or understands.

I've got to tell you that, when I finally read my whole RFP, overall, I got nervous. It's really asking for a lot, and it is very self-centered. It leaves me with two big questions. First, does anyone want to answer it? And, second, *can* anyone answer it?

I just can't help you with the first question, "Do you want to pay attention to me?" I can't make anyone want to serve me. That's your call, not mine. If I ever could actually issue an RFP, and take my money with me to a winning applicant, I'd do it. With one shot left between me and cross-country skiing, I've just got to take the best shot.

But you and I both know that I can't do that. I can't really shop, not much. Health care is a niche market, and my choices are very, very limited. In fact, the only thing more limited than my choices is the information on the basis of which I would choose, if I could choose.

That's changing. I hope it'll change fast. Transparency about results seems more and more important to me as I age and as my bone-on-bone wears away. I was interested that, even though nobody made them do it, John Toussaint at ThedaCare and colleagues in eight organizations in Wisconsin have taken it upon themselves to publish their own performance data, warts and all, on a whole bunch of indicators, and more over time, as part of the Wisconsin Collaborative for Healthcare Quality. I applaud them. That's one of the places in the country where I actually could make some choices on the things I care about. I just wish I could do that for my knee.

So, I'll have to turn to my second question, "Is this fantasy or can it be done? If anyone did want to try to meet my specs, could they?" Here, the answer is easier; it's "Yes." Nothing in my RFP, nothing at all, is out of reach. For almost every detail, I know a supplier right now. I can avoid surgical infections if I go to Intermountain Health Care. I can avoid ventilator-associated pneumonia if I go to Dominican Hospital in Santa Cruz. My indwelling IV won't get infected at Baptist DeSoto Hospital. My wife and kids can visit me any time, day or night, in the medical ICU at Geisinger Clinic. If I were cared for in the Military Health Command, I could carry my own medical record, and I could read it anytime I want. I might have no pain at all—I did have no pain at all—at Virginia Mason. My primary care delays would be zero because of open access schedules at Luther Midelfort or ThedaCare, and my specialty delays would be constantly falling at Alaska Native Medical Center in Anchorage. I could wear my street clothes in a Planetree Unit, and get to my doctors through email anytime at Group Health Cooperative of Puget Sound. At Ekjö Hospital in Jönköping County, Sweden, the costs of my care would be 40 percent of the US costs, with the same outcomes, lower complications, and more coordinated rehabilitation. My care would be integrated across inpatient and outpatient settings by an electronic medical record in the VA, and digital radiology in the Indian Health Service would allow me to clean out my closet.

In ten years of hard work, we have all together brought health care from the state of having no cloth to the state of having no quilt. The patches are made. The stitching is the problem. Look around you; almost everyone in this room has a piece of the answer. I could have exactly what I want if I could cut myself into pieces. I'd get my respirator care

at Dominican, my IV line at Baptist DeSoto, my medical record at the Washington Medical Center, my pain control in Seattle, and my appointments in Anchorage. I'd have the transparency of the Wisconsin Collaborative, the respectfulness of Planetree, the orderliness and sparseness of Jönköping, the teamwork and nursing morale of Hackensack and North Shore–Long Island Jewish, the flow management of Mayo Clinic in Rochester, Minnesota, and the email system of Dr. Gordon Moore in Rochester, New York, or Dr. Chuck Kilo in Portland, Oregon. I see what I want and need; it's just scattered all around.

Someone, please, now put it together. I need a quilt, not patches. This isn't just a speech for me. This is real. It will be dark one night, and your nurses will be tiptoeing outside my room. And I will be lying there, in the bed you make for me, scared and wondering: Am I safe? Will I die here? Will I ski again? Where is my wife? What are you thinking? Do you know I am here? Do you know my name? Do you know my name?

Do it right—for me or for anyone. No needless death, no needless pain, no helplessness, no unwanted waiting, no waste. Don't do it just for me . . . no, wait a minute—do it just for me.

Our theme for this National Forum is "courage." What does this have to do with courage? It's only a knee. Just a knee. Thank God. It could be my heart. It could be cancer. It could be ALS, or a disabling psychosis. It could be pain for years, not hours, or losing the ability to speak, or see, or reason, not just to ski the moguls. I could be, not an American with a bad knee, but a Thai with dengue or an African with AIDS.

There's the courage: to see myself in others. What if they're just like me? What if everyone I want to help is just me, in disguise? Tomorrow, Forum keynote speaker Paul Farmer will talk to us about some of the poorest people in the world—in rural Haiti. What if they're just like us? What if every one of them, whether we ask them or not, has an RFP, too, as complex, as poetic, and every bit as important to him or her, as mine is to me, or as yours is to you?

The great Gandhi sat with a child, and said, "I, too, have felt what I am asking you to feel." Then, and not before, he was able to help. We are no Gandhis, but I am coming to believe that we cannot relieve the pain of others until we feel our own. It is the only sustainable source of sufficient will for change. We will help them with what they need when we know what we need. We will honor and respect their wishes when we have trusted and respected our own.

Imagine the care you'll need before the Red Sox finally win. You couldn't be in a better place to search for it—four thousand strong at this Forum, four thousand more joining by satellite—a movement well

begun, waiting to help. Wish for what you need, trust what you wish for, and then promise no less to the people you serve. If we can have the courage to see it that way, then, I promise you, we'll sweep the Series—clean sweep. Red Sox, eat your hearts out.

FURTHER READING

Fisher ES, Wennberg DE, Stukel TA, Gottlieb DJ, Lucas FL, Pinder EL. The implications of regional variations in Medicare spending. Part 1: The content, quality, and accessibility of care. *Ann Intern Med.* 2003 Feb 18;138(4):273–287.

Fisher ES, Wennberg DE, Stukel TA, Gottlieb DJ, Lucas FL, Pinder EL. The implications of regional variations in Medicare spending. Part 2: Health outcomes and satisfaction with care. *Ann Intern Med.* 2003 Feb 18;138(4):288–298.