

## My Right Knee

Donald M. Berwick, MD, MPP

Despite some impressive recent gains, improving the glaring deficiencies in health care quality is proving to be very hard. Improvement is local, rather than system-wide, and is sustained with difficulty, rather than becoming an intrinsic feature of care.

My right knee will probably need to be replaced soon. This has given me the opportunity to define, in very personal terms, 5 specific dimensions of “total quality” that I will require from the medical institution that does my surgery and that every patient has the right to require of their encounters with the health care system. Don’t kill me (no needless deaths). Do help me, and don’t hurt me (no needless pain). Don’t make me feel helpless. Don’t keep me waiting. And don’t waste resources, mine or anyone else’s.

Given my requirements, it is not clear that any health care institution in the United States will want to take me on as a patient. Although at this point individual institutions can meet some of these requirements, no single institution can deliver on all of them. Generating the energy, insight, and courage we need to get to “total quality” may require those of us who work in health care to get much better at seeing images of ourselves in the people we help. As Gandhi said, “You must be the change you wish to see in the world.”

*Ann Intern Med.* 2005;142:121-125.

For author affiliation, see end of text.

www.annals.org

Times have been good recently for quality improvement in health care, but in 2004 the stakes on improvement went up for me personally. The problem we need to solve is this: Despite the good news, improvement is still happening in pieces. It must take some different level of energy, insight, and courage than we have mustered so far to get to total quality of care. Where will we find the courage we are going to need?

### A PROPOSAL

I propose this: If we are going to care enough to provide really different care, top to bottom, we are going to have to begin seeing patients and their lives not “out there,” but as mirrors of our own lives, “in here.” Mahatma Gandhi was asked to help a diabetic child stop eating sweets and starches, but before he was willing to do so, Gandhi stopped eating them himself for a few weeks. He could then say to the child, “I, too, have felt what I am asking you to feel.” Then, and not before, he was able to help.

Taking that hint, and wanting to help, I indulge, paradoxically, in an exercise of complete self-centeredness. These are my knees (Figure). I was born with 2 knees. Now, I have maybe 1.7 knees. Playing soccer one day while in medical school, my right kneecap subluxed laterally, then quickly flipped back into place. That hurt. When it happened again, I went to see a surgeon. He found bad knee mechanics and recommended surgery—a modification of the so-called Hauser procedure—which I had a few weeks later.

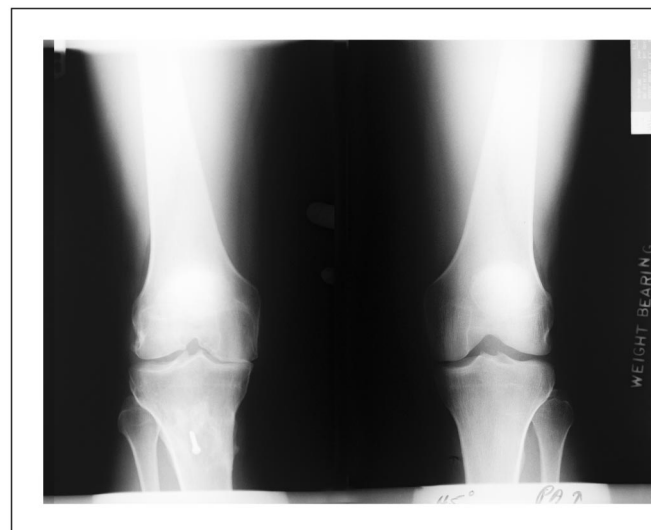
The postoperative pain when I woke up was severe, but, trusting medical care, I endured it with what I would now call “writhing optimism,” since at least my problem was now over. It was, sort of. My kneecap never again

subluxed laterally; a few weeks later, it subluxed medially. (Within a few years, by the way, when it was finally subjected to a long-term follow-up study, the Hauser procedure for my kind of knee problem was discredited; only 12% of patients had satisfactory results, dislocation recurred in 20% of the knees, and more than two thirds of the patients had developed osteoarthritis [1].)

Seeking relief, I went to another surgeon at a different hospital. He suggested a simple repair job, which went pretty well, except for a couple of days of shaking chills and a temperature of 104 °F after surgery. My knee never subluxed again.

That was that for many years. But sad to say, after several meniscus tears, followed inexorably by multiple

**Figure.** Radiograph of the author’s knees, showing “bone-on-bone” osteoarthritis of the right knee.



x-rays, magnetic resonance imaging scans, computed tomography scans, and arthroscopic surgeries in various cities, I have developed osteoarthritis (in the poetry of the orthopedic surgical literature, “bone on bone”). As a result, some time uncomfortably soon, I am going to need a total knee replacement, maybe even to walk, but certainly to do the things I love to do, like hike, cross-country ski, and climb.

But now, I have another problem besides osteoarthritis; namely, I am terrified of the treatment. 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 about what could go wrong.

In my opinion, the health care quality improvement movement should focus on 5 goals for health care change in the world, which I summarize as follows: No needless deaths, no needless pain, no helplessness, no unwanted waiting, and no waste. These are a slight, and more colloquial, rewording of the Institute of Medicine’s (IOM’s) dimensions of quality: safety, effectiveness, patient-centeredness, timeliness, and efficiency (2). Add the aim to achieve these “for all,” and we have the sixth IOM quality dimension, equity. At a system level, these are a vision. At a personal level, they are more than a vision; they are my needs.

So, my knee and I have decided to issue an RFP, a request for proposals, as a company does, for example, when it wants to get a contract. The specifications my knee and I are setting are the same as the “no needless . . .” list, with a little more detail.

### SPECIFICATION 1: NO NEEDLESS DEATHS

My RFP says it this way: “Don’t kill me.” Prospective applicants please note: I do not take this deliverable for granted. When I give you the contract on my knee, you become “007,” licensed to kill . . . me. You see, the minute I slip under your anesthetic and your knife, I will be taking the greatest risk to my life, statistically, that I have ever taken, greater by at least 1 order of magnitude, maybe 2. I have climbed Mt. Rainier, with its crevasses and vicious weather, 5 times. On those 5 climbs combined, I was running a risk for dying perhaps one fiftieth as great as I will take in your operating room.

Here are just some of the ways you can kill me: You can give me an infection during my surgery. You can mix up a blood transfusion. You can fail to prevent a pulmonary embolism. If I need a respirator for a while when I wake up, you can give me pneumonia. You can misplace a decimal point in the order for morphine. You can place the endotracheal tube by mistake in my esophagus (which, in the United States, happens on average in 8% of non-intensive care unit intubations [3]) and not realize it until it is too late.

Everything on that list, by the way, happens and can be prevented, not down to a rate of zero percent, but aw-

fully close to zero. Just please make me as safe in your care as when I crossed the crevassed glaciers of Mt. Rainier.

Without my RFP, I would be entering the “lottery” of safety that we now have in this country. For example, complication rates for total knee replacements in hospitals in southwestern Pennsylvania range from 2% to 33% (4). Now, 33% is unacceptable, but, frankly, even 2% doesn’t sound all that good to me. As far as I know, no members of the public have access to hospital-specific information on complications for these procedures at the time they are admitted. If you do not tell me your complication rate, then I have to assume that either you do not know or that maybe you have something to hide. I really do not think you have a right not to tell me your results and then expect me to give you my knee to work on.

### SPECIFICATION 2: NO NEEDLESS PAIN

In my own terms, this specification means, “Assuming you don’t kill me, don’t hurt me either.”

That is a little unrealistic, of course, because, after all, surgery is itself a form of hurting. I accept that. I am not asking for perfect results; I am asking for the least possible harm. I want you to know what is the least possible harm, anywhere, and offer that level of excellence to me. Specification 2 has three subparts: 2A, 2B, and 2C.

Specification 2A is “Don’t do things to me that will not help me.” I have a track record on this one. As it happens, I do not think that I needed the extensive, painful, since-discredited knee operation that I underwent initially; in retrospect, a brace and some exercises would almost certainly have been enough. I seem to have fallen into the very trap that Professor John Wennberg has been pointing out to us for over 2 decades: that, in much of health care, supply drives demand, without regard to the quality of outcomes of care (5). In fact, recent work shows that quality (for example, whether people reliably get the care that can help them) does not change at all with the intensity of hospital services (and cost); that is, until you reach the top quintile. And there, for some important measures, quality actually decreases (6, 7). These are frightening findings, with imponderably large implications for U.S. health care. Unfortunately, nobody powerful in U.S. health care seems to want to touch this inverse correlation between supply and quality with a 10-foot pole.

On thinking about it, if these authors are right, my first knee operation may well have been done not because my knee *problem* was there, but because the knee *surgeon* was there. I am convinced that that surgeon, a kind and thoughtful man, believed that he was going to do me good. But the fact remains: I know now that I had useless surgery for an essentially nonsurgical problem. Specification 2A says, in effect, “Don’t do that kind of thing again.” Act on evidence, not just on hope. And when the firm, scientific evidence is not there (as it often is not), at least let me know that.

Specification 2B is “Reduce the burden of disease I have from my bad knee and do not do things that will hurt me.” This is the obverse of Specification 2A. It is “Job 2,” just behind safety. For example, maybe you could start out by offering me a higher chance of great function with a new prosthesis that is less thoroughly tested than the old standby, but more promising. I can understand that; risks and results are frequently a tradeoff. What I want you to do is to involve me in that tradeoff decision.

Once we have decided, together, on what to do, do not add to my pain with a preventable complication, and please make every effort to choose your approach to anesthesia, prosthetic implant, postoperative recovery, and so forth, on the basis of credible, scientific clinical evidence. My right knee is on your left, and vice versa. I will therefore give you credit if your response to my RFP tells me how, while I am asleep, you will not get your signals crossed on which knee is the damaged one, and will execute all other aspects of your clinical plan absolutely reliably.

Suppose, for example, that the surgeon who was meant to operate on me gets the flu, and so a different surgeon has to do the operation. Will you guarantee that the exact same evidence-based care will happen anyway? When I get on an airplane, I do not 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? If the housekeeper, or student nurse, or anyone else in my operating room sees something that could help me, maybe even save my life, will he or she speak up loudly, promptly, and directly? And will the surgeon praise that participation, not discourage it?

Specification 2C is a special case of the other two. It reads, “Relieve my pain.” I am stoic, but not a Zen master. If it hurts, I want you to take the pain away. That includes relieving both physical pain and emotional pain. Physical pain you can get right by using the science. I already know that because during 2 of my own knee operations, at Virginia Mason Clinic in Seattle, Washington, I had not a single moment of pain at any time. World-class pain control. It wowed me.

Emotional pain is more subtle. My emotional pain happens when I am alone, or when I want to know something but no one will answer me, or when I feel criticized, or when someone gives me the impression that I am stupid, or when I am frightened. So, your reply to my RFP will have to tell me how you plan to help me with those needs. Will you promise me that my wife and kids will be allowed in the intensive care unit (as is now being done in some hospitals), recovery room, or emergency department any time I want them there? Will you promise me straight answers to my questions, and will you stick with me until I finally understand your answers?

### SPECIFICATION 3: NO HELPLESSNESS

When I agree to become your patient, you can take away my clothes, my privacy, my right not to be naked. You can make me look ridiculous in your hospital gown: childlike, undignified, vulnerable. 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 am looking for a place that will not let that happen. The 2 most important ways to prevent my helplessness are to share information with me and to give me choices. Informing me begins with my medical record. No one can touch my knee who will not give me my medical record to read any time I want it, no questions asked, and no delays. Better yet, let me keep a complete copy of my record with me, and I will let you use it any time you want.

Giving me choices includes having you (and all of your staff) treat “patient’s orders” (mine) as respectfully and carefully as you treat “doctor’s orders.” If you feel that this makes me a “difficult patient,” then save us both time and do not submit a proposal.

If I am not going to feel helpless, then I also need to be able to reach you later on, maybe months or even years later, with questions. I would really appreciate answers 24 hours a day, 7 days a week; e-mail access would work just fine. My knee, or the metal one you put into me, is going to be around for quite a while—20 years, if I am lucky—so I want you to remember me that long. In that connection, it is interesting to me, and sad, that the surgeon who did the first operation on my knee never followed up with me. How can he learn about what happens in 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. I’ll award even more points if you follow up patients regularly for years to understand the effects of your work on them over time.

### SPECIFICATION 4: NO UNWANTED WAITING

For this one, I want you to tell me how you prevent delays of all types. I am really busy, just like you are. The best wait for me, therefore, is no wait at all. In your clinics or offices, I would appreciate your using the open-access model (8) so I can get an appointment virtually any day I want it. In your hospital, I would appreciate it if you would use the powerful recent work on how to smooth flow through your system (9). That way, you will not leave me alone on a gurney in your hallway. You will start my surgical case when you say you will. If you need the results from a test that someone else has already done, you will use that test instead of repeating it. You will schedule my discharge in advance to the half-hour, and I will not have to wait around because a doctor’s signature is missing or because my medications haven’t arrived.

I am already helping you with this one. In my closet at

home, behind the sweaters, I have a file that contains almost all of the x-rays, MRIs, and CT scans taken of my right knee in the past decade. Some are copies, others are the original films. It is a complete file.

Why have I resorted to such extreme measures? Since 1991, I have had 8 different x-ray, MRI, and CT scan sessions in 5 different facilities. On no occasion did anyone who took care of me have anyone else's images to look at, except when I physically transported them myself. This required me to take time, travel to hospital file rooms, fill out forms, and wait while people searched. On 2 occasions, the facility told me the films were lost.

So, I figured, why not "lose" them to me? They are no more lost than they were before, except now at least 1 person knows exactly where they are lost *to*.

Since I began collecting my own films, every clinician I have seen about my knee has had every image of that knee done in the past 10 years. The lesson here, of course, is not that every patient should simply walk away with existing medical records or x-rays, which would obviously create a terrible mess and would perhaps even be a bit illegal. But it does argue for a system in which patients are given the opportunity to keep a copy of every bit of medical information recorded about them. Do you know that, in some Veterans Health Administration sites, patients have direct access to their own medical records?

### SPECIFICATION 5: NO WASTE

Do I really care about waste? 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, rather than mine?

Of course, the good citizen in me wants you to reduce your costs by reducing your waste. After all, in 2000, the nations in the Organisation for Economic Co-operation and Development (OECD) provided comprehensive, universal health care at an average of \$2000 per person per year, while in the United States we spent \$4800 (10). Why is this difference so great? Opinions in this country to the contrary, many of the most important answers we need for our health care lie outside of our national experience, not inside it. Knee surgery outcomes in Sweden are at least as good as ours. Their postoperative care is more integrated than ours. They have a national knee arthroplasty registry with over 70 000 entries in it (11). If, in your response to my RFP, you tell me how you are learning from other nations about how to make better care with less money, 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 that Paul O'Neill, former Secretary of the Treasury and former CEO of Alcoa, calls "a habit of excellence" (O'Neill PH. Plenary presentation. Institute for Healthcare Improvement's 15th Annual National Forum on Quality Improvement in Health Care, New Orleans, Louisiana, 5 December 2003).

You cannot say, "Be excellent here, but it is okay to be sloppy there."

Waste is a symptom of defective process. I want my knee in the hands of people 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 will be orderly, coordinated, anticipatory, and attentive.

### PUTTING IT ALL TOGETHER

Taken as a whole, my RFP makes me nervous. It is really asking for a lot, and it is very self-centered. It leaves me with 2 big questions: First, does anyone want to answer it? And, second, *can* anyone answer it?

I cannot help you with the first question. I cannot really shop widely for my care, because, as you know, health care is a niche market. In fact, the only thing more limited than my choices is the information on which I would base my choice if I had choices.

That is changing, and I hope it will continue to change fast. Transparency about results seems increasingly important to me as the bone in my knee wears away. Eight organizations in Wisconsin have taken it upon themselves to publish their own performance data, warts and all, on a range of medical outcome indicators (12). I applaud them. That is one of the places in the country where I actually could make choices on many medical things I care about. I just wish I could do that for my knee.

So, I will have to turn to my second question: If anyone did want to try to meet my specifications, could they? Here, the answer is easier. It is "yes." Nothing in my RFP is out of reach, right now. For example, I can avoid almost all surgical infections if I go to Intermountain Health Care in Salt Lake City, Utah. I can pretty much avoid ventilator-associated pneumonia if I go to Dominican Hospital in Santa Cruz, California. My indwelling intravenous line is very unlikely to get infected at Baptist DeSoto Hospital in Southaven, Mississippi. My wife and kids can visit me anytime, day or night, in the medical intensive care unit at Geisinger Medical Center in Danville, Pennsylvania. If I were cared for in some Veterans Health Administration sites, I could have access to my own medical record, and I could read it any time I want. I might have no pain at all (in fact, I *did* have no pain at all) at Virginia Mason Medical Center. My primary care delays would be effectively zero because of open-access schedules at Luther Midelfort–Mayo Health System in Eau Claire, Wisconsin, or ThedaCare in Fox Valley, Wisconsin. I could wear my street clothes in a Planetree unit at Griffin Hospital in Derby, Connecticut, and get to my doctors through e-mail any time at Group Health Cooperative of Puget Sound in Seattle, Washington. At Ekjö Hospital in Jönköping County, Sweden, the costs of my care would be 40% of the U.S. costs, with the same outcomes, lower complications, and more coordinated rehabilitation. My care would be inte-

grated across inpatient and outpatient settings by an electronic medical record in the Veterans Administration, and digital radiology in the Indian Health Service would allow me to clean out my closet.

In 10 years of hard work, we have together brought health care from a state of having no cloth to a state of having patches but no quilt. Someone, please, now stitch it together. For me, this is not just hypothetical. 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 even know my name?

For me, it is only a knee. Thank God. It could be my heart. It could be cancer. It could be amyotrophic lateral sclerosis, 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 just an American with a bad knee but a Thai with dengue or an African with AIDS.

Therein lies the challenge: finding the courage to see myself in others. What if everyone I want to help is just me, in disguise? What if every person, whether we ask about it 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?

Gandhi said, "You must be the change you wish to see in the world." We are not Gandhi, but we should take his hint. I am coming to believe that we cannot relieve the distress of others until we get better at sensing our own, and what we need to relieve it. That may be the only sustainable source of sufficient will for real change. We will honor and respect the wishes of our patients and their families when we have trusted and respected our own.

From the Institute for Healthcare Improvement, Cambridge, Massachusetts.

**Note:** This paper is based on a plenary address, "My Right Knee," delivered at the Institute for Healthcare Improvement's 15th Annual National Forum on Quality Improvement in Health Care, New Orleans, Louisiana, on 4 December 2003.

**Acknowledgments:** The author thanks Jane Roessner, Valerie Weber, and Frank Davidoff for their extraordinary help in preparing this manuscript.

**Potential Financial Conflicts of Interest:** None disclosed.

**Requests for Single Reprints:** Donald M. Berwick, MD, MPP, Institute for Healthcare Improvement, 20 University Road, 7th Floor, Cambridge, MA 02138; e-mail, dberwick@ihi.org.

## References

1. **Juliusson R, Markhede G.** A modified Hauser procedure for recurrent dislocation of the patella. A long-term follow-up study with special reference to osteoarthritis. *Arch Orthop Trauma Surg.* 1984;103:42-6. [PMID: 6466063]
2. **Institute of Medicine.** Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC: National Academies Press; 2001.
3. **Schwartz DE, Matthay MA, Cohen NH.** Death and other complications of emergency airway management in critically ill adults. A prospective investigation of 297 tracheal intubations. *Anesthesiology.* 1995;82:367-76. [PMID: 7856895]
4. Total Hip and Knee Replacement Surgery in Southwest Pennsylvania. Harrisburg, PA: Pennsylvania Health Care Cost Containment Council; December 1999.
5. **Wennberg JE, Cooper MM, eds.** The Dartmouth Atlas of Health Care 1998. Chicago: American Hospital Publishing; 1998.
6. **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;138:273-87. [PMID: 12585825]
7. **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;138:288-98. [PMID: 12585826]
8. Primary care access. Institute for Health Care Improvement. Accessed at [www.ihi.org/IHI/Topics/OfficePractices/Access/](http://www.ihi.org/IHI/Topics/OfficePractices/Access/) on 19 November 2004.
9. **McManus ML, Long MC, Cooper A, Mandell J, Berwick DM, Pagano M, et al.** Variability in surgical caseload and access to intensive care services. *Anesthesiology.* 2003;98:1491-6. [PMID: 12766663]
10. **Reinhardt UE, Hussey PS, Anderson GF.** U.S. health care spending in an international context. *Health Aff (Millwood).* 2004;23:10-25. [PMID: 15160799]
11. Swedish Board of Health, National Registry of Knee Injuries. Accessed at [www.sos.se/sosmenye.htm](http://www.sos.se/sosmenye.htm) on 21 November 2004.
12. **Wisconsin Collaborative for Healthcare Quality.** 2003 Performance & Progress Report. Accessed at [www.wiqualitycollaborative.org/pdf/WCHQ\\_report.pdf](http://www.wiqualitycollaborative.org/pdf/WCHQ_report.pdf) on 19 November 2004.