

How Will Health Care Professionals and Patients Work Together in 2020?

A Manifesto for Change

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Abstract

How can we accelerate the shift to a new paradigm of patient-centered health care? In this report, a manifesto for change is put forth, while acknowledging that health care systems are highly complex systems for which there is no simple solution. The starting premise is that one needs to launch and reinforce positive developments among both clinicians and patients. To this end, a vision is offered to transform medical schools into health professional schools; specific ways of leveling the knowledge playing field between clinicians and patients are described to empower patients to ask more questions and dissuade clinicians from “avoidable ignorance.” The Wennberg three-step action plan is proposed to demonstrate how a patient-centered health care paradigm can work for important process and outcome measures. To foster patients’ engagement within the health care system, an existing model that teaches health literacy to children in primary schools is described and possibilities are proposed to foster the delivery of quality health care information via the media and online communities, with the Internet being *the* technology that is most likely to complete the change in the dynamic of doctor–patient interaction. The 21st century is viewed as the century during which reform ushers in an adult conversation between patients and doctors.

Introduction

Immediately after the election of Barack Obama and in the midst of the worst economic recession since the Great Depression, the President Elect’s newly

designated chief of staff, Rahm Emanuel, pronounced what has since become known as the Emanuel Principle: “Rule one: Never allow a crisis to go to waste. They are opportunities to do big things” (Zeleny 2008). Stigler’s (1983) law of eponymy has it that a great idea is never named after the person who had it first. Corroborating this law, Emanuel’s observation echoed the advice of Niccolo Machiavelli in *Il Principe*: “Never waste the opportunities offered by a good crisis” (Machiavelli 1513).

We are indeed in the middle of a good crisis. Except in a few countries, health care systems in the industrialized world suffer from rising costs which, if not radically reformed, could soon bankrupt governments. The most glaring example is the system in the United States. Over the past few decades, U.S. health care costs have risen at a consistent 2.5 percentage points above the growth rate of the economy. If this trajectory were to continue until 2050, it is reckoned that Medicare and Medicaid (the government programs that insure the elderly and the poor, respectively) would together consume 20% of America’s GDP, almost as much as today’s entire federal budget (Economist 2009). Moreover, many experts expect that the health care reform that was finally passed in March 2010 will not reign in the drivers of America’s roaring health care costs (Economist 2010) and, according to a RAND analysis (based on the U.S. Senate version of the bill), will further increase America’s overall health care spending, relative to status quo projection (Ringel et al. 2010). America, of course, is not alone in this pickle. According to the Organisation for Economic Co-operation and Development (OECD), health expenditures grew rapidly in many countries between 2000 and 2003, with an annual average OECD growth rate of 6.2% over that period. In 2008, the highest health expenditures as a share of GDP were found in the United States (16.0%), followed by France (11.2%), Switzerland (10.7%), and Austria and Germany (10.5%). Health care costs have simply spiraled out of control.

As Muir Gray expressed at the start of this Forum: “The last 40 years have been fantastic” for public health, with ever-increasing resources, the development of sophisticated research methodologies and treatment procedures, and the build-up of modern infrastructure. The once-full coffers are emptying, however, and we are entering a new period of scarce resources precisely as economic demands on the health care system are increasing. These demands include, for example, expenditures on long-term care for an aging population and on the consequences of climate change, which is expected to worsen virtually every health problem known, from heart disease and heatstroke to salmonella and insect-borne infectious diseases (Brahic 2009).

Financial necessity, however, is not the sole driver of change. Change is also needed for ethical and clinical reasons. There is ample evidence that the 21st century Moloch—the medical–pharmaceutical complex, the modern rival of what President Eisenhower once called the industrial–military complex—makes systematically faulty (but profit-maximizing) assumptions about patients’ preferences. Treatment has become supply-centered rather than

patient-centered. Supply-centered medical treatment means that the care ordered for patients—such as diagnostic tests, hospital admissions, operations, specialist visits, and home nursing—is frequently driven by the financial, legal, and related needs of the providers, or by unresolved patient needs rather than by the medical needs of the patients. More care, however, is not appreciably better, and by some measures, it is worse than less care (see the various analyses reported in the Dartmouth Atlas of Health Care 2010). The crisis of the health care system is thus not just a financial one; it is also a troubling ethical one. A Moloch is so called for a reason. This Moloch keeps asking for costly sacrifices, forcing societies to neglect other important tasks (e.g., maintaining vital infrastructures such as schools or bridges), and damaging, for example, the global competitiveness of American businesses.

Taken together, there is a strong case to be made for change. The starting premise of this group report is that progress will occur: First, there will be efficient mechanisms and guidelines to enforce the complete and transparent reporting of research results. Second, future generations of medical students and health professionals will no longer suffer from statistical illiteracy but be trained to deal with, interpret, and communicate risk and uncertainty to their patients. Third, efficient ways of communicating unbiased evidence to health professionals and patients will be designed and implemented, enabling them to make shared decisions. All's well that ends well—except that we are not there yet. Before these new mechanisms can take full effect—and that is our second premise—we need to take action to foster change as quickly and as effectively as possible. How do we curtail this revolutionary period in which the old guard may want to retain the reigning paradigm and resist change as long as possible? Or, to use Thomas Kuhn's (1962) phrase of paradigm shift, how do we accelerate the shift into a new paradigm of patient-centered health care, how do we speed up the reform of the old system, and how do we render it likely that 2020 will not be a replay of 2010?

There are many actual and perceived barriers to implementing more patient-centered care. Table 19.1 lists the most prominent ones.¹ In this chapter, we address some of these barriers and ignore others. This is not a reflection of their importance (or lack thereof) but of our decision to focus on the health care professional (in particular, on the clinician) and the patient as units of analysis, rather than on the health care system per se. By treating both of these players separately, we do not mean to imply that they are separate. They are two key players tied up in the context of a larger system. Pulling the strings of one affects the movements of the other, and the parameters of the system that encloses them affect both. Therefore, any analysis of one player says something about the other. In our prescription for change, we aimed to be bold rather than timid. Yet, in highly complex systems like the health care system one cannot

¹ This table was inspired by, but is not identical to, a list of barriers to implementing shared decision making in clinical practice by Légaré et al. (2008).

Table 19.1. Barriers to implement more patient-centered care.

Overarching barriers:

- Evidence about risks, benefits and outcomes lacking for many complex conditions or where people have multiple health problems.
- Diseases associated with aging in industrialized societies may require lifestyle interventions rather than medical care.
- Concern of policy makers that patient-centered care will increase health care demands and costs.

Patient level barriers:

- Lack of confidence about ability to make judgments about information on potential benefits and risks.
- Emotions about illness lead to preference for external decision maker.
- Lack of understanding of potential role in decision making.
- Lack of understanding of treatment options and potential impact on health and well-being.
- Health status precludes active role.
- Multiple decisions may be required.
- May be seeking complementary or alternative care and not want to share details with health professional.

Health professional level barriers:

- Lack of time to explore patient preferences.
- Lack of skills to explore patient preferences.
- Unconvinced that patient-centered care/shared decision making is appropriate or provides the best outcomes.
- Preference for role of “benevolent patriarch/matriarch” rather than “patient-centered facilitator.”
- Unaware that patient values can differ from those of the health professional.
- Lack of knowledge, skills or capacity to provide social support and care rather than health care.

Organizational/system level barriers:

- Lack of awareness that behaviors of multiple care providers may interact and adversely affect patients.
- Lack of a single designated coordinator of care for the patient.
- System designed for acute care rather than ongoing management of chronic illness.
- Care required may be social support rather than health care and health system not well constructed to provide this care.
- Reimbursement systems may not be well aligned with the type of care that is required/chosen.

Interactional barriers:

- Relationship between patient and health professional not well established.
 - Poor communication between patient and health professional.
 - Patient may be receiving care from multiple providers who are unaware of or do not communicate with each other.
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simply press a reboot button; one needs to launch and reinforce the positive developments. Our approach was to work subversively within the system rather than to blow it up. After all, our manifesto for change has been written by a bunch of academics rather than health care “revolutionaries.”

How to Change Clinicians

We derived three tactics to spur change in clinicians. The first action targets medical education. We spell out a new kind of school and then propose to build on pockets of excellence that embody bits and pieces of this vision. The following fictitious report, describing the opening day of the new Strümgmann School for Health Professionals, introduces us to this vision. The second action aims to alter the dynamic between patients and clinicians by increasing the latter’s risk of looking, well, incompetent. The third action calls for a concerted research effort that paves the way for establishing informed patient choice in preference-sensitive conditions.

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New School for Health Professionals Opens

It is a sunny, fall Monday morning—the first day of the brand-new Strümgmann School for Health Professionals.

Opening in several primary care locations and other acute care settings across the inner city, it is not your usual medical school. No tall towers, no ivy-covered buildings; this school exists in a dispersed fashion, its faculty members also primary care clinicians and specialists, and other health professionals. It is heavily linked by videoconference and Internet connectivity, and it is difficult to tell the doctor from the nurse, from the student or other trainee. And another difference: some patients are considered “faculty.” They sit on curriculum advisory panels, giving direction and shaping the curriculum.

This is *interesting*, I think.

It took me several minutes to find the dean’s office for my interview. Other medical leaders I have interviewed in the past have entertained me in their large corner offices with couches, corner-window

views, and served coffee. This one is different: somewhere down a long hallway, the dean sits in her family physician consultant’s office. Her computer, I notice, sits on a small swivel stand and has two screens—more about that later. She is pleasant, though business-like, and reminds me of her time constraints. We start right away.

How and why did the school get started? She laughs. “That question alone would take 30 minutes to answer,” she says. “It’s a pretty long list, beginning, I think, with patient dissatisfaction. Not that patients didn’t like their own physician, but there was general unhappiness with the health care system, its overall impersonal nature and sense of ‘not being in the patient’s control.’ There were also other elements such as the ability of physicians to have time with their patients, their lack of understanding of what was happening to them—and yes, the occasional, perhaps more than occasional,

physician who treated the patient as an object, not a person."

I had read that the school spends a large amount of time on admissions and asked if that is so. "Yes," she replied. "Studies demonstrate that there are qualities we look for in clinicians which are modified, if not driven, by personality—elements of altruism, self-awareness, the ability to accept and respond to negative feedback, lifelong learning skills, an openness to teamwork, and collaboration. While we think that these are teachable and modifiable skills, we've developed a list of attributes which we seek with great diligence through our long admissions process. We think it pays off. The saying 'An ounce of prevention is worth a pound of cure' holds true in medical education as well."

"Oh," she adds, "and we look for smart kids, too." Science background? Well, yes and no; there are lots of smart science and math grads. "We're looking for those abilities plus others. And, at least so far, we haven't been disappointed."

What's your curriculum like? Looking at the clock, she answers, "Roughly, we've divided it into three parts: they are overlapping to a certain extent but there is a degree of mastery at each level before the learner can advance to the next. First there is the basic, core material—*anatomy, physiology, pathophysiology of disease, biochemistry, pharmacology, epidemiology*—the usual, but there are other things that we consider absolutely basic: *ethics and communication*—the two-way kind. These are very important, of course, even critical, but only the first of many building blocks. We also include an important core stream on *quality improvement, teamwork, and change management*. Some students can sail through the modules—all of them are online—passing each step as they go; some take longer to progress. Some of the modules require small group discussion; others require live, interactive

learning to give the learners a chance to role-play."

"Once they've demonstrated mastery of the core, they move to the second phase: the applied phase. Here, the student learns to work through problems to apply what he or she has demonstrated in the mastery phase. This is accomplished with standardized or real patients—real patient problems right here and elsewhere in the system. In fact, there are virtually no classrooms—all 'lectures,' you might call them, are online. We use patient experiences—real, videotaped, simulated, and paper problems—to emphasize the application of learning. We also use patient feedback extensively—very important for faculty development. Something new that we're trying is the patient-instructor, especially useful in chronic disease management. To accomplish this we have had to add a formal structure committed to teaching patients to be better advocates, to understand at some level the use of evidence to weigh options, and to be more assertive, true partners in their care. This cannot include all patients, of course, but we are privileged to be able to call on a select group of them as associate faculty members. By this and other means, students learn to apply skills of communication, shared decision making,"—strangely, she pats her computer at this point—"evidence and its application, formats of updating, and other issues."

"How long does this phase last?" I ask.

"As long as it takes," she replies. "Once the learner has passed all the competency measures here in the real-world setting—as judged by patients, by other staff members, by their peers—they then go to the third stage."

This third stage, I learn, is called "improvement"—and she hesitates here because we are almost out of time. Because of the hesitation, I think to ask her to explain why she touches her computer, intrigued by the small gesture.

“I am glad you asked, because this simple tool,” she says, pointing to the two screens, “has made so much possible. The patient gets to see her lab results, her graphs, her risk tables—anything that I can see—so that we can talk about it. I can print off important resources from web sites for her, have her interact with me here in the office, show her how her test results now conform to the benchmark (or not), how she might proceed (or not) with hip surgery, and much more—or we can do it later in her own home by email or on my CareBook page. It’s just a tool, you know, but I really like it: it enables us to share in decisions, takes a great burden off of me. I become much more the knowledge broker and facilitator—the patient, in many ways, then becomes her own care provider, just as she can provide feedback to, and therefore help teach, me and my students.”

And what of the third phase of the health professional school, I ask, thinking that I might steal a few minutes more.

“Oh that,” she says, getting up and holding the door open for me. “That’s called improvement; it begins with demonstrated mastery in all these competencies and, well, never really ends. That’s

why we call this the ‘health professional school without walls.’ It has to do with practice-based learning, working in systems, patient safety, teamwork, constantly updating our knowledge base. So you see, I am a learner here, too. Here’s a trick we learned years ago: a big part of the development of the new school hinged on the functional merger of traditional continuing education with quality improvement and patient safety as well as with faculty’s professional development. We began to see how it might work when we dedicated ourselves to patient safety and reduced variations in care—that was our ‘quality improvement phase.’ But, we realized how important this merger was when we began to appreciate the full impact of the ‘hidden curriculum.’ We would discuss altruism or teamwork, or quality improvement in undergraduate years, test for it, and then learned that these traits had diminished by the time students were exposed to jaded clinicians, and tired, overworked residents. Our faculty includes our patients, patient experiences, and my colleagues.”

And the students?

“The students teach us as well. Aren’t we lucky?” she asks.

Back to Reality

We realize that our model school is not just around the corner. The envisioned changes are unlikely to be fully integrated into the continuum of health professional education by 2020. Nonetheless, there are many examples of excellence in basic health professional education:

- Evidence-based health care curricula exist in many medical (e.g., McMaster), nursing (e.g., University of York), and other health-allied professionals’ basic or undergraduate training programs (e.g., University of Hamburg or the Center for Evidence Based Physiotherapy at the University of Minnesota).
- Patient-centered care is being used to drive the curriculum of some medical schools (e.g., University of Western Ontario);
- There are examples of interprofessional care in undergraduate nursing, medical, and other health professional educational programs (e.g., University of Minnesota);

- Patient decision support education has been incorporated into an undergraduate nursing curriculum (e.g., University of Ottawa).
- Innovative patient engagement strategy has been implemented at the Dartmouth–Hitchcock Medical Center’s Center for Shared Decision Making in Lebanon, New Hampshire.

We would strongly urge others to build on these successes, and to do something further: bring these elements together to form a more integrated curriculum, focusing on and developing evidence-based health care, patient-centered care, interprofessional care, and patient decision support. In addition to changes in undergraduate medical and health professional education, we note the development of several features of residency training that offer examples of best practices: the increasing emphasis on evidence-based medicine, patient-centered care, collaborative care models, practice-based learning and improvement, and shared decision making.

Given the long pipeline that produces physicians and other health professionals, however, continuing professional development or medical education (CPD or CME) demonstrates the potential to become a vehicle for change. In this regard, we view continuing education as a natural lifelong process, incorporating, but not using exclusively, conferences, courses, and workshops. Additionally, viewing CME or CPD as an accumulation of patient experiences, feedback, group discussion, teamwork, information at the point of care, and many other elements, we see progress toward more shared decision making being made on several dimensions, based on best evidence.

1. Regulatory changes in the United States and Canada have decreased the reliance on commercial support for CME activities, reducing if not entirely eliminating degrees of bias in presentation and messages to clinicians.
2. Movements in revalidation and recertification based on performance rather than just a simple accumulation of hours of credit can lead to performance measures related to shared decision making.
3. The increased emphasis on comparative effectiveness studies in the United States and on similar health technology and government- or insurance-funded comparative studies elsewhere can create content for clinicians to be used in shared decision making.
4. There are studies of incorporation of shared decision making into CPD activities that are promising from both practical and research perspectives.

Although not entirely conclusive, results from a Cochrane Review of interventions to improve the adoption of shared decision making by health care professionals suggest that multifaceted interventions (educational meetings, distributing educational materials to physicians, plus audit and feedback) may

be the most effective method for implementing it in clinical practice (Légaré et al. 2010).

When will we expect to see these changes? Perhaps we will see them in the smaller changes described above. Perhaps we will see them at the end of the new health professional school. To get there, however, we need to recognize that we are all in the same spaceship and that collaboration is necessary, hopefully enjoying the ride together, seeking what humankind has best to offer: well-being through a network of meaningful and respectful relationships.

Leveling the Knowledge Playing Field: Open Access and Dr. Google

Starting with Arrow (1963), the relationship between clinician and patient has been seen as a paradigmatic example of an agency relationship (e.g., Behrens et al. 2010). There are many situations in which one person, called the principal, delegates decision-making authority to another, called the agent. In medicine, the patient is the principal and the physician is the agent. The health of the patient depends crucially on the performance of the physician, and the patient faces myriad uncertainties: Is my physician capable and knowledgeable? Will she act unselfishly and on my behalf? Will she do everything medically possible to help me? Faced with these questions, the principal has two choices: try to employ a contract to bind the agent to perform as desired or else rely on trust.

Over the past few decades, the dependable and trust-inspiring Marcus Welby medical care system (Dranove 2001) has disappeared, if it ever existed. *Marcus Welby M.D.* was a popular television show in the early 1970s. The TV doctor “was everyone’s favorite primary care physician...He was wise, kind, and one of the most trusted members of his community” (Dranove 2001:7). According to Dranove, the primary care physician in the era of Marcus Welby medicine would make a house call, spend as much time as necessary to make an initial diagnosis, make a carefully described prescription, if necessary, and might even phone later to check on the recovery. If the patient was seriously ill, the physician would make a referral to a specialist. The doctor remained a staunch advocate for the patient throughout treatment, and the patient could trust him. The Marcus Welby medical system no longer exists. In the new medical world, built-in conflicts of interest between doctors and patients abound, rendering the heuristic just to trust the white coat no longer adaptive (Wegwarth and Gigerenzer 2010b). Unfortunately, the other choice available to the patient to respond to the principal-agent dilemma is not a good one either: Economists have outlined various limitations of contracting, rendering contracts “less than ideal for use in medicine” (Dranove 2001:15), including the problem that contracts can hardly cover all possible contingencies of the medical care process as well as the problem of hidden actions and hidden information.

With nowhere to go—because patients cannot unconditionally trust any longer and cannot employ contractual solutions—what can patients do? How

can they level the playing field? To avoid misunderstandings: Physicians spend four to five years in medical school and another four to six years in residency training, and have many additional years of experience. Patients cannot catch up on this medical expertise. Outside of sending patients to medical schools, however, numerous things can be done to make physicians' "avoidable ignorance" (Albert Mulley, pers. comm.) untenable. Our rationale is the following: Anything that increases clinicians' perceived risk of losing face by being unable to answer patients' questions should foster their willingness to work toward avoiding their avoidable ignorance. How? Here are some concrete proposals:

1. Open access: Patients should have access to the same data as the clinicians (interpretation of lab reports, systematic reviews, individual research report, medical file). Remember the two-screened monitor in the new school for health professionals. Another form of open access is to render accessible medical knowledge and recent evidence not only to health care professionals but also to patients, patient advocates, relatives, and, more generally, citizens. Tools to provide this access are, for instance, that of the "patient university" in Hannover or Jena, Germany (MHH 2010; GU 2010).
2. Do not waste education opportunities: Provide learning opportunities for patients. For example, the British health care system sends out 1.5 billion letters (e.g., communications with the patients about invitations to screenings, reminders) but misses hundreds of millions of opportunities to educate patients, for example, by offering additional information about the screening, risk information, decision aids, or links to decision aids (see, e.g., the Ottawa Hospital Research Institute's A-Z inventory of decision aids [OHRI 2010]).
3. Wisdom of the crowd: Are there ways to foster communication among patients, so that patients can benefit from the experience of others and vicariously learn what the important questions are? Let us introduce the patient to the patient (using Internet portals such as patientslikeme, healthtalkonline, krankheitserfahrungen), and link patients to the current 20,000-plus medical web sites on the World Wide Web.

Let us not be naïve, however. The Internet can empower patients but will not replace the traditional doctor-patient relationship anytime soon. Nor is the information provided by medical web sites necessarily objective or even correct. To make matters more complex, different web sites may give conflicting information, and the resulting confusion may become a major headache for physicians. But let us also not get on a high horse: By Ioannidis' (2005) calculations, most published research findings are false, and according to an analysis carried out by *Nature*, *Wikipedia* comes close to *Britannica* in terms of the accuracy of its science entries (Giles 2005; see also *Nature* 2006).

The rationale behind our proposed actions is to enable patients to pose questions and eventually to ask better questions when communicating with their health care providers. Admittedly, this may not always work. Some patients may turn into smart alecks, and some doctors may become obstinate when challenged. Also, a little knowledge can be a dangerous thing. But differing from Alexander Pope's original meaning, unpredictable knowledge on the part of patients can be a dangerous thing to the clinicians: Nobody wants to keep looking incompetent.

Let us not end without bringing up a truly cherished resource beyond knowledge that the Internet offers—time. For clinicians, time is the final constraint, and a widespread perception is that doctors spend less time with their patients, relative to the past. In contrast to this perception, studies show that the average length of consultations in the United Kingdom and the United States actually increased in the 1990s (Mechanic 2001; Mechanic et al. 2001). Clinicians' perception that less time is being spent with patients may stem from the need to do more during a patient visit (e.g., provide preventive care), from raised patient expectations (e.g., more information), and from the growing complexity of health care. For patients, time is less of a severely limited resource because they typically only need to worry about themselves rather than a host of other patients. A patient, therefore, has more time than a clinician to search for information, read, and reflect, and as of now this resource has mostly been untapped. With the help of the Internet, this resource could be harnessed, for instance, by no longer narrowing the consultation to face-to-face time with the doctor. Figure 19.1 illustrates an expanded consultation using a patient's concern about breast cancer. By involving patients in the process of information search and decision making, doctors may be able to use the face-to-face consultation more meaningfully and more satisfactorily—for themselves and patients. The expanded consultation, however, does expect the patient to prepare for the visit at the doctor's office. Such preparations and follow-up work can range from becoming acquainted with anatomical and medical terms or taking a family history to assess a risk to using a decision support web site to reflect on the information and treatment options discussed during the face-to-face consultation.

The Proof of the Pudding Is in the Eating

According to Kuhn's (1962) analysis of scientific revolutions, a paradigm shift is more likely to occur when the new paradigm offers concrete solutions to scientific anomalies. Without a concrete solution, no scientist will be persuaded to switch to a new paradigm. To the extent that Kuhn's analysis generalizes to paradigm shifts in health care systems, we can take advantage of his "demonstrate-to-me-that-it-works" heuristic to foster a shift to the new health care paradigm of patient-centered care and shared decision making. Admittedly, this heuristic is only one of several strategies toward persuading clinicians (see

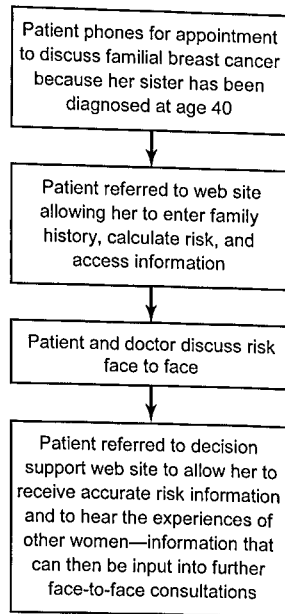


Figure 19.1 Stages of an expanded consultation that uses web-based tools to redesign the model of traditional clinical practice (courtesy of Muir Gray).

Cialdini 2001). Yet, it would be ironic if a community devoted to the utility of evidence were not betting on this heuristic. Table 19.2 spells out an action plan—courtesy of John Wennberg—to get research on the potential efficacy of informed and shared decision making off the ground, with the goal of demonstrating its benefits, and ushering in a new health care paradigm by the year 2020. Key components of this research endeavor—the measurement of preferences (e.g., Sepucha and Ozanne 2010) and patient decision aids (e.g., Elwyn, Frosch et al. 2009)—are already in place.

It is possible that the “demonstrate-to-me-that-it-works” heuristic could work across a range of variables, such as decision quality, patient satisfaction (e.g., more compliance, fewer complaints, fewer law suits), clinician satisfaction, and, possibly, costs. The last one, of course, will be particularly crucial for policy makers, and many appear to operate under the assumption that if patients have more say in the decision-making process that they will inevitably demand more costly treatment. In fact, the opposite may be true. Initial evidence suggests that people, once comprehensively and transparently informed about the costs and benefits of treatment options, tend to prefer the more conservative course of action (e.g., not taking hormone replacement therapy; O’Connor et al. 2009); similarly, the more (and the better) patients were informed about the costs and benefits of screening for prostate cancer with PSA tests, the less likely they were to partake in screening (Frosch et al. 2001). More generally, shared

Table 19.2 The Wennberg three-step action plan for change.

Goal: To establish informed patient choice as the standard for determining medical necessity for treatments for selected preference-sensitive conditions by the year 2020.

Step 1. Years 2010–2014

1. Undertake pilot projects (and build on existing ones) for selected conditions to test implementation strategies in shared decision making using decision aids. Include various clinical centers, emphasizing primary care sites but not excluding surgical specialty sites.
2. Develop decision quality measures designed to evaluate patient knowledge of relevant facts and concordance between individual patient concerns about treatment outcomes and the treatment choice the individual makes.
3. Evaluate and improve upon implementation of pilot strategies, decision quality measures, and patient decision aids (see Elwyn, Frosch et al. 2009).
4. Funding for these projects—from payers.

Step 2. Years 2015–2018

1. Broadly implement successful models with costs paid for by payers.
2. Measure continuously decision quality to evaluate shared decision-making processes.
3. Reward primary care physicians (and specialists) who successfully implement shared decision making (i.e., good scores on decision quality).
4. Promote advocacy of the ethic of informed patient choice by primary care physicians as the cornerstone of their professional responsibility.

Step 3. Year 2019–2020

1. Based on success of above, payers establish informed patient choice as a standard of practice and a requirement for payer willingness to pay for selected discretionary surgery and diagnostic screening tests.
2. As a result of research and development, extend the list of preference-sensitive conditions.

List of priority preference-sensitive conditions for inclusion in the pilot project:

Conditions	Treatment options
Silent gall stones	Surgery vs. watchful waiting
Chronic stable angina	Percutaneous coronary intervention vs. surgery vs. other methods
Hip and knee arthritis	Joint replacement vs. pain medication
Carotid artery stenosis	Surgery vs. aspirin
Herniated disc	Back surgery vs. other strategies
Early prostate cancer	Surgery vs. radiation vs. waiting
Enlarged prostate	Surgery vs. other strategies
Mental health (depression)	Antidepressants vs. psychotherapy
Breast cancer	Lumpectomy vs. mastectomy

decision making appears to be effective in lowering overuse (e.g., Evans et al. 2005) and raising underuse (O'Connor, Bennett et al. 2007).

We end with a question to which there is both an ideal and a pragmatic answer: Which of two strategies should be pursued in realizing patient-centered

care? Should each clinician eventually aspire to be a good communicator and learn the ABCs of shared decision making, or should a team environment with a designated decision coach (Stacey et al. 2008) compensate for undeniable interindividual differences in communication skills and plain empathy (e.g., Wagner's Chronic Care Model discussed in Bodenheimer et al. 2002a, b)? Although the second approach appears to be more pragmatic, it carries the risk that the decision-making process is rated second or third, relative, say, to the heroic skills of a surgeon. Remunerating the decision coach as highly as or more than the surgeon, however, would quickly disrupt the old regime's hierarchy.

How to Change Patients' Engagement with the Health Care System

The title of this Forum stipulates a controversial concept, namely, that of "better" patients. Although proponents of shared decision making can probably agree on what constitutes a better doctor, the concept of a "better" patient is much more controversial. Disagreement centers on the question of the extent to which patients can and should be expected to take responsibility in the process of making decisions. To appreciate the difference in views, let us describe two opposing positions: The first begins with the assumption of patient heterogeneity and takes the position that not every patient can be expected to live up to our lofty ideals of shared decision making. According to this view, patients ought to be empowered to define their own goals but cannot be expected to do so under all circumstances. Take, for example, a working mother who has two teenage children and an abusive alcoholic for a husband. She has just received the dreadful news that she has breast cancer. The psychological reality for this patient—and many other patients who have just received news of a life-threatening disease and are in the grip of fear, confusion, and depression—may be that she simply does not have the mental resources to define her values and ponder which of the treatment options meets them best.

According to the second view, there are limits to a patient's autonomy in the following sense: People have no right to futile care. Specifically, if the available treatment options require a discretionary choice involving trade-offs, then patients have an *obligation* to get involved. From this premise follows, for example, that an elective surgical procedure will not be offered to a person who does not want to get involved.

The positions just outlined represent two somewhat opposing views (of course, more and less extreme variants of these views exist) in this necessary debate concerning the ethical implications of shared decision making for patients. We ourselves did not achieve agreement as to which of the two positions is more appropriate. We did, however, agree that future patients are likely to be patients who will make different demands of their doctors. That is, it is less

likely that health care professionals will be able to restrict their role to that of interventionists curing specific medical conditions. Instead, the management of change will become increasingly more important, and therefore patients and their health care providers will devote more of their shared decision-making process to lifestyle changes: to preempt medical conditions, to attenuate them, and to render it possible to adapt to them.

Moving beyond a clarification of the controversial concept of a better patient, let us turn to how we aim to nudge the patient to make informed and better decisions. Our action plans are focused on the following domains: early education, health care in the media, and ways to enlist the environment.

Becoming Health Literate: The Earlier the Better

Thinking about our health and practicing a healthy lifestyle should not wait until our first serious encounter with the medical repair shop. The long-term benefit of *early* health education could be spectacular: acquiring a skill that people will be able to draw on throughout their lives. Just as children learn to read and write, they should also learn how to understand frequencies and probabilities, thus equipping them, for example, to evaluate risks accurately. Before learning the mathematics of uncertainty, younger children could experience the psychology and biology of health (e.g., Why do I get goose bumps? Why am I ticklish? What happens to the food I eat?). Early health literacy could be the foundation upon which adults make sounder lifestyle decisions throughout their lives.

A health curriculum is not a lofty idea. Successful models already exist. One example is a program called ScienceKids—Kinder entdecken [children explore]. Its goal is to create interest in health-related topics among children during primary school education (age six to ten years). The program has been developed by the AOK Baden-Württemberg, a branch of the largest German public health insurance company, in cooperation with the Department of Culture and Education in the state of Baden-Württemberg (AOK Baden-Württemberg 2010). The program is embedded in the curriculum of primary schools and its main goals are:

1. Find answers, using an exploratory approach, to (sometimes delicate) questions that are linked to the function of the body, nutrition, exercise, sports, and well-being.
2. Teach children the meaning, relevance, and joy of pursuing a healthy lifestyle.
3. Build a foundation for improved health competence by enabling children to experience and figure out their own body.
4. Raise parents' awareness of health-related topics and offer specific support.
5. Establish an activity-based sustainable health education.

6. Develop a concept for improving health literacy and creative skepticism.

The modular structure of the curriculum is flexible enough to be implemented in classrooms, in workshops, and as part of extracurricular activities. As Figure 19.2 illustrates, first-hand experience takes the place of moralistic exhortations. Children are treated as scientists, thus harnessing their natural curiosity and joy in experimenting with the world. Each school participating in the program is offered a mini-laboratory, which can accommodate up to 30 students and enables teachers to conduct experiments during regular lessons. If children are empowered to search for answers to their questions—what happens to the food that I eat; what are my body’s needs; what does it take to feel good—chances are that their newly gained competence and knowledge will have a longer-term impact on their health behavior.

How was the curriculum designed? At the outset and using the children’s magazine of the AOK, children were asked to submit their questions concerning diet, exercise, and health. Based on this “raw material,” experts in the field of nutrition science, sports, and didactics of science developed the instructional material. During a week at a summer science camp, nearly 50 children, scientists, and students then jointly vetted the material. Subsequently, the curriculum was pilot-tested in 70 schools, with experts further optimizing the program and tailoring it to the primary school setting. To boost its reach, the program has since then been incorporated into the teachers’ training, and ScienceKids multipliers offer to train teachers and schools in this curriculum. Last but not least, the web site (AOK Baden-Württemberg 2010) offers teachers up-to-date information and additional background material to teachers.

Although the benefits of using schools as a conduit to health literacy are obvious, introducing another topic into what is already a packed curriculum

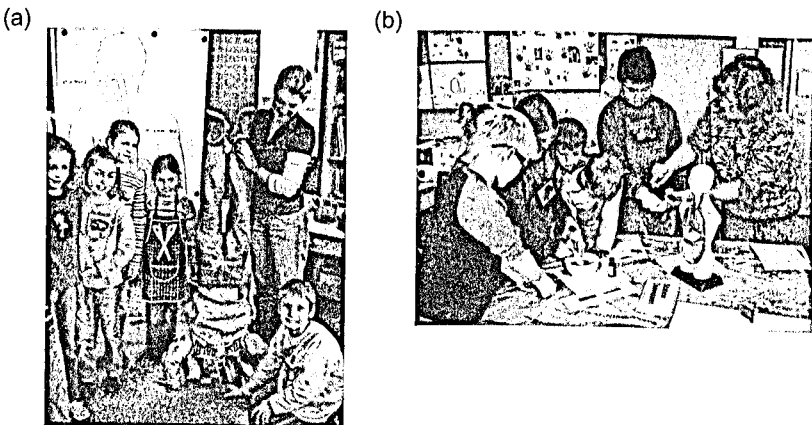


Figure 19.2 Children in the ScienceKids program learn through hands-on experience about their body. (a) Can one drink while doing a handstand? (b) How does our digestive system work? (Used with permission; © AOK Baden-Württemberg)

is a tough sell. Advocates for extending this program nationwide and into secondary schools' curricula² will need to enlist opinion leaders, parents and teacher organizations, and payers to lobby for a *health and risk school* (see Bond 2009). We believe one key to persuading not only these stakeholders in children's health literacy but also school boards and policy makers lies in the power of the "demonstrate-to-me-that-it-works" heuristic. The ScienceKids program represents a bold and inspiring step in this direction.

Nudging the Public

There are at least two routes to changing people's behavior. One is to target them directly by, for example, educating them. Another is to target the environment of which their behavior is a function. Herbert Simon (1992:156) stressed that if "people were perfectly adaptable, psychology would need only to study the environments in which behavior takes place" to understand how they think and function. He illustrates this with the example of predicting the shape of a gelatin dessert: Would you stand a chance of correctly guessing its shape by understanding the internal properties of gelatin? Probably not; looking at the shape of the mold it was poured into, however, will do the job.

Let us illustrate the power of the environment using the thorny problem of organ donation. Since 1995, some 50,000 people have died waiting for a suitable organ donor (Johnson and Goldstein 2003; for a more general treatment, see Thaler and Sunstein 2008). Although many people assert that they approve of organ donation, relatively few sign a donor card: only about 28% in the United States (Johnson and Goldstein 2003). So why don't more sign up as potential donors? Do they lack empathy for the suffering of others? Or are they concerned that, should an emergency room doctor discover that they are potential donors, the doctor may not work as hard to save them? In light of these concerns, why then are 99.9% of the French or Hungarians potential donors? The striking difference in the rates of potential donors between countries makes lack of empathy or fear unlikely to explain the big picture. A simple heuristic could explain such striking differences in the rate of potential donors across countries (Gigerenzer 2008). The default heuristic's policy states: "If there is a default, do nothing about it." The default heuristic leads to different outcomes because environments differ. In explicit-consent societies such as the United States, Germany, and the Netherlands, the law prescribes that nobody is a donor unless they choose to be a donor. In presumed-consent societies such as France and Hungary, the default is the opposite: Everyone is assumed to be a donor, unless they choose not to be a donor. From a rational choice perspective, the default should be toothless because people are assumed to disregard it if it

² A curriculum of health literacy for secondary schools has recently been developed and pilot-tested (Steckelberg et al. 2009).

conflicts with their preference; that is, in an explicit-consent environment they should opt in, whereas they should opt out in a presumed-consent environment.

Regardless of whether one believes that a presumed-consent environment promotes a public good or heightens the risk of overusing a costly technology, the organ donation example illustrates the power of the environment to effect a target behavior.

For another illustration, take the endemic problem of poor diet and physical inactivity—a problem that, according to Mokdad et al. (2004), will soon be the leading cause of mortality in the United States. As in the organ donation example, it is instructive to compare different societies. The proportion of obese U.S. Americans (22.3%) is about three times as high as that of the French population (7.4%; see Rozin et al. 2003). Why is that? After all, French cuisine is not renowned for its caloric asceticism. The lower obesity rate in France is likely to result from a multitude of factors, but one powerful environmental factor appears to be crucial: portion size. Rozin and colleagues compared average portion sizes in restaurants, supermarkets, and cookbook recipes, and found that, on average, French portion sizes were substantially smaller, relative to U.S. portion sizes. This was even the case within the same global chain of fast food restaurants: a medium portion of French fries at a McDonalds restaurant in France was 90 g, relative to 155 g in Philadelphia.

Our environment—in terms of mundane properties, such as the frequency of convenience stores or the neighborhood's walkability—affects what and how much we eat (Story et al. 2008) and the scope of our physical activities (Saelens et al. 2003). These and many other examples illustrate that health care professionals, policy makers, and citizens should co-opt the environment as a powerful ally in nudging ourselves toward healthier behaviors and shared decision making (e.g., by changing representations of risk and uncertainty; see Gigerenzer et al. 2007).

How to Get Better Information to the Patients

Currently, the mass media (e.g., newspapers, TV, magazines, the Internet) are likely to be the most important sources of health knowledge for the general public (and, in some cases, even for the physician). Can we foster higher-quality information in the media (see Wormer, this volume)? We realize that media products are produced to be sold and that the laws of the market will not change anytime soon. Yet, one could try to nudge the media toward presenting higher-quality information. Here is a simple but admittedly time-consuming approach. Volunteers of a scientific society or institution (such as the EBM network) could monitor, for example, the prime-time news of the four most important TV stations (e.g., on German TV: ARD, ZDF, SAT1, RTL) and/or some of the nationwide daily newspapers (e.g., in Germany, the *Süddeutsche Zeitung*, *Frankfurter Allgemeine Zeitung*, and *Die Welt*) for a specified period. Rather than fuming in their ivory towers over glaring mistakes, the experts

could routinely submit a letter to the editors-in-chief of these media outlets, explaining mistakes and pointing out how information could have been presented in a more reader-friendly way. Be polite and not condescending, and hook the editor by focusing on the audience and its attraction to a newspaper article or a TV show that enables them to understand the uncertainties of the modern world. Of course, some in the media industry may not care, or may perceive the experts' interference as an act of self-promotion; however, others may see a niche for their product in a highly competitive environment. One outcome of this endeavor could be that "friendly monitoring" becomes a media issue, calling attention to the importance of the public's right to high-quality information. Additionally, media houses themselves may invite experts (or their students) to editorial conferences ("our embedded uncertainty expert") or teach statistical reasoning courses to journalists (in-house seminars or in journalism schools).

In the future, which already began yesterday, a major source of health-related information will be online communities. They represent both opportunities and risks (discussed above). Let us focus on the risks for the moment. The Internet allows each user to spread even the most nonsensical health myths. This can happen without any evil intent, as individuals share personal experiences and their interpretations thereof. Such personal case reports can be biased and biasing in any direction: They can also impact on people's decisions more than statistical information (e.g., Fagerlin et al. 2005). Online communities, of course, are also easy targets for those who intentionally want to spread misinformation. Sneaking into patient forums, for example, and claiming to have been cured by whatever method is an obvious way for people with a commercial interest to do this.

Notwithstanding these risks, online communities grant experts a wide window onto patients' reasoning and concerns. Moreover, experts—as in the case of newspapers—can help to foster high-quality information. They can, for example, train a few members of the community to operate as a "chief medical officer." Community-based glossaries and wikis, such as *Wikipedia*, could be regularly monitored and—if necessary—improved (the German *Wikipedia*, for instance, appears to fail important criteria of evidence-based patient and consumer information; see Mühlhauser and Oser 2008).³ Debates of, for instance, new treatment options in online communities may also foreshadow future questions that doctors will be asked during regular visits (thus allowing the medical community to prepare Q&As). Finally, some online communities, when systematically studied, may even reveal pertinent information to medical researchers about target patients' attitudes, beliefs, behaviors, and outcomes. In fact, this information is already being harnessed, for instance, by various web

³ Based on its search engine ranking and page view statistics, the English version of *Wikipedia* has already surpassed other online health information providers (e.g., *MedlinePlus*) as a source of online health information (Laurent and Vickers 2009).

sites (PatientsLikeMe 2010). Clearly, public health experts cannot afford to ignore this information marketplace in the Internet.

Conclusion

Our manifesto for change aims for better doctors *and* patients. To nudge doctors to change, we envision evolving medical schools into health professional schools. We spell out existing clusters of excellence that can provide parts of a blueprint for such a new educational institution. We suggest concrete ways of leveling the knowledge playing field between clinicians and patients, thus empowering patients to ask ever-better questions. Fearing those questions, the clinician should no longer be able to afford the luxury of “avoidable ignorance.” People are creatures of habit. However, if one can demonstrate that the new health care paradigm works on important process and outcome dimensions, this may help break such habits. To this end, we propose the Wennberg three-step action plan for change (see Table 19.2).

How can we change patients’ engagement with the health care system? We propose bringing health literacy into high school curricula and describe an existing model of teaching health literacy to children in primary schools. We also remind others and ourselves not to overlook the environment as an important ally for change. Engineering a smart environment can complement the approach of empowering people to learn, reason, and decide for themselves. In the future, the visit to the doctor will no longer mark the beginning of patients’ opportunity to learn about their ailments. Their reasoning will begin prior to the visit and will last beyond (Figure 19.1). The Internet and web-based resources such as online communities will completely change the dynamic of the doctor–patient interaction. We propose a few pragmatic ways in which health care providers can help to foster good information in these new realms of knowledge.

Ostensibly, our manifesto for change ignored numerous key barriers to change, some of which are listed in Table 19.1. Possibly, our most glaring omission is that we did not—at least not explicitly—speak about the levers of change. Although we, for instance, spelled out a vision of the health professional school of the future, we did not name the levers that could be pushed to bring about the desired institutional changes. We can imagine several of these—accreditation standards, increased training of faculty, government and social imperatives—but are reluctant to pinpoint precise levers of change because there is no single cross-country solution. Deciding which combination of levers—including economic incentives (e.g., fee-for-service system versus fee-for-health system), regulations and laws, education and information, appeal to the idealistic streak in health care professionals, and, of course, evidence—seems appropriate must hinge on the players and institutions in question. It will depend on how the virtuous goals (including moving toward patient-centered

care, curbing costs, or extending coverage) are prioritized, and which go in tandem or are in conflict. It will also depend on the historically evolved idiosyncrasies of the health care system in question, and so on. Thus, our reticence to talk explicitly about leverage points is owed to the lack of a silver bullet, and we did not want to replace it with platitude.

The 20th century was the century of fantastic progress in medical research, the implementation of a rich health care infrastructure, and ever-increasing resources that societies devoted to health care. However, those golden days are over. We expect that scientific progress will continue at a staggering rate, but more will have to be achieved with fewer resources. Care in the 21st century needs to become patient-centered and the patient lobbyist can help to spur a new culture of decision making, transparency, communication, and patient participation in the world of health care. A pinnacle of individual freedom is the freedom of choice. In the act of choosing, individual freedom unfolds (e.g., Schwartz 2004). The litmus test for a society's commitment to freedom and democracy is the degree to which its citizens can choose between religious beliefs (including the belief to disbelieve), political parties, opinions, and sexual orientation. The litmus test for a democratic health care system is the degree to which patients are empowered to choose, based on transparent information. The 21st century should be the century during which the wind of change ushers in an adult conversation between patients and doctors.