Patients as Decision Makers

The idea behind CDHC is to put patients in the driver’s seat when it comes to their own healthcare. Since some of the expense comes out of their pockets, they should have greater incentive to make the most cost-effective choices. But are patients really prepared for this responsibility? And is the information they need to make informed decisions readily at hand? What should physicians do to help their patients in the process?

Fast Facts

▲ A 2006 national telephone survey of 1,209 adults by the Council for Affordable Health Insurance showed that 84 percent wanted healthcare prices to be published and 70 percent said that, if they had cost information, they’d shop around for the best prices. Page 62.

▲ Data from a 2005 Employee Benefit Research Institute/Commonwealth Fund survey showed that fewer than 16 percent of those using CDHC plans said they had access to information about the cost and quality of their healthcare providers and hospitals. Page 63.

▲ Zagat Survey, LLC, the company that provides restaurant and shopping guides, recently teamed up with WellPoint, Inc., the nation’s largest health benefits company, to launch an online physician rating service designed to help consumers find top-quality providers. Page 66.

Consumers shopping for housing, automobiles, furniture, groceries, and almost everything else compare prices and quality ratings to find the best buy. “Information makes ignorant people smart,” says Regina Herzlinger, in her book Who
When these radio hosts say “this one is for the ladies” it takes on a whole new meaning.

Dr. Mazzullo
Lisa Mazzullo, MD, OB/GYN, Feinberg School of Medicine, Northwestern Memorial Hospital

Dr. Streicher
Lauren Streicher, MD, OB/GYN, Feinberg School of Medicine, Northwestern Memorial Hospital

Tune into Advances in Women’s Health, an in-depth series for medical professionals hosted by two of America’s top women’s health physicians. Only on ReachMD, it covers everything from breast cancer to osteoporosis. For a complete program review, visit ReachMD.com, the first and only 24/7 radio network developed by medical professionals.
Killed Health Care? (McGraw-Hill, 2007). “I confess I have only the dimmest notion of how a car functions...[so] how is it that an ignoramus like me can easily find cars that are better and cheaper?” What makes her an intelligent car buyer is objective, trustworthy information in newspapers and magazines like *Consumer Reports*. “As in the automobile market, informed consumers who have access to good information and the freedom to choose healthcare plans and providers will make our healthcare system better and cheaper,” writes Dr. Herzlinger.

But comparison shopping for healthcare is more complicated than car shopping. In the Galen Institute’s 2005 report *Consumerism in Health Care: Early Evidence is Positive*, Grace-Marie Turner cites a Harris poll of 2,000 consumers in which people were able to guess the price of a new Honda within $300 but were wrong by over $8,000 on their price estimates for a four-day hospital stay.

One reason many CDHC plan enrollees can’t make informed choices is that their plans don’t provide enough information about the exact costs of specific services, medications, and out-of-pocket expenses. “There are numerous documented cases of consumers who have experienced considerable frustration when trying to determine something as simple as the cost of a procedure,” economist Paul Hughes-Cromwick and his colleagues write in a 2007 *Business Economics* article. “This is particularly important as the cost of a routine procedure can vary dramatically—as much as 500 percent—from hospital to hospital.”

Consumers want to be more informed about healthcare costs. A 2006 national telephone survey of 1,209 adults by the Council for Affordable Health Insurance showed that 84 percent wanted healthcare prices to be published and 70 percent said that, if they had cost information, they’d shop around for the best prices. But they find the information difficult to come by.
from a 2005 survey commissioned by the Employee Benefit Research Institute (EBRI) and the Commonwealth Fund showed that fewer than 16 percent of those using CDHC plans said they had access to information about the cost and quality of their healthcare providers and hospitals. Physicians often don’t have this information, either, which makes it difficult for them to help patients who ask about ways to control their costs.

Cost is only part of the decision-making process. Patients also want to know that their healthcare professionals provide quality care. That turns out to be even more difficult to measure in a meaningful way.

After reviewing the decision-support tools from five large CDHP insurance carriers, the U.S. Government Accounting Office (GAO) reported that these resources included only limited hospital- and physician-specific quality data and provider-cost information. For example, while each of the plans’ support tools provided three or more measures of hospital quality (such as outcomes data, procedure volumes, and patient safety ratings), none provided similar quality measures on individual physicians. The GAO also reported that three of the insurance companies provided average hospital payment rates and average physician payment rates for selected services, but none provided the actual payment rates that would be charged at the specific hospital the patient was using or by the specific physicians providing the patient’s care. According to some industry representatives, legal barriers such as antitrust laws and health-plan contracts limit carriers’ ability to provide this information.


**Ratings Wars**

Having access to similar information about medical care, including prices for procedures and information on a practice’s patient satisfaction ratings and health outcomes, is key for con-
sumers to make informed choices. But many insurers still don’t provide physician ratings; and those that do often base their ratings on differing data sources, making it difficult to compare.

There is also a wide range of opinions on how quality healthcare is best measured. Some rating methods emphasize process—looking at whether the physician or other care provider follows the accepted standard of care, such as whether the physician monitors A1c levels for patients with diabetes. But some argue this doesn’t take into account the individual needs of a particular patient, nor does it track whether the patient actually benefited from the care. Other methods emphasize outcomes—such as looking at whether diabetic patients avoid complications. But some argue that these methods penalize physicians for taking on tough cases, patients with economic, emotional, or physical complications that make adherence to a prescribed treatment plan difficult.

In the U.S. GAO April 2006 analysis, company representatives blamed a lack of consensus across their industry over what constitutes ideal quality measures and what methods should be used to obtain data on quality and patient satisfaction. They also noted that physicians feared “negative personal ramifications” if patients obtained access to this information.

Indeed, interpreting the data isn’t straightforward. For example, while a growing number of healthcare organizations measure patient satisfaction levels, research suggests that patient satisfaction alone isn’t an accurate gauge of a physician’s true quality of care. In a 2006 *Annals of Internal Medicine* study, John T. Chang, MD, MPH, and colleagues from the University of California, Los Angeles, and RAND Health checked patients’ medical records to determine whether care for 22 conditions met previously developed quality-of-care standards. Results showed that patient ratings of quality were not indicative of the technical quality of care, but instead were correlated with how satisfied patients were with the physician’s communication skills.

When health insurance companies have attempted to provide physician ratings, they’ve met a stormy reception. The rating programs encourage consumers, often through financial incentives, to pick doctors who get the best ratings. However, some medical groups and regulators have claimed that the ratings are
confusing and may steer patients to the cheapest, rather than the best, doctors.

In a statement released by the AMA, president-elect Nancy H. Nielsen, MD, PhD, said, “The AMA is committed to the goal of empowering patients to become more informed purchasers of healthcare. A lack of proper oversight, however, has allowed health insurers across the country to unfairly evaluate the individual work of physicians. Physician evaluations can be skewed through the use of economic criteria, insufficient sampling of patient cases, questionable quality measures, and poor adjustments for risk. Distorted evaluations can mislead patients and erode confidence and trust in physicians, and disrupt patients’ longstanding relationships with physicians who have cared for them for years.”

Doctors have brought lawsuits accusing insurers of libel, unfair business practices, and breach of contract. In Connecticut, doctors asked a state Superior Court judge to halt UnitedHealth Group’s and CIGNA’s rating systems. In New York, state Attorney General Andrew Cuomo initiated a probe into the way health plans measure—and publicly disclose—how doctors are rated on quality-of-care and cost-efficiency measures.

As a result of his investigation, Mr. Cuomo was able to secure agreements with several insurance companies to help guard against inaccurate, biased, or unfair information about physicians. The companies—including Aetna and CIGNA—have agreed to use nationally accepted standards when ranking and rating physicians. Both companies have agreed to hire an independent group to monitor the systems. The changes will affect the companies’ physician-ranking systems in all states—and may usher in a national standard for physician ratings to help patients make more informed decisions. The AMA has commended these agreements, saying that they “offer crucial protections to patients and physicians.”
Zagat’s for Doctors?

Although doctors may cringe at automobile- and hotel-style ratings, physician evaluations have become increasingly available, as the Internet market is stepping in where others fear to tread.

Many physicians already know about the AMA’s “DoctorFinder” Website (http://webapps.ama-assn.org/doctorfinder/home.html). Patients—and physicians—who check the AMA Website can find generalists and specialists in their geographic area and access basic professional information on virtually every licensed physician in the U.S.—more than 690,000 doctors. (AMA members are able to submit additional information for their entries.) But the AMA site offers little more than contact information and hospital affiliation.

For-profit Websites provide more extensive information, much of it generated by patients themselves. For example, at no charge, the RateMDs.com Website offers patients a way to “give your doctor a checkup.” Patients can browse rated doctors by city, specialty, or name and, importantly, can add ratings and comments on their own physicians. The rating system ranks physicians from 1 (worst) to 5 (best) on three attributes: punctuality, helpfulness, and knowledge. The overall quality rating is the average of the physician’s helpfulness and knowledge ratings, which is what determines whether the doctor’s listing is graced with a yellow “smiley face” or a blue “frown face.”

How interested are consumers in obtaining physician ratings? Very interested, as shown by the tracking statistics at each Website. For example, RateMDs.com reports an average of 400 new ratings per

Personal Health Records

If it’s difficult for patients to find information about physicians and quality of care, it can be even more difficult for them to get access to their own personal health records. Despite widespread use of computerized records in almost every type of business, a 2007 Commonwealth Fund survey ranked the U.S. as fifth out of six comparable countries in providing “high clinical-information functions.” These measures included use of electronic records, electronic prescribing, computerized safety alerts, and patient-reminder systems and registries.

“We live in an era that has seen our knowledge of medical science and treatment expand at a speed that is without precedent in human history….But for all the progress we’ve made, our system for delivering medical care is clearly in crisis,” says Bill
Gates, chairman of Microsoft Corporation, in a 2007 Wall Street Journal editorial. “At the heart of the problem is the fragmented nature of the way health information is created and collected. Few industries are as information-dependent and data-rich as healthcare,” continues Mr. Gates. “But every clinic, hospital department, and doctor’s office has its own system for storing it. Today, most of those systems don’t talk to each other.”

Mr. Gates says that increased digitization of healthcare information won’t solve the problem, since nearly every procedure, test result, and prescription is already recorded in digital form and sent on its way to insurers. The problem, he says, is access to this information: “Patients never see this data, and doctors are unable to share it,” he explains.

“What we need is to place people at the very center of the
healthcare system and put them in control of all their health information....so we will have the information we need to make intelligent choices that will allow us to lead healthy lives—and to search out providers who offer care that does as much to help us stay well as it does to help us get better.”

But giving patients access to information doesn’t mean they’ll understand it. Traditionally, medical records are designed for use by trained health professionals, rather than laypeople. “Few patients would have the medical background to even understand, let alone manage, their medical records,” according to Arnold S. Relman, MD, in his book A Second Opinion: Rescuing America’s Health Care (PublicAffairs, 2007).

The situation may be improving. The AHIP January 2007 census of 69 U.S. health insurance companies representing 3.6 million people covered by HSA-eligible, high-deductible health plans indicates that most enrollees now have access to consumer information tools, including online access to account information (93 percent), health education information (95 percent), healthcare cost information (88 percent), and personal health records (72 percent).

Resources such as the RelayHealth service of McKesson Corporation are already providing an interactive “technology platform” through which physicians and their patients can conduct online medical consultations and related services. The service enables patients to maintain their personal health records at home, view prescription medication lists, request renewals, set appointments, and receive test results. Physicians can use the service to triage patient requests, send appointment reminders, and deliver test results.

According to Ken Tarkoff, vice president and general manager of consumer solutions at RelayHealth, physicians purchase a subscription to the service that allows them to utilize patient messaging, physician-to-physician messaging, and e-prescribing. Instead of faxing back and forth to pharmacies, practices can now use the relay service. Patients can make appointments by e-mail so that they don’t need to call during office hours.

Patients pay nothing for the basic service. However, RelayHealth also offers a fee-based webVisit®, a secure, insurer-reimbursed online consultation for non-urgent health needs. When
the patient logs in and states what the question is about, he or she is told whether his or her insurance will cover the e-visit and how much the co-pay will be. At the end of the online session, the patient enters a credit card number for payment. According to Mr. Tarkoff, physicians usually receive $70 per webVisit®, which is about 40 percent of a typical level-3 office visit.

He says patient satisfaction with and demand for the service is extremely high, but patients complain that too few physicians offer it. “With everyone doing things online, about 80 percent of patients want this, but the number of physicians who are doing anything online is still only 20 to 25 percent,” he says. “Technology adoption in the physician community is slow. There’s a big gap between patient demand and physician readiness.”

**Do Consumers Evaluate Medical Information?**

There may also be a gap between what information patients say they want and what they can or will actually use. Even when quality information about physicians was available to them, only 54 percent of CDHC plan members surveyed by EBRI and the Commonwealth Fund in 2005 said they had tried to use the

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### Consumer Decision-support Tools Available to HSA/HDHP Enrollees, 2007

<table>
<thead>
<tr>
<th>Consumer Decision-support Tools</th>
<th>Percent of Companies Offering</th>
<th>Available Online</th>
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</thead>
<tbody>
<tr>
<td>Patient Access to HSA Information</td>
<td>93%</td>
<td>93%</td>
</tr>
<tr>
<td>Health Education Information</td>
<td>99%</td>
<td>95%</td>
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<tr>
<td>Hospital-specific Quality Data</td>
<td>86%</td>
<td>85%</td>
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<tr>
<td>Physician-specific Quality Data</td>
<td>50%</td>
<td>49%</td>
</tr>
<tr>
<td>Other Physician-specific Information</td>
<td>97%</td>
<td>97%</td>
</tr>
<tr>
<td>Healthcare Cost Information</td>
<td>88%</td>
<td>88%</td>
</tr>
<tr>
<td>Personal Health Records</td>
<td>72%</td>
<td>72%</td>
</tr>
<tr>
<td>Other*</td>
<td>52%</td>
<td>50%</td>
</tr>
</tbody>
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*Percent based on online availability of related information, not for the tools themselves or access to health plans.

*e.g. clinical or Rx information, health plan comparison resources

Do Consumers Understand the Plans?

Consumers who enroll in CDHC plans often face a shaky start in managing their deductibles, understanding what their plans cover, and making decisions about when and whether to seek care.

An August 2006 U.S. GAO survey showed that many patients could not understand the details of the HSA-eligible CDHC plans. They had problems distinguishing between preventive services and other services provided during a routine visit to a doctor. Many were unaware that some laboratory tests associated with preventive visits weren’t considered to be preventive services, and thus weren’t paid for by their plan. Participants in one focus group reported that they couldn’t determine whether services were provided by an in- or out-of-network provider, particularly in emergency situations, and were confused about what medical expenses qualified for payment through their HSA.

Cost shopping is the exception, not the rule, even for elective or “cosmetic” treatments for which patients pay the full bill. For example, Ha T. Tu and Jessica H. May reported on a survey of consumers having laser-assisted in situ keratomileusis (LASIK) vision-correction surgery in a 2007 issue of *Health Affairs*. The survey showed that the great majority relied on word-of-mouth recommendations from previous LASIK patients, rather than the extensive online and printed information available from the Federal Trade Commission, the American Academy of Ophthalmology, and other reliable sources. Data from more than 100 LASIK practices nationwide indicated that three in five patients choose their surgeon by asking friends and relatives.

Are patients unwilling to use other sources of comparison data on prices and quality? No, Dr. Herzlinger believes, since people of all ages, including children, now surf the Web for health information. Her book *Who Killed Health Care?* cites studies
showing that, in 2005 alone, 95 million people used the Internet for health information—6 million of them daily. This includes the millions of people who spent an average of 20 minutes at the government’s National Institutes of Health Website viewing medical journal articles. So many patients routinely come to their physicians’ office with printed information from the Internet that some pundits call it the “cyberchondriac phenomenon.”

However, unlike consumer goods, “most healthcare purchases are time sensitive, so there is no time to shop around,” says Massachusetts obstetrician-gynecologist B. Dale Magee, MD. This is also unfamiliar territory for patients. “Most [healthcare] purchases involve items that the patient has not purchased before and often does not plan on purchasing again,” adds Dr. Magee.

The amount of information available can also put a crimp in the patient’s research. In his book Dr. Gratzer warns, “The Internet is the Wild West of modern medicine. Yes, people can find studies from the most prestigious journals and advice from the most august medical bodies, but also offers of snake oil and plenty of misinformation.”

Peer-reviewed journals may be the best source of reliable information, but these articles are often difficult to understand and interpret. Some studies suggest that even trained physicians have trouble evaluating health research. In a 2007 study published in the *Journal of the American Medical Association*, 277 medical residents answered 20 multiple-choice questions about statistical information encountered in widely read general medicine journals. The mean score on the test was only 41 percent.

M. Gregg Bloche, MD, JD, professor of law at Georgetown University and nonresident senior fellow at the Brookings Institution, believes that the potential of health information tools to improve decision making by even the savviest patients has been oversold. “The complexity and individualized nature of clinical decision making have long frustrated efforts to reduce medical judgment to algorithms, usable by either lay people or physicians to outperform doctors’ case-by-case assessments,” he writes in a 2007 *Health Affairs* article.

Dr. Bloche is also concerned that Internet-based information won’t help those who need help most. “Those at the economic and social margins are least likely to have access to emerging
online information sources, least likely to be able to make their way through the information resources they can reach, and most inclined toward anxiety and doubt as they confront healthcare’s clinical and bureaucratic complexities,” he writes.

**Should Patients Make Medical Decisions?**

Even assuming that consumers can adequately understand medical information, many critics question whether people who aren’t physicians have sufficient knowledge or judgment to make their own medical decisions and treatment choices. Although they may make good decisions in easy cases—like deciding not to go to the hospital with a common cold—they’re less able to interpret test results or decide which of several medications would work best.

“The role of the consumer is taken too far, as if consumers can replace doctors and make medical decisions entirely on their own,” write Michael E. Porter, PhD, MBA, and Elizabeth Olmsted Teisberg, PhD, MS, ME, in *Redefining Health Care: Creating Value-Based Competition on Results* (Harvard Business School Press, 2006).

David S. Sobel, MD, MPH, director of patient education and health promotion for Kaiser Permanente Northern California, sees it differently. “People already make many health decisions,” Dr. Sobel says. “About 80 percent of all illness episodes are self-diagnosed and self-treated, without patients entering the healthcare system.” Patients already ask themselves questions about when and where to seek care: “Is it life-threatening? Does my spouse or neighbor think I should seek care? Do I have to pay for it? Is it convenient to get parking or child care?” He believes the real issue is the challenge of whether people are making the best or most informed decisions. “It can fly either way,” he says. In some instances, unnecessary expense and inconvenience could have been avoided if patients had a little more information and confidence in making a self-diagnosis and self-treatment that they could have managed more easily at home or at work. On the other hand, Dr. Sobel finds, “Sometimes people don’t seek care when we really could help them and they should come in, such as early signs of heart attack and stroke where we could save heart muscle and brain function.”
Especially in emergency situations, patients facing a health decision don’t have time to check Internet information and evaluate possible alternatives. In many areas of the country and with many health insurance plans, the choice of doctors and hospitals is small, leading patients to rely on the advice of friends or simply to choose the most convenient provider that also accepts their health insurance.

What Do Patients Want?

Patients want to be able to rely on doctors for help whenever they need it, without having to spend time debating costs and choices, says Humphrey Taylor, who, as chairman of the Harris Poll, keeps his fingers on the pulse of national opinion. Sharing his findings in a 2007 Pharmaceutical Executive article, Mr. Taylor explains, “Throughout the history of medical care, most patients have relied on the advice of their doctors to determine what care is and is not appropriate. It is difficult for a patient who is afraid or in pain to make those decisions.”

Mr. Taylor says it’s a myth that the American public welcomes CDHC and wants to be empowered to take personal responsibility for its own care. As he reports, “‘Empowerment’ and ‘personal responsibility’ are code words for increasing out-of-pocket costs, which is not something the public wants or welcomes.”

Lawrence D. Brown, PhD, of Columbia University in New York City, sees it the same way. In the consumer goods marketplace, the consumer is the source of demand and can make his own decisions. With healthcare, the doctor is better able to decide. “Why the healthcare market doesn’t behave like a normal marketplace is that a doctor knows more about a patient’s condition than the patient does. In plans with the doctor in charge, I go to him to find out what I need,” Dr. Brown says.

For many consumers, general information and friendly advice are no substitute for a good doctor-patient relationship. Dr.
CDHC and Informed Consent

In the modern era of electronic information overload, it’s ironic that lawsuits involving CDHC would focus on patients’ lack of essential information. With consumers playing an active role in treatment decisions, both physicians and insurers have a responsibility to provide the full, up-to-date information needed to make those decisions.

“The philosophical principle of individual autonomy, or personal self-determination, lies at the heart of modern American bioethics,” says Marshall B. Kapp, JD, MPH, in a 2007 *Journal of Legal Medicine* symposium report on legal and policy implications of CDHC. “As interpreted and applied by a panoply of courts, legislatures, administrative agencies, and professional organizations, this doctrine requires healthcare providers to obtain a patient’s…voluntary, competent, and informed consent prior to carrying out a clinical intervention involving that patient,” he explains. “Breach of the healthcare provider’s obligation to obtain informed consent as a condition precedent for proposed clinical interventions gives rise to potential tort liability of the provider.”

As the word “informed” implies, consent requires adequate information. Dr. Kapp notes that a majority of states have enacted statutes and regulations enumerating the specific information that is required to obtain informed consent. He cites several cases that could someday be relevant to CDHC issues, including a 1972 District of Columbia Circuit Court opinion in the *Canterbury v. Spence* case (464 F.2d 772, D.C. Cir. 1972). While finding no evidence of negligence in the patient’s diagnosis or treatment, the Court ruled that the patient’s physician “negligently breached his fiduciary or trust duty to act in the patient’s best interest, by failing to make certain that the patient’s consent to undergo a risky and invasive diagnostic procedure was based on proper information.”

How can a physician determine what qualifies as “proper” information? According to Dr. Kapp, physicians must provide information that

Bloche says, “Sick patients have both a deep yearning to trust their doctors and an aversion to relying on contrary information from other sources.”

At IBM, Paul Grund, MD, MPH finds that when they poll their employees about what they want in healthcare, “The topmost thing they tell us that they want is a trusting relationship with a provider who knows them and their needs. Years ago, the
might make a difference (“material information”) in a patient’s
decision-making process. The basic elements of information disclo-
sure include the diagnosis or nature of the problem as well as risks
and benefits of the proposed intervention and reasonable alternatives,
including forgoing the treatment.

So far, court cases have not provided definitive legal guidance about
the need for cost information, but this will be an important element of
consent for CDHC patients. “As patients ask that the financial context
of their lives be considered as part of their medical and social histo-
ries, physicians find themselves caught in the uncomfortable position
of serving as both medical and financial advisors for those in their
care,” explain James T. Hardee, MD, and colleagues in a 2005 Journal
of General Internal Medicine report.

When cost concerns conflict with a medically indicated treatment,
the common result is an anxious patient and a frustrated doctor. To
facilitate informed consent, Dr. Hardee’s group prescribes “empathetic
communication.” For example, a physician who is recommending that
a patient receive in-hospital treatment for pneumonia rather than at-
home oral antibiotics may say to that patient: “I understand that it
costs more for hospital care. I wish there were a less expensive alter-
native in terms of treating your pneumonia. However, given the severity
of the x-ray findings, I really don’t think that sending you home
with oral antibiotics is a safe option. I’m hopeful that with the power-
ful intravenous antibiotics and close observation, we can get you bet-
ter more quickly.”

In this example, the physician used an “I wish” statement to empa-
thetically acknowledge the patient’s cost concerns and facilitate
informed consent while clearly communicating his expert opinion.

Considering physicians’ time constraints, detailed discussions to
obtain informed consent on cost as well as clinical decisions would
surely take longer than the typical 15-minute primary care visit. But
the time spent in clear, empathetic information sharing could be a
good investment to avoid legal repercussions.

most modern relationship would be a doctor taking his model T
and driving to your home. Now modern technology means you
can talk with your physician by computer and obtain computer-
ized health information.” Even with modern conveniences, Dr.
Grund says, a consumer’s main concern still is to have meaning-
ful engagement with his or her physician.