Promoting The Dissemination Of Decision Aids:
An Odyssey In A Dysfunctional Health Care Financing System

What stands in the way of more widespread adoption of useful information tools as patients choose among treatment options?

by John Billings

ABSTRACT: The usefulness of patient decision aids (PtDAs) is well documented, yet they are not in widespread use. Barriers include assuring balance and fairness (auspices matter), the cost of producing and maintaining them, and getting them into the hands of patients at the right time. The Foundation for Informed Medical Decision Making and its for-profit partner, Health Dialog, have developed a creative business model that helps overcome these barriers and has greatly expanded the reach of decision aids.

Virtually all major medical decisions involve some amount of weighing of benefits and risks. For many of these decisions, reasonable people might disagree about the importance or value of the benefits and about the seriousness or degree of the risks. And, in many cases, choices must be made for which the quality of evidence about the options is weak, which introduces another layer into the decision-making process on which people can be expected to differ widely: how to make a choice in the face of uncertainty.

As detailed elsewhere in this collection of papers, there has been increasing interest in decision aids to help patients make choices in these situations, together with their physicians. Effective patient decision aids (PtDAs) typically help frame the issues involved in a treatment or screening decision, provide patients with the available evidence base on the options and associated outcomes specific to their circumstances, and help elicit and clarify patients’ values and preferences related to these choices.

The usefulness of PtDAs and this “shared decision-making” process is well documented: Patients who participate (1) are more knowledgeable about treatment options and their benefits/risks, (2) make decisions that are more consistent with their own attitudes toward these benefits/risks, (3) have more-informed discourse with their physicians, (4) choose options that are consistent with available scientific evidence, and (5) generally make choices that are less costly (opting for less surgery than their more aggressive physicians would choose).²

So what’s holding us back? Why not develop and make available to patients and their physicians decision aids on the broad range of medical decisions on which individuals might differ about benefits and risks or for which the evidence on outcomes is not definitive? That was certainly the perspective of the founders of the Foundation for Informed Medical Deci-
sion Making, established in 1989 to produce and disseminate decision aids (initially in the form of interactive video programs) for an anticipated library of sixty or more topics. But reality does bite, and the foundation's experience in attempting to achieve these goals is instructive about the barriers that will likely appear as the need to improve decision quality becomes more paramount and as a complex range of issues emerges about auspices, conflicting interests, and the role of government and private interests in health care.

**Reality no. 1: auspices matter.** The foundation was established as a not-for-profit entity based on the fundamental principle that in the case of decision aids, auspices matter. The manner in which information is framed and presented can have an important impact on patient choice, and decision aids can by inadvertence (or intent) steer patients toward or away from a particular course of treatment or diagnostic procedure.

Of course, in many cases, patients can judge for themselves whether information appears to be biased or is presented in a biased manner. But there is a large body of literature demonstrating that how a decision is framed can influence choice. The issue is not the accuracy of the data but, rather, how they are presented; these effects are often not apparent to patients. For example, patients' preferences have been shown to change depending on whether outcomes are described as the chances of living or the risks of dying. In one study, 44 percent chose a specific course of therapy when risks were presented as the chances of dying, but only 18 percent did so when outcomes were expressed as the chances of living. Other factors that have been shown to influence choices include the amount of data; the vividness of the presentation (real versus abstract patients); whether outcomes are expressed as numbers, graphs, or narratives; whether harms are presented as absolute risks or relative risks; and the use of lay language versus medical terminology.

Because these effects are subtle and generally not apparent to patients, auspices (who paid for and produced the decision aid) can become critical; this raises serious questions about the need for disclosure about sources of funding and some process or mechanism to ensure that decision aids are balanced and fair. Annette O'Connor and colleagues suggest the need for some accreditation body for decision aids. In 1989, when the foundation was established, such ideas were not even on the radar screen. The foundation's approach was to opt for not-for-profit status, to initially restrict sources of funding for development of its decision aids to philanthropic sources, and to develop its decision aids by contracting with scientific experts who were free of conflicts (receiving no drug or device company money, for example). But this approach had its consequences: see Reality no. 2.

**Reality no. 2: decision aids cost real money.** While the costs of decision aids are trivial in the context of overall medical care spending, they can be costly to produce and maintain, regardless of the medium used. At the core of any decision aid is a complete assessment and summary of available evidence about benefits and risks of outcomes and possible side effects. Depending on the complexity of the issues, the extent and quality of the research base, and the prior existence of a systematic review of the evidence, such an assessment can be costly. When the foundation was established, Patient Outcome Research Teams (PORTs) were beginning their short-lived existence, with funding from the Agency for Healthcare Research and Quality (AHRQ, then known as AHCPR). These multidisciplinary teams were awarded $1 million annual grants to assemble, assess, and disseminate available scientific evidence for specific medical problems, and the foundation expected them to be an important source of content for its library of decision aids. Of course, Congress axed the PORTs in 1995, largely as the result of strong lobbying by orthopedic and ophthalmic surgeons who were not happy with some of their findings. This meant that the foundation would be required to support its own scientific teams to develop the content for any decision aids.

But there are other costs as well. For a PtDA
to be most useful, it is also critical to understand the symptoms and outcomes patients care about most and the risks that are of greatest concern. For example, in their groundbreaking work examining benign prostatic hypertrophy, John Wennberg and colleagues found that while doctors tended to focus on urine flow rates and acute retention, patients cared more about how much the symptoms affected their lives and the risks associated with surgery such as retrograde ejaculation. Medical "experts" can provide only part of the needed information; talking to patients in the development process is critical, and the patient focus groups or surveys necessary to provide this information add more expense. Also, given the rapid pace of medical research and development (R&D), it is critical to update the evidence base regularly to incorporate new findings. More expense—and expense that will be ongoing.

Where should the money come from to develop decision aids? The pharmaceutical industry is out for obvious reasons, and government is conflicted (it is a major purchaser with strong interest in cost control); besides, government has too often proved to be an unreliable partner subject to political interests (as the PORT situation exemplifies). Not surprisingly, the foundation turned to philanthropy for initial support. However, these funders are generally interested in a one-time award that produces a tire-kickable product that can be shown to the board and that fits in with their program areas of interest. Sixty programs and support for continual updates are a big lift, even for the most well-endowed foundation. Moreover, foundations typically view themselves as the venture capital of the not-for-profit world—ongoing, recurring expenses after the demonstration is over are somebody else's problem. Another reality.

Reality no. 3: a creative business model will be required. There is one more problem: There are no obvious champions in the health system for getting decision aids into the hands of patients.

Perhaps right-thinking clinicians or provider organizations interested in having their patients make good decisions could include these expenses as one of the costs of medical practice. Unless, of course, one choice means revenue (admit the patient and do the surgery) and another means less revenue (watchful waiting)—even the most patient-centric physician or hospital might begin to have reservations about a decision aid (it's likely to confuse the patient, or it's too long, and so on). Besides, as O'Connor and colleagues note, there are often serious logistical problems in getting decision aids to patients "just in time" that may require redesign of the clinical process to accommodate use of decision aids in everyday practice.

Indeed, this was the experience of the foundation in its first years as it attempted to market its interactive video decision aid programs to large group practices and staff-model health maintenance organizations (HMOs). While the programs had proved enormously "successful" in experimental mode in several practice sites (with strong patient satisfaction and reductions in rates of surgery), the market did not respond. Part of the problem related to the media format (interactive video disk requiring special equipment and space for viewing), but even in partnership with Sony Medical (1992–94), the costs of developing and distributing the programs far exceeded the revenues from the limited number of users.

After numerous false starts with various potential partners, in 1997 the foundation entered into a new commercial arrangement with Health Dialog, a privately held, for-profit venture founded by George Bennett and Chris McKown that offers health coaching (nurse call service), decision support, and chronic disease management services to health plans, employers, and provider organizations. In return for exclusive marketing rights to the foundation's decision-support programs (now predominantly in linear videotape format), Health Dialog pays royalties to the foundation based on its gross revenues. The foundation develops and maintains editorial control of the content for the programs, which are produced and distributed by Health Dialog.

In the current fiscal year, the royalties from
Health Dialog are expected to reach $6 million, enabling the foundation to expand its library of programs to twenty-one by the end of 2004, support a cadre of fourteen academically based medical editors (to develop content for decision aids and assure that it remains up-to-date with research developments), and to fund a small portfolio of research related to decision aids (studying issues such as framing effects and evaluating the impact of decision aids on patients' decision making).

Health Dialog's success in the marketplace has greatly expanded the reach of decision aids (with more than 20,000 video programs distributed to patients and their families in the past year), and this creative business model has gone a long way toward addressing the need for sizable, ongoing financing (Reality no. 2). However, potential concerns remain. For example, auspices matter (Reality no. 1). The foundation takes no funding from makers of drugs or devices. An independent board, strict rules about conflict of interest, and careful procedures to ensure balance and fairness in the development of program content provide some reassurances and are important steps that have been taken to insulate the foundation from threats to its neutrality. Nonetheless, although the foundation continues to receive some support from philanthropy, the overwhelming majority of its revenues comes from its royalty arrangement with Health Dialog. Health Dialog has fully embraced the importance of and need for balance and fairness (hence its relationship with the foundation) and has supported development of numerous programs that are economically neutral to plans (for example, breast cancer treatment decision aids) or even potentially cost-inducing (for example, breast reconstruction after mastectomy or treatment of benign uterine conditions). However, in the cynical health care marketplace, the appearance of potential conflict is obvious when major clients include health plans (which most consumers perceive to have strong incentives to reduce spending).

Another limitation of the current business model from the perspective of promoting decision support is the insurance plan-centric nature of Health Dialog's business to date. Although Health Dialog has marketed assiduously to provider organizations, its largest contracts remain with health plans. Provider organizations still aren't buying in large numbers. Although in some markets these plans have a sizable market share (and a more direct relationship with local clinicians), entry through a health plan can place Health Dialog at arm's length from physicians, despite its best efforts to engage them. As noted by O'Connor and colleagues, there are distinct advantages to embedding decision support into routine medical practice, especially at the primary care level, where physician incentives on choice of treatments are generally neutral. For its health plan clients, Health Dialog is largely dependent on its nurse call line/coaching service to identify patients in need of decision support.

Health Dialog also has an innovative claims data-mining capacity that can be used to identify patients that may be facing medical decisions (for example, patients with back pain who have had magnetic resonance imaging, or MRI), but in many cases, this information comes too late or too far along in the decision-making process for patients. Timely identification of patients in need of decision support can be done in a provider setting most efficiently and effectively, but given the current dysfunctional health care market, direct provider involvement remains a challenge that Health Dialog struggles to adapt its product to address.

The future for decision aids and shared decision making. O'Connor and colleagues have proposed demonstrations for various models of decision support to help establish the feasibility of more widespread implementation of decision aids. James Weinstein and colleagues have suggested that the Centers for Medicare and Medicaid Services (CMS) redesign the fee-for-service (FFS) reimbursement system to reward providers who implement shared decision making in accordance with the authority granted in Section 646 of the Medicare Prescription Drug, Improvement, and Modernization Act (MMA) of 2003. Others have also suggested increased reimbursement for physicians using decision
aids (in effect, inducing demand for decision aids). 12

But none of these issues is high on the policy agenda in Washington. Until incentives are realigned and providers have an incentive to help patients make informed medical choices that are consistent with their values toward benefits and risks, things are unlikely to change much.

It is clear, however, that patients' desires to be involved in their own medical decisions are likely to increase, especially as baby boomers begin to age into more intensive consumption of health services. Decision aids, especially those with rigorous and complete assessment of available medical evidence, can help meet this need. And providing high-quality decision support to patients before they are subjected to a major medical intervention may be the best way to reduce unwarranted variations in care and the number of costly treatments that have little value to patients. 3 The Foundation for Informed Medical Decision Making/Health Dialog arrangement has found a market niche in a health care marketplace that remains dysfunctional; it is hoped that innovative approaches will continue to evolve so that decision aids can have even further reach.

The author acknowledges the thoughtful advice provided in reviewing this paper by George Bennett, Chris McKown, Al Mulley, Jack Wennberg, and Jack Fowler. Their dedication to the expanded dissemination of decision aids is a remarkable testament to the strength of their convictions and will.

NOTES

2. A.M. O'Connor et al., “Decision Aids for People Facing Health Treatment or Screening Decisions” [Cochrane Review], in The Cochrane Library, Issue 1 (Chichester, England: John Wiley and Sons Ltd., 2004).
3. The foundation's founders were John Wennberg, Albert Mulley, Robert Derzon, and the author.
7. O'Connor et al., “Modifying Unwarranted Variations in Health Care.”