Promoting Informed Choice: Transforming Health Care To Dispense Knowledge for Decision Making

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Ours is an era in which patients seek greater engagement in health care choices, increasing the demand for high-quality information about clinical options. Providing support for informed choice is not straightforward, however, because of challenges faced by clinicians, health systems, and consumers. Greater use of written or electronic tools can help to clarify choices for patients, but decision aids cannot replace the human element in facilitating informed choice. The ideal solution is to couple *information* with high-quality decision *counseling* to help patients understand the potential risks, benefits, and uncertainties of clinical options and to assist them in selecting the option that best accommodates their personal preferences. Decision counseling can be offered by 3 types of providers: clinicians who lack formal informed-choice training ("usual care"), clinicians with formal informed-choice training, or trained third parties who function as impartial decision counselors. Controlled studies are needed to determine which model is best, but none appears to be ideal.

The health care system cannot truly support informed decision making without correcting the underlying obstacles that impede patient access to needed information. New information technology solutions, training programs, and reimbursement schemes are necessary. Patient demand for guidance will only increase as clinical options multiply and the world of information continues its rapid growth. Today's health care system is unprepared for the convergence of these 2 burgeoning domains, and the need to address systemic deficiencies will grow more urgent over time.

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Patients need good information to make good choices, but supplying that needed information is not something that physicians and hospitals do well. Among the great ironies of the modern health care system is how poorly it delivers knowledge at a time when society enjoys unprecedented access to information. Americans can obtain so many facts with the click of a button yet must struggle to gather well-tailored information about their clinical options or ways to care for their own health. Consumers encounter a system designed to deliver the material commodities of care (such as tests and drugs) but not knowledge. According to the results of a Commonwealth Fund survey published in 2004 (1), the frequency (33%) with which sick patients in the United States leave the physician's office without getting important questions answered is the highest among the 5 countries studied (the others being Australia, Canada, New Zealand, and the United Kingdom).

The mounting need for consumer information is, in many ways, a contemporary phenomenon. Generally speaking, patients of previous generations merely needed to decide whether to seek medical attention and whether to follow their physician's advice; it was not their place to decide which options were best. Physicians tended to fill a paternalistic role, maintaining exclusive purview over medical knowledge. The expectation of both providers and consumers of health care was that the physician knew what was best (2). Today, roles and expectations for information have shifted, giving way to the newer model of informed choice and active patient participation in care (3). This dynamic is placing new demands on both the provider and the health care system, perhaps too quickly for either entity to respond.

In this article, we outline patients' expanding needs for decision support and the challenges clinicians and health systems face in meeting those needs. We then explore 2 categories of solutions to facilitate informed choice: expanded information resources for decision support and the coupling of information with decision counseling. We conclude that no current model can succeed without a major transformation in system design to make knowledge a key commodity accessible to all participants.

THE PATIENT'S EXPANDING ROLE IN MAKING DECISIONS

For millions of Americans who lack health insurance or a regular clinician—problems that disproportionately plague the poor and minorities—informed choice is a marginal concern eclipsed by the larger priority of gaining access to care (4). However, among those with established access (and even for those without), deeper engagement in decision making is increasing for several reasons: increased patient autonomy, broader access to information, expanding clinical options, rising costs, ascendancy of chronic illness, complex tradeoffs, and greater accommodation of personal values.

See also:

Web-Only
Conversion of tables into slides

Increased Patient Autonomy

The culture of consumerism in the United States encourages the public to exercise control over life choices (5). This trend and the ethical imperative to respect patient autonomy have shifted the locus of control in the clinician–patient relationship toward a patient-centered model that eschews paternalism and invites patients to engage actively in the decision-making process (6, 7).

Broader Access to Information

This increased desire for control arises in an era of 24-hour news, direct-to-consumer advertising, search engines, and high-speed Internet connectivity. Patients have grown accustomed to accessing information and are acquiring the tools to research clinical options and review personal medical data. The physician is no longer the sole purveyor of medical knowledge (8).

Expanding Clinical Options

Advances in medications and biotechnology have yielded a complex menu of choices for conditions that once had a single standard of care. The sophistication of these procedures gives patients the added task of processing scientific nomenclature, data, and technological concepts, a special challenge for those patients with literacy, numeracy, or language barriers (9–12).

Rising Costs

Consumers must consider the economic implications of clinical choices as they encounter higher insurance copayments and deductibles (13). Medical savings accounts and defined contribution plans are promoted on the premise that patients will pay closer attention the cost of health care services.

Ascendancy of Chronic Illness

Active engagement is vital for the growing number of patients with chronic diseases (14). Self-management, a centerpiece of effective long-term care, requires greater access to information (15, 16).

Table 1. **Components of Informed Decision Making**

Themes Addressed in Informed Decision Making*	Components of Shared Decision Making†
The patient's role in decision making	Understanding the risks associated with the condition
The clinical issue or nature of the discussion	Understanding the options, including the risks, benefits, alternatives, and uncertainties
The alternatives for management of the patient's condition	Weighing personal values regarding potential benefits and harms
The potential benefits and risks of proposed management options	Participating in decision making at the level desired
The uncertainties	
The patient's understanding	
The patient's preferences	

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Complex Tradeoffs

Patients face a more difficult task in weighing benefits and harms (17). Yesterday's patients confronted tradeoffs with less difficulty by relying on the intuitive judgment of clinicians. Today's patients expect clinicians to help them to understand sophisticated probability data used to weigh the tradeoffs of a therapeutic option, such as the number of patients per 1000 who benefit from an intervention versus the number who are harmed (18, 19).

Greater Accommodation of Personal Values

For the growing number of decisions for which the "best choice" depends on personal preferences (20), patients must consider how procedures will affect their lives and must cope with the scientific uncertainties surrounding outcomes. For this kind of analysis, patients require *informed decision making* (21), which involves a level of counseling that goes beyond the offhand advice that clinicians conventionally offer in busy practice (22). On topics ranging from screening tests (23) to surgery and end-of-life care (24–27), patients cannot properly weigh the benefits and harms without examining the evidence in light of personal values (28). To do so, they require the more substantive support offered by informed decision making and shared decision making (19, 29–32), as shown in **Table 1**. The intensity of informed decision making must be calibrated to the type of clinical decision, as others have elucidated (29).

Promoting informed decision making is motivated not only by moral arguments (that beneficence requires knowledge of what the patient wants) but also by economic and legal considerations (33). The high costs taxing the U.S. health care system stem largely from costly procedures that often have weak supporting evidence; some of these procedures might be deferred if patients knew more about possible complications and other tradeoffs (34). A notable example is intensive care and other interventions at the end of life, which are often inconsistent with the preferences of patients (35, 36). Teno and associates (36) reported that 60% of seriously ill Medicare beneficiaries preferred comfort care over aggressive interventions, but only 41% of these patients believed their care reflected this preference. Unwanted, costly interventions might become less common if they were preceded by well-informed discussions with patients and loved ones.

CHALLENGES TO INFORMED DECISION MAKING

Even when information is readily available, the public faces difficulties with informed decision making (37–39). Although people generally want to be educated about health care options and appreciate having the freedom to participate in decision making, not everyone wants this role (40–43). Patients face cognitive and emotional challenges in vetting complex decisions (19). Minorities and disenfranchised patients often arrive at the clinical encounter with less knowledge about certain topics (44) and are less likely to be actively engaged in decision making (45–47).

Clinicians also face barriers to implementing informed decision making (48). The busy pace of patient care leaves little time for long discussions and detailed presentations of options and statistics. Few clinicians can quote accurate data or divorce themselves from personal biases to ensure a balanced presentation of options. Many lack the time or aptitude to consider patients' risk profiles, to predict preferences, or to help patients apply these values to select the best personal choice (49–52). The best approach to informed decision making varies by patient, requiring clinicians to adjust to the individual. Low literacy and cultural barriers intensify the challenges in communicating facts and eliciting preferences (53, 54). Clinicians, caught in a struggle for economic survival, receive little reimbursement for this effort.

The health care system as a whole faces its own difficulties in implementing informed decision making because it is not well designed for this task. Health care has been slow to respond to society's appetite for communication and has not reorganized itself to provide high-quality information about options and outcomes. The system is not equipped to inform patients in a manner that is timely, easily understood, and jargon-free, nor does it encourage people to consider consequences, to ask questions, to clarify values, and to express preferences.

POTENTIAL SOLUTIONS AND THEIR LIMITATIONS

Thus, the problem at hand is an expanding need to help patients navigate complex decisions set against the limitations of the health care system in delivering the salient facts and guidance. We explore 2 potential solutions: information resources for decision support, and the coupling of these tools with decision counseling.

Information Resources for Decision Support

The Information Superhighway

Much of the information that patients require is available amid the vast resources of the Internet and other media. The Internet is especially helpful because of its accessibility, convenience, and capability for interactive tailoring of information. However, the quality of Web sites and chat-room information is suspect (55), and patients do not always recognize embedded advocacy and sponsor biases. The sheer volume of available information is itself a problem, making it difficult for patients to locate crucial facts. Disadvantaged persons are especially at risk for falling into the digital divide when their physical or financial limitations prevent them from easily accessing the Internet and other new technologies (56).

Nonetheless, the Internet has done much to connect patients with relevant knowledge. For example, MEDLINEplus, a service of the National Library of Medicine, offers a rich collection of information on more than 600 conditions (57). *Information therapy*, as advanced by Kemper and Mettler (58), envisions clinicians using handheld devices or electronic medical records to "prescribe" tailored educational materials and e-mail hyperlinks to relevant Web sites (59). These tools, however, are rarely organized in a format to support decision making.

Decision Aids

Greater use of decision aids and interactive software technology could help. Decision aids are available in a variety of formats—print publications, decision boards, videos, audio-guided workbooks, and Web applications—and help to clarify choices by providing information about the condition and possible treatment options, probabilities of relevant outcomes, exercises to clarify values, and coaching in the steps of decision making (60–63). Controlled trials have shown that decision aids increase patient participation; reduce decisional conflict and indecision; and improve indicators of decision quality, such as knowledge, perceptions of probabilities, and concordance between values and choices (64).

Decision aids offer clinicians a validated format for presenting facts that surpasses conventional advice in terms of balance, accuracy, and consistency. They also offer a medium for expanding counseling beyond the time constraints of busy office visits. Patients can study decision aids at their leisure, contemplate their preferences, and return for another appointment for further discussion.

The Internet has spawned a new generation of decision aids (65). The Cochrane Inventory of Patient Decision Aids lists 50 Web-based tools (66). For example, the Ottawa Personal Decision Guide uses interactive technology to help people assess decision-making needs, make plans, and track progress (67). CollaborativeCare.net (68) uses textual information and online videos to present options and tradeoffs for 13 "crossroad" decisions faced by women with breast cancer.

However, electronic or print material is not the only answer, in part because of limitations in existing products. The current generation of decision aids and software tools is of variable quality (61, 69) and cannot fully accommodate patients' questions and information needs. Experts are not certain how to frame decisions accurately and how to present numerical information to achieve clarity, objectivity, and balance (70–75). Decision aids are even less useful for patients with literacy or language barriers (76), and they may not perform well cross-culturally (77).

No electronic platform is likely to replace the human being's capacity for guidance: the innate sensitivity to the needs and desires of the patient and the ability to employ interactive dialogue and nonverbal cues to communicate facts, values, emotions, and advice. In a randomized trial involving women with menorrhagia, Kennedy and associates (78) demonstrated that decision aids had no effect on hysterectomy rates or patient satisfaction unless they were coupled with nurse interviews aimed at clarifying values.

Web sites and decision aids cannot function as partners in such decisions. Some experts believe that the benefit patients obtain from human involvement in decision support is less about cognitive learning than about the interaction and relationships that such counseling engenders.

Finally, decision aids of any form are unlikely to offer optimal guidance unless they are integrated into medical care. Clinicians possess vital information for determining the best choice for an individual, such as risk factors and medical history, treatments attempted in the past and their outcomes, and the availability of local resources; these details are unknown to off-the-shelf aids or counselors with weak collaborative ties to the clinician. What seems like the best choice under nominal conditions might be a poor choice when contextual and clinical circumstances are considered. A strategy of decision support that ignores this context could propagate poor advice and frustrate care.

Information Coupled with Decision Counseling

Counseling by Clinicians without Informed-Choice Training

One solution, often suggested for physicians who lack the time or skills to facilitate personally informed decision making, is to start a discussion and then refer patients to nurses or other office staff who have more time to distribute educational materials and answer patients' questions. This model allows informed decision making to be integrated into patient care within the immediate environs of the physician.

The strategy has its drawbacks, however, because most practices cannot afford to dedicate staff time to patient counseling or to fund training in informed choice. Typically they must call on personnel with competing clinical duties and inconsistent skills. Consequently, what patients experience as informed decision making varies in content across personnel and practices. Aside from compromising patient education, this inconsistency makes reimbursement by health plans unlikely.

Counseling by Clinicians with Informed-Choice Training

Clinicians or their staff may opt to undergo formal informed-choice training, emphasizing the communication and negotiation skills required for the 7 elements in **Table 1** (21, 79). A Cochrane review found that such training can significantly increase the patient-centeredness of consultations (80). Raising the informed decision-making skills of the average clinician would spare patients from needing to look outside the patient–clinician relationship for help from an unfamiliar advisor. Patients trust the primary clinician, who has the benefit of knowing both the patient and the specialty in detail. Formal informed-choice training, which could begin as early as medical (81) or nursing school and be credentialed through certification, might qualify for sufficient reimbursement to subsidize the extended sessions and staff time that informed decision making imposes on practices (82).

The disadvantage of this model is that many clinicians may not pursue such training for themselves or their staff, especially if they see little to gain from their time and financial investment. The time required to support informed decision making (for example, maintaining a library of decision aids [83]) might not be feasible for busy practices. The overhead expenditures associated with this model, some of which may not be reimbursed by health plans, can also strain tight budgets. Finally, despite the best informed-choice training, clinicians may still have difficulty shedding conflicts of interest, biases, and preferences when presenting options.

Counseling by a Trained Third Party: Decision Counselors

A third solution is for patients to turn to decision counselors outside their physician's practice for help with informed decision making. Decision counselors, a new type of health care professional in many communities, can help patients to understand options, to consider the probability of benefits and harms and the supporting evidence, to explore beliefs and fears, to determine the desired level of control in making decisions, and to find motivation to engage with the primary clinician. We envision offices of decision counselors that provide a quiet environment to use high-speed Internet workstations, a complete library of decision aids, and other patient education materials.

Decision counselors offer certain qualities that clinicians may lack: a talent for assembling the best educational resources for patients without the interference of competing agendas and specialty bias, and the expertise to guide patients in recognizing and applying personal preferences. Although these advisors may not possess the clinical expertise that is the forte of specialists (on whose advice patients would still rely), they function as highly skilled knowledge brokers. Their libraries of decision aids can help patients review the key evidence to consider when weighing options. Skilled counselors can coach patients to understand preferences, become engaged in care, and express their preferences to clinicians. Their focus on facilitating informed decision making makes decision counselors conceptually distinct from thematically related professions, such as informationists, decision analysts, ethicists, patient navigators, and patient advocates (84, 85). Two models for this form of counseling can be envisioned: autonomous and coordinated.

Autonomous third-party counseling would occur independently from primary clinicians. An example is the counseling provided by Health Dialog (Boston, Massachusetts), under contract with employers and health plans. Health Dialog furnishes "health coaches," who motivate patients to participate in treatment selection, prepare for discussions with physicians, weigh the implications of options, and translate decisions into action (68, 86). These consultations are not always formally coordinated with the primary clinician, however (82).

In the second model, *coordinated third-party counsel-*

ing, decision counselors collaborate with primary clinicians. Patients who face difficult "close-call" decisions (20) and who would benefit from decision counseling might be referred by their providers (or self-referred) for such counseling to ensure that their choices are well-informed and tailored to personal preferences. These counselors may have offices located conveniently within hospitals and outpatient office buildings, enabling them to serve both individual practices and integrated delivery systems. Primary clinicians would detail pertinent clinical background and recommended options on requisitions. Decision counselors would reciprocate with written reports and direct communication. A referral to a decision counselor might be required for certain tests or procedures, just as genetic counseling is mandatory for certain genetic tests. For high-risk or costly procedures, Medicare and private health plans might make reimbursement contingent on previous consultation with a decision counselor.

This model has been successfully pioneered by the Center for Shared Decision Making at Dartmouth-Hitchcock Medical Center (87). Located in a suite on the main floor of the hospital, the center offers consultations with a decision-support nurse and lends videotapes and other decision aids to patients to review at home. The center prepares patients for clinical encounters while also helping clinicians by including relevant clinical data in reports that summarize patients' preferences and decision needs. Using this service has become routine for hospital physicians; almost all spine surgeons at Dartmouth-Hitchcock ask patients to examine decision aids before consenting to surgery. Other hospitals engaged in an ongoing multicenter trial have adopted this approach (88).

In an effort to coordinate decision counseling with clinical care, Health Dialog uses claims and pharmacy data to identify patients facing decisions that might benefit from counseling. It distributes to primary care providers registries of patients with multiple chronic conditions and those with gaps in care that suggest inattention to important decisions.

Decision counseling offers a mechanism for assisting patients in ways that busy clinicians cannot. Centralizing this service within a decision counselor's office provides greater consistency, efficiency, and quality control than is possible when informed decision making is conducted at primary practices. Decision counseling excels over impersonal decision aids and Web sites by offering a human face and personal assistance to patients who might be overwhelmed in their efforts to extract trustworthy information from the sea of available knowledge. Counselors can employ special approaches and materials to assist patients with low literacy or with language or cultural barriers (89).

The most negative aspect of third-party decision counseling is that it appropriates the role of the primary clinician. The model introduces triangulation that can undermine trust, continuity, and other valued elements of the patient–clinician relationship, potentially weakening the healing power of the caretaker conversation (90). Decision counselors who collaborate with the clinician as part of an integrated plan of care can mitigate this problem, as generally occurs with genetic counseling. If coordination is lacking, however, inconsistencies in the guidance offered by the clinician and counselor may confuse the patient and trigger resistance from the clinician. The intrusion of a third party can also introduce inefficiency, as when extra office visits become necessary to resolve confusion over treatment plans.

Table 2. **Advantages and Disadvantages Associated with 3 Models of Decision Counseling***

Variable	Untrained Clinician Provider	Trained Clinician Provider	Third-Party Decision Counselor*
Disadvantages			
Provider bias	▲	▲	▽
Variable skill and quality of counseling	▲	▽	▽
Large time and financial expenditure needed to obtain training	NA	▲	NA
Overhead expenditures for allocating staff time for counseling	▲	▲	▽
Triangulation of patient–clinician relationship	▽	▽	▲
Lack of clinical expertise	▽	▽	▲
Unfamiliarity with pertinent clinical data	▽	▽	▲
Confusion and inefficiency if not coordinated with primary clinician	NA	NA	▲
Uncertain professional and legal liability	▽	▽	▲
Advantages			
Occurs in context of trusted patient–clinician relationship	▲	▲	▽
Integrated with primary care	▲	▲	▽
Less demanding on primary clinician	↔	▽	▲
Consistent, efficient delivery of patient-centered counseling	▽	↔	▲
Improved prospects for reimbursement	▽	▲	▲
High-quality counseling techniques	▽	↔	▲
Talent and resources of "knowledge broker"	▽	▽	▲
Clinical autonomy and independent analysis	▽	▽	▲
Ideal, centralized physical environment for counseling	▽	▽	▲

*▲ = increased likelihood; ∇ = decreased likelihood; ↔ = highly variable; NA = not applicable.

Decision counselors may also overlook pertinent clinical issues. They may lack the content expertise and training of specialists and the firsthand knowledge of patients' personal histories to properly individualize potential benefits, barriers, and alternatives. Although their training may make them the best at presenting options with consistency, they cannot fully rid themselves of biases or achieve the standardization and convenience that decision aids and Web sites offer. Finally, it is unclear who is professionally and legally responsible for adverse outcomes resulting from actions (or inaction) propagated by decision counselors.

WHICH APPROACH IS BEST?

Each of the aforementioned models has advantages and disadvantages (**Table 2**); which model is best is unclear. Studies suggest that decision aids can reduce the use of some procedures (91–93), but one cannot predict which models for informed decision making will decrease or increase utilization or will optimize the quality of decisions. The ideal goal is to improve health outcomes linked to patient values and satisfaction while minimizing costs and litigation. Case reports describe adverse legal consequences from offering informed decision making (94). Controlled studies are ultimately needed to determine the effect of each model on the quality of decisions; health outcomes; liability; costs; and acceptability to patients, clinicians, and systems of care.

CONCLUSION

Regardless of which of the decision-counseling models is most effective, none seems capable of delivering the information and guidance needed for informed choice without introducing discontinuity or disruption in patient care. Less disruptive solutions are unlikely to satisfy patients' information needs. The ultimate long-term solution, then, is not merely to choose among the aforementioned models but to correct the larger defects in the current health care infrastructure that impede the delivery of the information patients need when they need it (95). The design of the current system reflects an outdated service model that viewed medicine's primary product as therapeutics and the delivery of information as a secondary service to enhance patient satisfaction.

Modern thinkers understand that information is power, as Francis Bacon presciently observed long ago (96). Berwick considers knowledge to be the primary commodity of health care (97). Experts know that, for many conditions, the success or failure of clinicians' work depends on what patients understand. Informed choice is important not only as a moral duty to patients, who deserve to know how options affect their health, but to society as a whole. The costly consumption of health services at the macro level originates at the micro level in decisions made by individual clinicians and patients. If informed decision making shifts the dynamics of these choices, the effects on health care costs and other resources can be sweeping, with ripple effects that influence benefits packages, health insurance premiums, and access to care.

One may safely predict that the passage of time will only increase the demand for information and guidance as clinical options increase (both in number and in technical complexity) and as the stunning expansion of information continues. Today's health care system is unprepared for the intersection of these 2 realities. The system clings to an outdated model—relying on busy clinicians to keep their patients informed—a holdover from an earlier time when a physician's impromptu advice was sufficient and when there was little concern about its inherent incompleteness or bias (98). The traditional office or bedside conversation remains an important anchor for patients but is inadequate for facilitating thoughtful analysis of tradeoffs and connecting patients to the world's best information.

Systems of care cannot support informed choice without redesigning their infrastructure. New information systems are needed to link patients with the best resources and decision aids available. Clinicians require training programs to raise their skill levels. Imaginative models for redesigned office care and restructured reimbursement schemes are needed to provide sufficient time and incentive to counsel patients. Current reimbursement incentives reward costly procedures and rushed visits; they discourage the counseling that ensures that procedures are warranted in the first place and that gives patients the self-management tools on which the effectiveness of those treatments often depends (15).

Today's leaders may dismiss informed choice as too great a luxury for major monetary outlays or infrastructure changes, but the underlying problem will not go away. Perhaps nothing is changing more dramatically in health care than the increased volume and influence of information. Patients face a growing need for assistance in knowledge management and for access to professionals who are qualified for this task. As the volume of information and the complexity of choices increase, this need will only grow more urgent.

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