Patient-Centered Decision Making: A View of the Past and a Look toward the Future

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Med Decis Making 2001; 21; 241
DOI: 10.1177/02729890122062532

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A View of the Past and a Look toward the Future

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I would like to share with you some observations on the past and some thoughts about the future regarding "Patient-Centered Decision Making." This term has many meanings depending upon the audience. In a quick Internet search, I found several hundred citations, representing a wide range of content areas. In more focused searches of the medical literature, the majority of citations relate more specifically to shared decision making and decision aids for patients, rather than decision support tools. I'd like to focus on patient-centered decision making, specifically as it relates to the use of medical decision analyses as decision support tools, tailored to the concerns, characteristics and risk profiles of individual patients.

Through the field's more than three decade history, decision analyses have focused on many levels of patient care, spanning the spectrum from individualized, patient-specific decisions, to policy-level decisions about large classes of patients. As shown in Figure 1, analyses performed for individual patients focus much time and effort on a very specific decision problem within the context of a distinctive medical scenario. As shown to the left in this figure, "Patient-Specific Decision Analyses" are structured to shed light on the "best" decision for an individual patient. In their very structure, they detail the specific medical scenario, decisions, chance events, and outcomes faced by the individual patient. They use patient characteristics to determine the probability of specific chance events and outcomes; and they may use individual patients' preferences for these outcomes and health states. Detailed examples of such analyses can be found in the Clinical Decision Cases published in past years in our journal, *Medical Decision Making*.

Large-scale policy analyses, which are created to examine health policy issues for populations of patients, lie at the other end of the spectrum of decision analytic applications.[1] These analyses have been used to help set priorities for governmental funding of health care programs, to guide policy within a particular managed care organization, or even to set guidelines for reimbursement by third party payers. As shown at the right side of the figure, "Policy Level Decision Analyses" attempt to identify the "best" decision for groups of patients. They examine more generic (rather than specific) clinical settings. They use average risks and outcomes for classes of patients; and they may involve additional outcome measures, such as cost, as in cost-effectiveness or cost-utility analyses. Tammy Tengs[2] and her colleagues performed an extensive review and summarization of more than 500 such analyses in an article, with which many of you are familiar, published in 1995 in *Risk Analysis.*

For certain common medical problems, generic models have been developed which examine broader clinical questions in less restricted settings. Many of these models fall within the middle of this spectrum of decision analytic applications. Well known and time-honored examples include Ransohoff's[3] analysis of prophylactic cholecystectomy in patients with "silent" gallstones, Molitch's[4] analysis of patients with a solitary thyroid nodule, Pauker's[5] followed by Weinstein and Stason's[6] analyses of coronary artery bypass surgery, and Pauker and Pauker's[7,8] genetic counseling analysis of the decision to perform amniocentesis.

While generic models represent a more "economical" approach to clinical decision making, they sometimes fail to capture the important subtleties that differentiate one patient from another. In response to this issue, many members of SMDM have begun to create models which can be

Received 6 October 2000 from the Division of General Internal Medicine and the Center for Clinical Effectiveness, University of Cincinnati, Cincinnati, Ohio. Revision accepted for publication 4 January 2001.

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This article was first presented as the Presidential Address, 22nd Annual Meeting of the Society for Medical Decision Making.

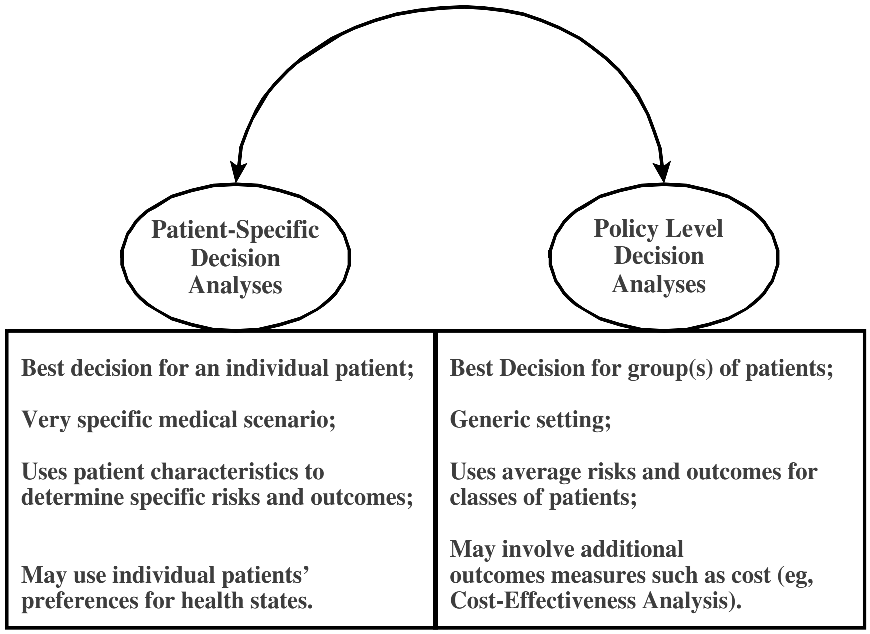


FIGURE 1. The spectrum of decision analytic applications and their associated characteristics. At one extreme, patient-specific decision analyses examine the optimal strategy for a specific patient under a unique set of circumstances, while at the other extreme, policy-level analyses examine decisions for large prototypical groups of patients.

applied to different individuals encompassing a wide variety of clinical scenarios within a particular range of presentations. In these models, a single decision tree is used, while patient-to-patient variability is captured through a number of internal parameters (see Figure 2). For some clinical decisions, patient-to-patient differences are driven by biologic variability. Patients may have different risk factor profiles for the progression or complications of disease. Identifiable patient subgroups may have varying efficacies of treatment, and varying risk associated with testing or treatment. They may have different disease prevalences, and different excess mortality risks attributable to coincident disease processes. This type of patient-to-patient variability can be modeled by varying parameter values for probabilistic events.

For other medical decisions, the driving forces that best capture patient-to-patient variability are patient preferences for the potential health outcomes. A good example of this type of decision problem is the dilemma women face who have one of the breast-ovarian cancer susceptibility gene mutations: BRCA1 or BRCA2. These individuals are at increased risk for both breast and ovarian cancer. Prophylactic interventions may include various combinations of bilateral mastectomy and oophorectomy. In analyses presented at last year's annual meeting, a number of reports[9–13] showed that the screening decision, as well as decisions regarding surgery, are profoundly dependent on women's preferences for these health states. Therefore, the optimal decision for any individual must take her utilities and preferences into account.

A second good example in which "shared decision making" procedures have been used to inform patients' choices about treatment alternatives has been the decision regarding surgery for benign prostatic hypertrophy. Using interactive videodisc technology to develop a shared decision

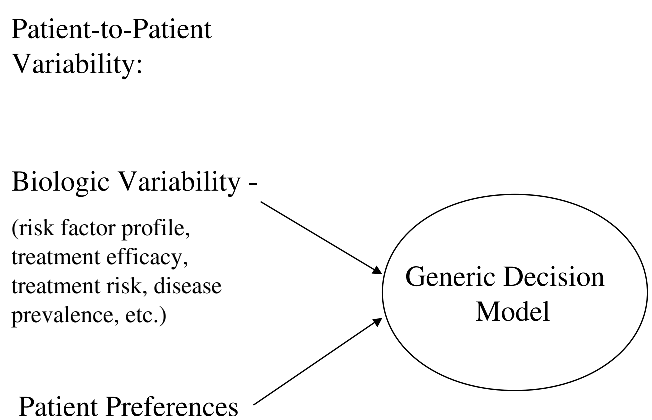


FIGURE 2. Generic decision models can be "patient-tailored" by incorporating parameters into the model that vary in predictable ways from patient to patient. These patient-to-patient differences can be captured by either biologic variability and/or variability in individual patient preferences for health states.

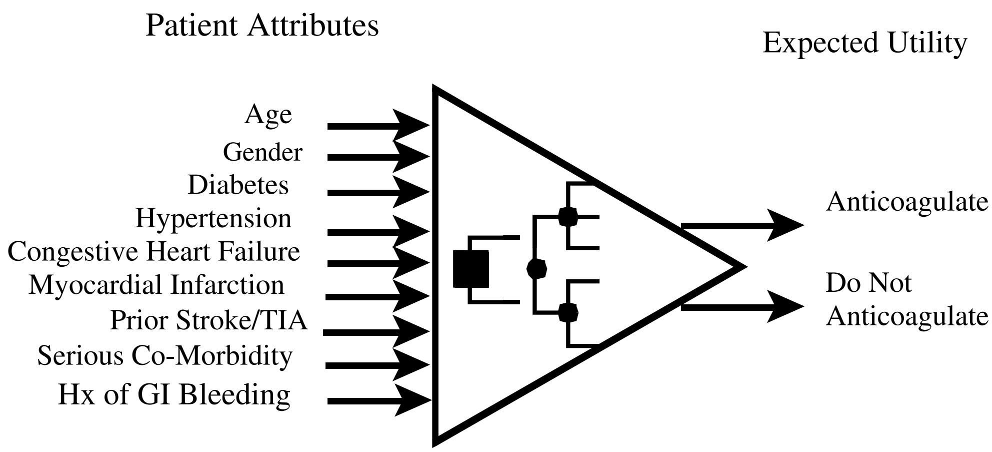


FIGURE 3. Patient-specific decision making for nonvalvular atrial fibrillation. Individual patient characteristics are used to estimate thromboembolic and hemorrhagic risk as well as demographic-related mortality rates (eg, μ_{ASR}). Each combination of patient characteristics generates an expected utility for both strategies and a unique optimal strategy for the individual patient. Although not shown in the figure, patients' personal values for states of health may also be incorporated into the decision analysis.

making program regarding the natural history of BPH, and the outcomes and complications of surgical intervention, Michael Barry and colleagues[14] demonstrated that patients valued the program, and that they made decisions that were consistent with their assessed preferences.

The decision whether to anticoagulate patients with atrial fibrillation exemplifies a commonly recurring medical question for which an individualized but systematic approach may be helpful. While guidelines have been published that recommend antithrombotic therapies based upon stroke risk,[15–18] few consider the specific balance of risks and benefits for individual patients, particularly for patients at increased risk for hemorrhagic complications. These guidelines also may be difficult to apply to patients for whom the optimal decision may be influenced by the side-effects and inconvenience of taking aspirin or warfarin.

Shown in Figure 3 is an example of patient-specific decision making for nonvalvular atrial fibrillation.[19,20] This model is designed to make individualized recommendations regarding the use of anticoagulant therapy for patients at different degrees of risk for thromboembolism and hemorrhage. Embedded risk prediction models from the medical literature allow individual patient characteristics to be used to estimate both thromboembolic and hemorrhagic risk. As shown in the figure, the covariates of the prediction models include patient age, gender, histories of diabetes, hypertension, congestive heart failure, myocardial infarction, prior stroke or TIA, serious co-morbid illnesses, and gastrointestinal bleeding. The individualized risk calculations are then used to generate specific transition probabilities in a Markov decision model. Each combination of patient characteristics generates an expected utility for both strategies, and a unique optimal strategy for the individual patient. Although it is not shown in this figure, patients' personal values for states of health also may be incorporated in this paradigm.

Figure 4 shows examples of patient-specific decision making for two different individuals with nonvalvular atrial fibrillation.[19] Shown at the left, for a 72 year old man with non-insulin dependent diabetes and hypertension, ANTICOAGULATION is preferred, yielding an expected utility of 7.2 Quality-Adjusted Life Years (QALYs), versus 6.8 QALYs for DO NOT ANTICOAGULATE. Shown at the right of this figure, for a 67 year old man with a history of gastrointestinal bleeding, DO NOT ANTICOAGULATE is preferred, yielding 10.2 QALYs, as compared with ANTICOAGULATION, which results in 8.3 QALYs.

Consider how this model might be employed in practice. You are a clinician in your office who earlier in the day had seen a complicated patient with nonvalvular atrial fibrillation. You weren't quite sure whether to anticoagulate this patient. You sit down at your computer, and access the interactive web page shown in Figure 5.

Your patient is an 81 year old man, with a history of hypertension, non–insulin dependent diabetes, congestive heart failure, and a myocardial infarction last year. He also has a history of a gastrointestinal bleed for which he required a transfusion of 2 units of packed red blood cells. As shown in Figure 6,

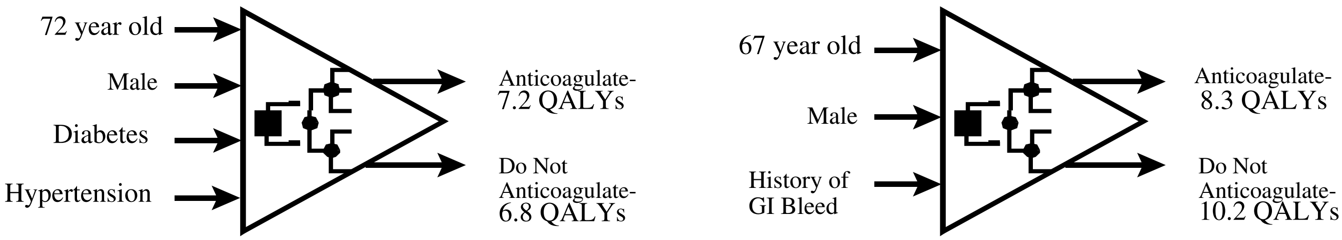
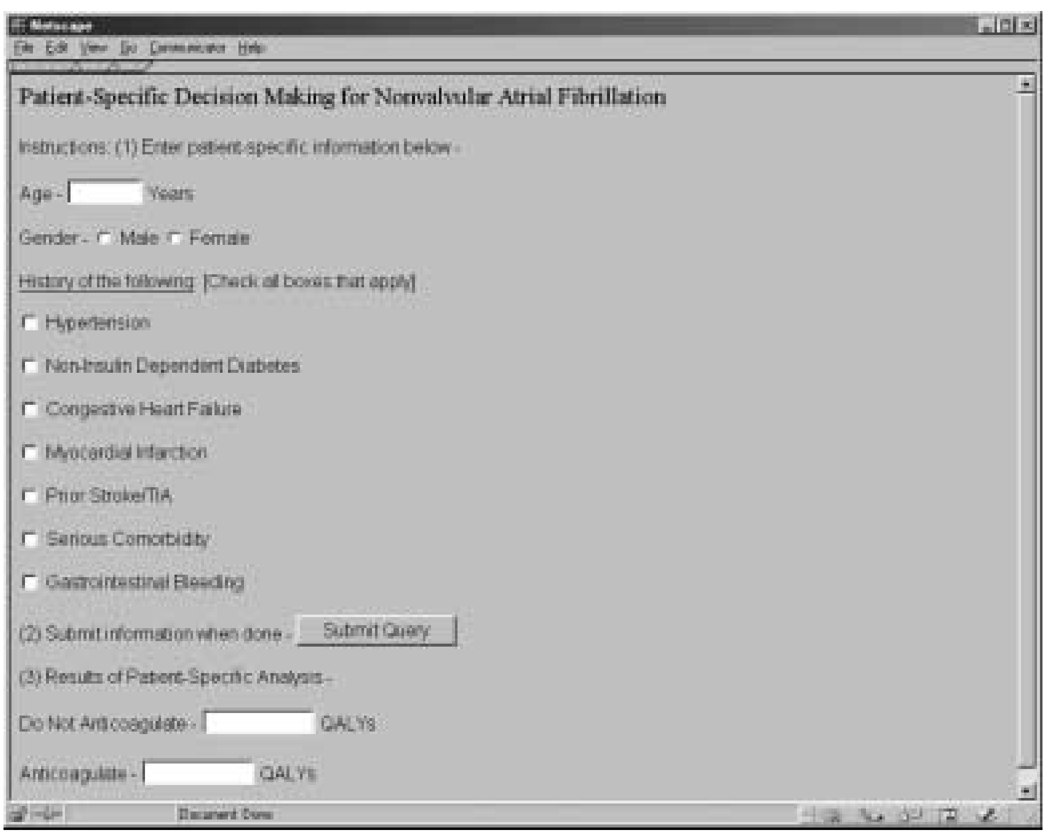


FIGURE 4. Examples of patient-specific decision making for two patients with nonvalvular atrial fibrillation. For a 72-year-old man with noninsulin-dependent diabetes and hypertension, anticoagulation is preferred, yielding an expected utility of 7.2 quality-adjusted life years (QALYs) versus 6.8 QALYs for do not anticoagulate. For a 67-year-old man with a history of gastrointestinal bleeding, do not anticoagulate is preferred (10.2 QALYs) over anticoagulation (8.3 QALYs).

you click on the appropriate radio buttons and check boxes, and within seconds receive projected life expectancies for your patient under both strategies. As you can see, despite the history of gastrointestinal bleeding, anticoagulation results in a life expectancy gain of a little more than 2 months.

On another section of the web page you find hot links to relevant journal articles on the subject. Details of the model are available, including the decision tree, patient-specific risks for major hemorrhage and thromboembolism, and all additional parameter values. Having set the risks for bleeding and thromboembolism to patient-specific

FIGURE 5. Interactive web page as a decision support tool facilitating patient-specific decision making. In this example, providing decision support to clinicians for patients with nonvalvular atrial fibrillation, the user inputs values for a number of categorical and continuous variables. These are used by the interactive web page interface to calculate patient-specific rates for major hemorrhage and thromboembolism. Those parameter values are passed to the decision model, which then calculates patient-specific quality-adjusted life expectancy for both clinical strategies. The decision model passes the results of the simulation back to the interactive web page and they are posted.



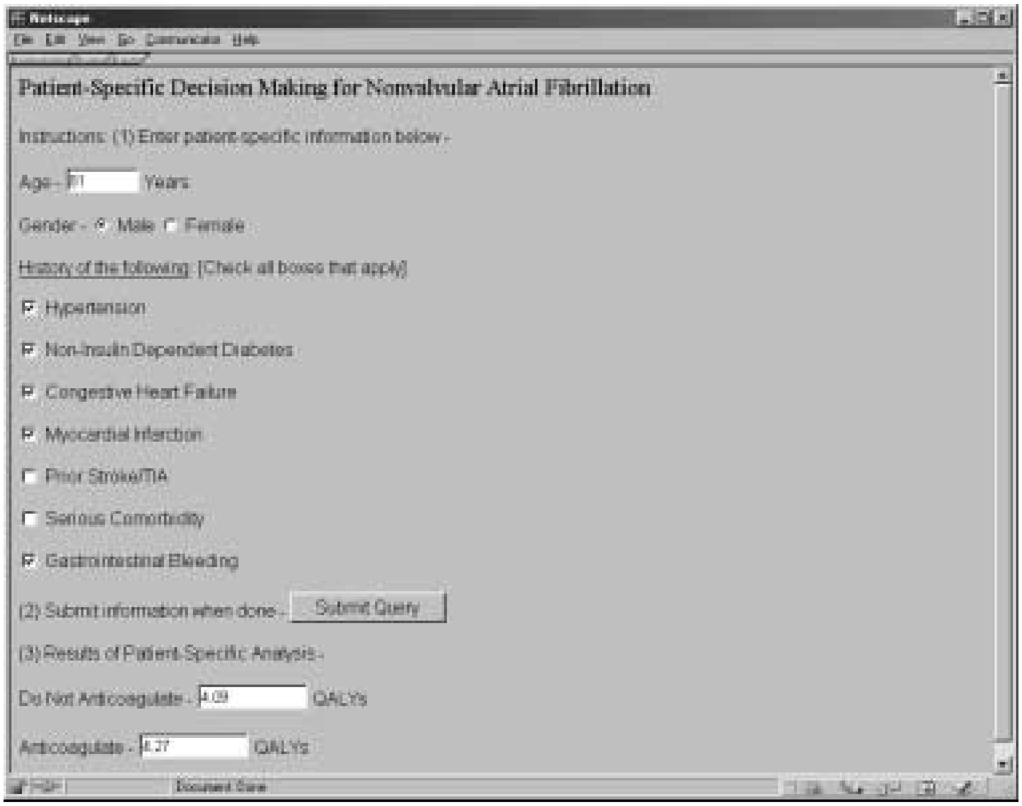


FIGURE 6. Example of interactive web page decision support tool delivering results for an 81-year-old man with hypertension, non-insulin dependent diabetes, and a history of congestive heart failure, myocardial infarction, and gastrointestinal bleeding. Anticoagulation is preferred, yielding an expected utility of 4.27 QALYs versus 4.09 QALYs for do not anticoagulate.

values, should you be interested in exploring sensitivity analyses on additional variables, these can be requested as well.

This type of interactive interface has been implemented nicely by Gillian Sanders at Stanford University and her colleagues as part of the Cardiac Arrhythmia PORT.[21] At this web site, they have a full description of a Markov model examining the implantable cardiac defibrillator and amiodarone as anti-arrhythmic therapy. Users can view the decision tree and click on sub-trees to focus on further details of the model. Base case values for parameters are shown along with the ranges explored in sensitivity analyses. Users also may enter new values for these variables to examine their impact on the results. Sensitivity analyses also can be performed, resulting in the dynamic presentation of results requested by the user.

A number of investigators have performed extensive and systematic reviews of the medical literature dealing with the topics of informed decision making, shared decision making, or the use of decision aids.[22–24] They have identified a number of gaps in this research, as well as opportunities for the future. Annette O'Connor and her colleagues exhort us to consider carefully the "essential ingredients in . . . these . . . decision aids . . . and before we invest extraordinary efforts in their dissemination . . . identify the patients who are most likely to benefit from more complex versions."[23] They further suggest that we more closely study and understand how these tools affect physician-patient interactions, the patient-doctor relationship, and, ultimately, how they impact on the quality and cost of care.

There is a growing need for patient-centered decision making. Entirely new fields have developed, such as genomics, whose applications cry out for decision analytic and patient-centered approaches. What are we to do with the onslaught of genetic tests that are starting to appear in clinical use? Should we be using them? If so, for whom? And, how should we utilize their results? Many of these decisions will be driven by patients' preferences, as in the decision regarding prophylactic mastectomy or oophorectomy in patients with the BRCA1 or 2 cancer susceptibility genes. The National Institutes of Health has identified as a new priority area for funding, interdisciplinary research translating new genetic information and scientific breakthroughs into prevention strategies that will require researchers from diverse disciplines to collaborate. Surely, the decision sciences will be among these disciplines.

Where are we headed with patient-centered decision making? Clearly, we have much left to do in terms of decision model and interface development. Certain ingredients must exist to make such a model useful and tractable:

1) For any given medical scenario, choices and chance events for a wide range of individual patients must be described with reasonable fidelity by a generic decision tree model.
2) Patient-to-patient variability must be represented adequately by differences in parameter values and not tree structure. These differences will reflect either describable biologic variability between patients, for example—disease prevalence; or the probability of some complication of disease, such as stroke in patients with atrial fibrillation; or the risk of a complication of therapy, such as bleeding with anti-coagulation or thrombolytic therapy; or differences in patient preferences for health states for decision problems that might otherwise be "toss-ups."[25]
3) The clinical characteristics used to generate patient-specific risk profiles or probabilities must be easily obtainable in normal clinical settings; and/or the decision must be driven by patient preference.
4) Since many of these models will require embedded predictive instruments, such as logistic regressions or cox proportional hazards models, to generate patient-specific probabilities or rates, it is necessary that these predictive models either exist or be developed. Furthermore, careful attention must be given to the evaluation of the performance of any embedded prediction models (e.g., discrimination and calibration).
5) Finally, the decision problem must be common enough to warrant the effort of constructing a generic, but patient-tailorable decision model.

As we work on the development of friendly and informative interfaces with these patient-centered decision models, I believe there are wonderful opportunities for young researchers to explore and better understand the types of information that are most helpful for clinicians and our patients. We must explore the best manner in which to present this information to our different target audiences. Pioneers like Edward Tufte[26] have developed innovative techniques for the visual display of quantitative information. Can similar techniques be used to dynamically present the dense information pouring out of our decision models?

To disseminate our models, the internet provides an unprecedented common platform that can facilitate easy access by clinicians, and if desired, by patients. Interactive web pages provide an easy mechanism for capturing patient-specific information and then providing patient-specific results.

Finally, once we have developed these decision analytically-driven decision support tools, we must estimate their potential impact; and then, if promising, develop studies to evaluate their actual impact—on patient outcomes, on resource utilization, and on patient and physician understanding and satisfaction with the decision making process.

References

1. Detsky AS, Naglie IG. A clinician's guide to cost-effectiveness analysis [see comments]. Ann Intern Med. 1990;113(2):147–54.
2. Tengs TO, Adams ME, Pliskin JS, et al. Five-hundred life-saving interventions and their cost-effectiveness [see comments]. Risk Anal. 1995;15(3):369–90.
3. Ransohoff DF, Gracie WA, Wolfenson LB, Neuhauser D. Prophylactic cholecystectomy or expectant management for silent gallstones. A decision analysis to assess survival. Ann Intern Med. 1983;99(2):199–204.
4. Molitch ME, Beck JR, Dreisman M, Gottlieb JE, Pauker SG. The cold thyroid nodule: an analysis of diagnostic and therapeutic options. Endocr Rev. 1984;5(2):185–99.
5. Pauker SG. Coronary artery surgery: the use of decision analysis. Ann Intern Med. 1976;85(1):8–18.
6. Weinstein MC, Stason WB. Cost-effectiveness of coronary artery bypass surgery. Circulation. 1982;66(5 Pt 2):III56–66.
7. Pauker SP, Pauker SG. The amniocentesis decision: ten years of decision analytic experience. Birth Defects Orig Arctic Ser. 1987;23(2):151–69.
8. Pauker SG, Pauker SP. Prescriptive models to support decision making in genetics. Birth Defects Orig Arctic Ser. 1987;23(2):279–96.
9. Tengs TO, Winer EP, Paddock S, Aguilar-Chavez O, Berry DA. Testing for the BRCA1 and BRCA2 breast-ovarian cancer susceptibility genes: a decision analysis. Med Decis Making. 1998;18(4):365–75.
10. Tengs T, Berry D. The cost-effectiveness of testing for the BRCA1 and BRCA2 breast-ovarian cancer susceptibility genes. Med Decis Making. 1999;19:526.

11. Stalmeier PF, Unic IJ, Verhoef LC, Van Daal WA. Evaluation of a shared decision making program for women suspected to have a genetic predisposition to breast cancer: preliminary results. Med Decis Making. 1999;19(3):230–41.
12. Stalmeier P, Unic I, Verhoef L, van Daal W. Prophylactic mastectomy or screening: a study of women's choices, medical and decision analytic recommendations. Med Decis Making. 1999;19:526.
13. Dembitzer A, Sanders G, Goldstein M, Owens D. Cost-effectiveness of programs that screen for BRCA mutations in women. Med Decis Making. 1999;19:526.
14. Barry MJ, Fowler FJ, Jr., Mulley AG, Jr., Henderson JV, Jr., Wennberg JE. Patient reactions to a program designed to facilitate patient participation in treatment decisions for benign prostatic hyperplasia. Med Care. 1995;33(8):771–82.
15. Risk factors for stroke and efficacy of antithrombotic therapy in atrial fibrillation. Analysis of pooled data from five randomized controlled trials. Arch Intern Med. 1994;154(13):1449–57. (A published erratum appears in Arch Intern Med. 1994;154(19):2254.)
16. Laupacis A, Albers G, Dalen J, Dunn MI, Jacobson AK, Singer DE. Antithrombotic therapy in atrial fibrillation. Chest. 1998;114(5 Suppl):579S–89S.
17. Thomson R, Parkin D, Eccles M, Sudlow M, Robinson A. Decision analysis and guidelines for anticoagulant therapy to prevent stroke in patients with atrial fibrillation. Lancet. 2000;355:956–62.
18. Albers GW. Atrial fibrillation and stroke. Three new studies, three remaining questions. Arch Intern Med. 1994;154(13):1443–8.
19. Eckman MH, Pauker SG. Decision analytic issues in the management of atrial fibrillation. In: Falk RH, Podrid PJ, eds. Atrial Fibrillation: Mechanisms and Management. Philadelphia: Lippincott-Raven, 1997; p 469–88.
20. Eckman MH, Levine HJ, Salem DN, Pauker SG. Making decisions about antithrombotic therapy in heart disease: decision analytic and cost-effectiveness issues. Chest. 1998;114(5 Suppl):699S–714S.
21. Sanders GD, Hagerty CG, Sonnenberg FA, Hlatky MA, Owens DK. Distributed decision support using a Web-based interface: prevention of sudden cardiac death. Med Decis Making. 1999;19(2):157–66.
22. Molenaar S, Sprangers MA, Postma-Schuit FC, et al. Feasibility and effects of decision aids. Med Decis Making. 2000;20(1):112–27.
23. O'Connor AM, Rostom A, Fiset V, et al. Decision aids for patients facing health treatment or screening decisions: systematic review [see comments]. BMJ. 1999;319(7212):731–4.
24. Bekker H, Thornton J, Airey C, et al. Informed decision making: an annotated bibliography and systematic review. Health Technol Assess. 1999;3(1):1–156.
25. Kassirer JP, Pauker SG. The toss-up [editorial]. N Engl J Med. 1981;305(24):1467–9.
26. Tufte E. The Visual Display of Quantitative Information. Cheshire, CT: Graphics Press, 1983.