Communicating Evidence for Participatory Decision Making

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Physicians should create collaborative partnerships with patients (and families) in which clinical decisions are made using the best available evidence, consistent with patients’ values, goals, and capabilities. However, this ideal is rarely achieved. Physicians typically spend less than 1 minute out of a 20-minute visit discussing treatment and planning. Informed decision making occurs in only 9% of outpatient office visits, and physicians ask patients if they have questions in less than half. Although patients generally want more information about their illnesses, they recall only a fraction of the information physicians transmit.

Communicating evidence to patients has practical, relational, and ethical goals. Informed patients are more likely to participate actively in their care, make wiser decisions, come to a common understanding with their physicians, and adhere more fully to treatment; however, currently there are no evidence-based guidelines for discussing clinical evidence with patients in the process of making medical decisions.

Objective To identify ways to communicate evidence that improve patient understanding, involvement in decisions, and outcomes.

Data Sources and Study Selection Systematic review of MEDLINE for the period 1966-2003 and review of reference lists of retrieved articles to identify original research dealing with communication between clinicians and patients and directly addressing methods of presenting clinical evidence to patients.

Data Extraction Two investigators and a research assistant screened 367 abstracts and 2 investigators reviewed 51 full-text articles, yielding 8 potentially relevant articles.

Data Synthesis Methods for communicating clinical evidence to patients include nonquantitative general terms, numerical translation of clinical evidence, graphical representations, and decision aids. Focus-group data suggest presenting options and/or equipoise before asking patients about preferred decision-making roles or formats for presenting details. Relative risk reductions may be misleading; absolute risk is preferred. Order of information presented and time-frame of outcomes can bias patient understanding. Limited evidence supports use of human stick figure graphics or faces for single probabilities and vertical bar graphs for comparative information. Less-educated and older patients preferred proportions to percentages and did not appreciate confidence intervals. Studies of decision aids rarely addressed patient-physician communication directly. No studies addressed clinical outcomes of discussions of clinical evidence.

Conclusions There is a paucity of evidence to guide how physicians can most effectively share clinical evidence with patients facing decisions; however, basing our recommendations largely on related studies and expert opinion, we describe means of accomplishing 5 communication tasks to address in framing and communicating clinical evidence: understanding the patient’s (and family members’) experience and expectations; building partnership; providing evidence, including a balanced discussion of uncertainties; presenting recommendations informed by clinical judgment and patient preferences; and checking for understanding and agreement.

Context Informed patients are more likely to actively participate in their care, make wiser decisions, come to a common understanding with their physicians, and adhere more fully to treatment; however, currently there are no evidence-based guidelines for discussing clinical evidence with patients in the process of making medical decisions.

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Clinical decisions has its perils. It is difficult to reconcile evidence based on populations with care directed toward individuals having unique needs, concerns, and expectations. Quantitative estimates of probability of given outcomes can be difficult to establish prospectively. The values ascribed to relevant outcomes are often subjective and depend on factors that may be intangible but personally significant (eg, a death with dignity), context-dependent factors (eg, risk of pregnancy), and the perspective of the decision maker (eg, physician, patient, or social institution such as Medicare). Presenting evidence to patients on intermediate outcomes such as “response rate” rather than morbidity and mortality may lead patients to believe that they will feel better or live longer when, in fact, the intermediate outcome measure (eg, shrinkage of the tumor demonstrated by computed tomography scan) may only be one marker of disease activity and meaningless in terms of mortality or functional status. The “utility” of each given outcome is notoriously value laden. Utilities are not universal but rather emerge through dialogue. Formal decision analysis may use patients’ values to guide recommendations but is not a method for informing patients about evidence.

While the skills in recognizing clinical questions that might drive a search of the medical literature (sometimes by eliciting the patient’s view of the problem and forming a researchable question have been described, the communication skills required to conduct the important dialogues with patients have not, and are not routinely covered during training in evidence-based medicine. In this article, we explore how physicians can translate findings from a literature search to the clinical encounter in a way that enhances patient understanding and participation in their care. We frame those communication skills within the context of participatory decision making; they also apply to other situations, such as informing patients about prognosis. In order to generate recommendations, we conducted a systematic search of the published literature.

**METHODS AND RESULTS**

Using MEDLINE to search articles from the period 1966 to 2003, we conducted a systematic review of articles that (1) reported original research, (2) dealt with communication between clinicians and patients, and (3) directly addressed methods of presenting clinical evidence to patients (details of the search strategy are available from the authors on request). Two investigators and a research assistant screened 367 abstracts and 2 investigators reviewed 51 full-text articles, yielding 2 articles that clearly met criteria; 5 others were considered “marginal.” Reference lists of these and other articles, and searches of authors’ names, yielded no additional references. One recent, not-yet-indexed additional reference was sent to us by an astute librarian. The focus-group studies proposed skills for communicating evidence were discussed above.

Chao et al used hypothetical scenarios presented to preclinical medical students to examine 4 methods of presenting survival benefits on chemotherapy decisions. Students’ responses confirmed prior studies that suggested that presenting information using relative risk reduction (eg, “This treatment will improve your chances of recovery by 50%”) may be misleading by exaggerating the significance of a positive effect, especially if the absolute benefits are small or if the effects of the intervention are realized in the distant future. Absolute survival benefits or numbers needed to treat were difficult for patients to interpret; combinations of methods led to confusion. In contrast, students were able to interpret absolute risk reductions clearly and without confusion. However, the study cannot be generalized to patients having less medical sophistication.

Mazur and Merz presented volunteers with a series of survival curves comparing 2 hypothetical treatments and noted that the order of presentation of the graphs influenced subsequent decision making, especially in less-educated and older patients.

Schapira et al conducted focus groups composed of women aged 40 to 65 years to compare different types of graphic displays for presenting evidence. They suggested graphics using human stick figures or faces for single probabilities and vertical bar graphs for comparative information between 2 options. Stick figures or faces were judged...
easier to identify with, more understandable, and less “clinical” than graphs. However, patients sometimes interpreted the stick figures as representing higher risk; this was true especially among less-educated patients. Schapira et al also suggested using lower denominators (eg, 1 stick figure out of 10 rather than 10 out of 100) for stick-figure graphics. Graphs with vertical bars were preferred to those with horizontal bars. Shapira et al did not study pie charts.

Describing proportions (eg, “One in 10 women will get breast cancer”) was considered more “people-oriented” than was describing probability (eg, “You have a 10% chance of getting breast cancer”), which was considered more mathematical and more difficult to understand by less-educated patients. However, proportions were more likely to lead patients to attribute risk to others; they assumed that they belonged to the healthy group.

Less-educated women felt that confidence intervals were “wissy-washy,” whereas better-educated women preferred the expression of uncertainty. Women younger than 50 years preferred 10-year risk time frames, whereas women aged 50 years or older preferred estimates of lifetime risk. The generalizability of these findings is unclear. Also, graphs may require in-person explanations to help patients interpret them correctly.

Decision aids are interactive products that use computer or workbook formats to present information, options, and guidance through a decision process. Some present evidence, but most simply elicit values without explicit discussion of research findings. None of 87 studies of decision aids in a 2001 Cochrane review directly addressed patient-physician communication, although they did report presumed results of improved communication, such as improved patient knowledge, satisfaction, and patient involvement in decision making. The impact of the decision aid on actual decisions or clinical outcomes is mixed, and it remains unclear whether the effect is due to empowerment, provision of information, or enhanced patient-physician communication triggered by the use of a decision aid. We found only 2 studies, both investigating the same decision tool, which addressed—albeit indirectly—communication between physicians and patients. These studies suggested that more time may be required for postintervention visits and that decision aids can facilitate discussions with family members.

Other than the choice of graphic formats, the literature review gave few detailed suggestions about how physicians can effectively incorporate clinical evidence into routine medical encounters and no empirical support for those suggestions. None of the articles addressed whether the method of presenting clinical evidence to patients or discussing it with them affects clinical outcomes. The following sections build on our review by considering possible methods for communicating evidence to guide clinical decisions, drawing on the general communication literature when available.

**PRESENTING EVIDENCE**

**Clinical Example**

Consider a patient who has been successfully treated for major depression with antidepressants and now, after 12 months of treatment, wonders if the antidepressants should be continued or discontinued. A systematic review of 31 randomized trials comparing antidepressant continuation with discontinuation concluded that continuing antidepressants reduced the risk of relapse within the next 12 months. The average risk of relapse across trials was 18% with active treatment and 41% with placebo (number needed to treat, 4.3). Stated conversely, 59% of patients treated with placebo did not experience relapse. These data come from aggregated studies; individual risks of relapse depend on factors such as genetic predisposition and the number, severity, and length of prior depressive episodes. The literature and clinical experience suggest 4 ways of presenting these research findings: description of benefits and harms in general conceptual terms, numerical translation of clinical evidence, graphical representation of quantitative data, and decision-aid programs.

Describing benefits and harms in general conceptual terms is considered appropriate in settings in which scientific precision might obscure lay understanding. Although we found no relevant research in medical settings, in experimental settings verbal and numerical probabilities led to equal estimates of the likelihood of a precise binary event (eg, winning/not winning a lottery). For a patient who is not numerically oriented, the physician might say something like, “Continuing this medicine makes it less likely that the depression will return, but many people can stop the medicine and not have a recurrence.” Further discussion depends on patients’ understanding of the evidence (eg, “Does this mean that the depression will come back if I stop the medicine?”) or values (eg, “I hate being on medication, so I would really like to try stopping”). If the patient asks, “How much will it reduce my chances of relapse?” the clinician can use a more quantitative approach. However, there is tremendous variation in the interpretations of some, but not all, expressions of probability. For example, the word “rare” was interpreted as a 24% probability (SD, 30.5%) by patients and 5% (SD, 6%) by physicians, whereas “frequent” was interpreted similarly by physicians and patients. These kinds of miscommunications are even more likely when physicians and patients are not of the same race, ethnicity, or socioeconomic status.

Numerical translation of clinical evidence generally provides a description of the “average” patient. However, no patient is an average patient. Individualized numerical translation of clinical evidence requires estimating each patient’s risk of relapse, comparing it with that estimated for the research study sample, and extrapolating the clinical evidence to the individual patient. Although few stud-
ies currently provide algorithms for such calculations, over time this approach may become more precise. Such precision may not be needed, though. For example, if a particular patient had a strong family history of depression and had experienced a prior episode, the clinician might say, “Most patients have a 40% chance of another episode of depression in the next 12 months if they stop taking the medication. But depression runs in your family and you’ve had other episodes in the past, so I’d guess your chances of another episode if we stop the medication are quite a bit higher. That means that you might benefit more than most by continuing the medication.” Conversely, if there were no family history or prior episodes, the risk of relapse might be adjusted downward. One such discussion is shown in Box 2.

Word choice can introduce framing biases56; a patient might make a different decision about a treatment if the physician said, “There is a 90% chance that it won’t help” rather than “There is a 10% chance of benefit.” Presenting statistics both ways is preferred.

Graphical representation of quantitative data may facilitate numerical translation, particularly for commonly encountered clinical questions.59 Methods include pie charts,60 bar graphs,61 line graphs,62 icons,63 and graphics using stick figures or faces.64 These often require explanation for patients to interpret them correctly.

Decision-aid programs may be useful when comparing treatments that might produce different outcomes and potential adverse effects that are valued differently by separate patients. Decision aids may present a more balanced presentation of options, improved patient participation in and satisfaction with the decision, and some changes in patient preferences compared with oral presentation of the information by the physician.65 Criteria for selecting decision aids have been reviewed elsewhere.28

Considerations in Presenting Evidence to Patients

Generally, a “relationship-centered” approach13-48 not only provides opportunities for information transfer but also enhances the patient’s ability to participate in care. Relationship-centered care differs from paternalism (in which the physician has all of the relevant information and sole decision-making responsibility) and from a radical “independent choice” model48 (in which clinicians simply present “the facts” without making a recommendation and place sole responsibility for the decision on the patient).49 The consumer movement, physicians’ fears of lawsuits, and a genuine desire not to influence patients all promote informed choice. But patients and families should not be deprived of the clinician’s prudent judgments50 grounded in the knowledge of the patient, his or her family, the illness, and the relevant medical literature. Clinicians should not merely tolerate input from the patients but should implement relationship-centered care that includes active encouragement and coaching to help patients be involved in medical dialogue and decisions.

Describing evidence to patients and their families depends on the characteristics of the evidence (type of mea-
No single approach will work with all patients, even in similar clinical situations. For example, a study of women at risk of familial breast cancer found no consensus regarding how they wanted their clinicians to explain their personal risk. Some wanted numbers, whereas others preferred words. Those wanting numbers varied among preferences for percentages, proportions, or (rarely) odds. Thus, clinicians need a variety of techniques to communicate evidence about diagnosis, treatment, risk, and prognosis, as well as several ways of verifying that the information has been understood.

Interpretations of medical evidence are always matters of subjectivity and values. For example, a patient with asymptomatic human immunodeficiency virus infection may understand the evidence that early initiation of antiretroviral treatment can delay symptoms related to the infection. However, this fact should be interpreted in the context of the patient’s values; the patient might decide that early treatment does not warrant the inconvenience, potential adverse effects, and possible future viral resistance.

Family members of patients are often involved in health care decisions, whether or not they are present during the clinical encounter. Patients from some cultures tend to entrust the primary responsibility for medical information and decisions to family members. But there may be conflicts of values among family members; in one study of a decision-analysis program for prostate cancer screening, men preferred a no-screening approach, whereas their wives favored screening to a greater degree and also expressed less concern about the impact of impotence and incontinence on quality of life than did their husbands. Thus, the clinician should simultaneously welcome family input and be vigilant about maintaining the patient’s primacy in the decision-making process. Patients’ desire to have family members involved in health care may not be explicit, so it is useful to ask whenever there is a major decision about a potentially worrisome illness.

**RECOMMENDATIONS FOR PRACTICE**

Because of the paucity of evidence in our review, we also used related literature and clinical experience to guide our recommendations. Evidence from the general communication skills literature suggests that actively listening, providing information in small “digestible” amounts, and pausing to check for patient understanding will likely improve understanding and may shorten visit times by eliminating transfer of information that the patient neither needs nor wants. When the patient is distressed, delaying discussions of evidence until the patient is more receptive can reduce misunderstandings. Situations such as initiation of antihypertensive medication are usually not urgent, and the increased patient commitment gained by judicious delay may improve concordance to a mutually agreed-upon plan. Time spent thinking and talking with family members can help in the interpretation and presentation of complex information and raise additional questions that are important to the patient.

Once options have been presented to the patient, detailed discussions may follow; we propose a 5-step process that is informed by the needs and perspectives of the patient as well as by the physician’s expertise (Box 3). The model recognizes that decision making is only partially a rational process; it also includes elements of trust, confidence, and values.

**Step 1: Understand the Patient’s (and Family Members’) Experience and Expectations**

The scope and importance of the issue should be understood from the patient’s standpoint as well as the physician’s. Even if the clinician has inquired about the patient’s perspective earlier in the visit, it is helpful to delineate the patient’s specific needs, fears, expectations, and context specific to this issue. Also, this is the time to invite family members to participate when appropriate.

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Box 3. A Hypothetical 2-Minute Discussion That Incorporates Clinical Evidence

Physician: It sounds like you’ve done well on the antidepressant but don’t know whether it’s worth continuing. Is that right?
Patient: Yes.
Physician: This is a difficult choice, and the answer is not quite clear. Most people do well even if they don’t take an antidepressant medication. But, research shows that quite a few people will have a relapse. And, if you take the medication, you’re less likely to have another episode of depression in the next 5 years.
Patient: Well, what would you do?
Physician: This is not an easy choice, so I think that different people would make different decisions. But first, let me make sure that you understand the issue.
Patient: Well, I think I understand, but how certain is it that the depression will come back? The pills are okay, but I really don’t want to be on them for the rest of my life—they do affect my sex life a bit.
Physician: Do you want statistics?
Patient: Okay—let’s try.

Physician: There have been several research studies, and it seems, overall, that of 10 patients with depression who stop the medicine, 4 will have a recurrence within the next year, while 6 will remain healthy. If they continued the medicine, only 2 out of the 10 would have a recurrence. Are you following me?
Patient: What’s the choice then? I really don’t want to feel that way again!
Physician: You’ve hit the nail on the head. You first said you did not want to take medication forever, and now you are telling me that you clearly don’t want to have a relapse. And that is the choice we should make together.
Patient: I understand now. I guess the million-dollar question is whether I’m going to be in the healthy group or the depressed group. Is there any way to tell?
Physician: That’s a good question—the problem is, we really don’t know. But we know that depression runs in your family, so your risk for relapse might be somewhat higher than what is reported in the research. So, a lot of physicians would suggest that you continue, and I guess that I would agree, as long as the side effects are tolerable. And, if not, there are other medications. And we can talk again in 6 to 12 months to see if it makes sense to continue.
Patient: Got it. I’ll probably do it. I’m going to need to think about this for a while.
Physician: Is there anything that we’ve discussed that you don’t understand?
Patient: Not really. I just need time to think.
Physician: Should we talk again next month? Maybe continue the medication until then?
Patient: Okay, sounds reasonable.

Step 2: Build Partnership
Relationship-building activities include the expression of empathy (eg, “You might feel uneasy”), acknowledgment of the complexity or difficulty of the issue, an expression of mutual understanding (eg, “I think I understand...”), increasing patient/family involvement (eg, “I would like to help you understand”), and fostering partnership (eg, “We need to make this decision together”). This approach builds trust and facilitates transfer of important information.46,47

Step 3: Provide Evidence, Including a Balanced Discussion of Uncertainties
Generally, patients want more information from their physicians than they receive.60 Since some patients may not know the appropriate questions or may be hesitant to ask, physicians should anticipate critical unasked questions and suggest discussing them. Presenting clinical uncertainty in simple lay terms can be challenging. Avoiding discussions about uncertainty might preclude a patient’s full understanding of a critical decision. Overemphasizing uncertainty can also be problematic, as some patients will lose confidence.34,61-65

Balance is achieved by explaining the limitations of what is known while maintaining confidence that this represents the imperfections of medical science rather than lack of competence of the practitioner.61 It is at this phase that the clinician should determine the appropriate format for presenting evidence—for example, general descriptions, numbers, educated guesses, graphics, or decision aids. Patients may have already found information that they may or may not spontaneously discuss with the clinician.

Step 4: Present Recommendations
Recommendations should only occur after the clinician has integrated clinical evidence with the patient’s values. Some decisions, especially when the evidence is uncertain or mixed, may represent true equipoise—ie, the physician may not have a specific recommendation—in which case the physician should present options dispassionately. For other situations, in which the evidence about benefits or harms is clearer, the physician may have recommendations for how to best meet the patient’s goals. If so, the physician should inform the patient which course of action is recommended and explain how that recommendation is generated clearly from the patient’s goals and the evidence. The physician then has the burden of differentiating evidence-based recommendations from those generated from personal experience or bias (eg, religious or financial concerns; desire for convenience).

Step 5: Check for Understanding and Agreement
Sometimes simply asking “Does that make sense to you?” may be adequate, and a positive response can indicate that you can continue with your recommendations and planning. In complex situations (such as the choice between cancer chemotherapy regimens) it is helpful to ask the patient to summarize what he or she understands and the
rationale for the choice made. If the patient appears not to understand, seems to agree but appears apprehensive, or actively disagrees, that is an invitation to go back to exploring the patient’s values, ideas, and expectations, or to provide detailed information. Sometimes patients and families feel comfortable enough to try out a treatment while receiving full agreement with the plan.

Additional resources may be useful for improving understanding and recall; these include carefully selected Web sites, printed handouts, handwritten instructions, review with nurses, audio recordings of the visit, and follow-up appointments.

Clinicians who have the flexibility to use different approaches can more easily adapt to the different ways in which people learn or process information. Finally, clinicians should be open to reconsidering medical decisions; many medical decisions are at least partially reversible. By leaving the door open for future discussions there is the possibility of responding to changing patient needs.

COMMENT

We have proposed methods of helping patients and their families make use of results of medical research to reach decisions that incorporate evidence and patients’ values. The ingredients for effective use of evidence include understanding the patient’s preferred style, informed flexibility in presenting the information to accommodate to the patient’s needs, a visit that is characterized by dialogue rather than lecturing, and an active partnership in which the patient is encouraged and coached to take a more active role in the consultation. Paradoxically, although relationship-centered consultations in which there is shared understanding and participatory decision making are associated with better outcomes, there is little evidence to guide many of our other recommendations. Further research will help define optimal ways of incorporating evidence into clinical conversations.

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Character cannot be developed in ease and quiet. Only through experience of trial and suffering can the soul be strengthened, ambition inspired, and success achieved.
—Helen Keller (1880-1968)