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The Next Step in Guideline Development

Incorporating Patient Preferences

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CLINICAL PRACTICE GUIDELINES (CPGs) ARE SYSTEMATICALLY developed statements to assist both patient and practitioner decisions. A fixture of modern medical care, guidelines link the practice of medicine more closely to the body of underlying evidence, shift the burden of evidence review from the individual practitioner to experts, and aim to improve the quality of care.¹

But do guidelines take into account what patients want and value? Consider the following examples. A patient with mild to moderate hypertension has shown some lowering of blood pressure but has not achieved her guideline-recommended target with salt reduction, exercise, and weight reduction. After considering the potential risks and benefits, she prefers to avoid drugs and continue with her behavioral interventions. Another patient with atrial fibrillation prefers to begin taking warfarin rather than aspirin, even though he is at low risk of stroke. He is a surgeon, and a stroke would be a career-ending event. Both of these patients have made what appear to be rational choices, but choices that are at odds with what guidelines^{2,3} recommend.

One potential reason for this discordance is that guidelines do not sufficiently take patient preferences into account. They may not include published evidence about preferences, include patient perspectives in the process of guideline formulation, acknowledge that an optimal decision in some circumstances is determined by preference, and actively encourage patients and practitioners to make decisions on the basis of preferences.

The term *preferences*, in its broadest sense, represents the desirability of a health-related outcome, process, or treatment choice. For example, in considering options for atrial fibrillation, a patient may have strong feelings about preventing stroke (an outcome), taking warfarin and having her international normalized ratio monitored (the process), or warfarin as a treatment strategy, which includes the prospect of all potential outcomes (a treatment choice). Concepts of greatest relevance would include health values in the bioethics literature; concerns, desires, and expectations in the psychology literature; and utility in the decision analysis and economics literature.

In the context of practice guidelines, the idea of tailoring treatment to preference is distinct from the notion of clinical tailoring. Tailoring treatment to age, sex, disease severity, overall risk profile, and combinations of comorbidity⁴ is an important part of the modern evolution of CPGs. This, however, is different than taking an individual's values and priorities into account.

Evidence on the Role of Preferences in Guidelines

The few studies that are available on this topic support the idea that guidelines do not consistently take preferences into account. Primary care clinicians may not always implement guidelines in part because they perceive a direct conflict between considering patient preferences and applying CPG recommendations. Protheroe et al⁵ demonstrated that for management of atrial fibrillation, marked disagreements were found between the best choice for an individual (as determined by incorporating personal preferences into a clinical decision analysis) and the treatment suggested by CPGs. Chong et al⁶ reviewed 51 evidence-based CPGs and found that only 5% of the word count and 6% of references in the guidelines related to patients' preferences. Relative to evidence about effectiveness, evidence about preference was less often searched for and was considered less completely when formulating recommendations.

Preferences and Evidence-Based Medicine

Why are preferences, which clearly seem to be important in this era of patient-centered practice, not given their due in CPGs? The main reason may be that the guidelines movement has its intellectual roots in evidence-based medicine (EBM), which has historically had a relatively limited role for patient preferences. Evidence-based medicine traces its origins to 18th-century British medicine and has flourished in distinct US, UK, and Canadian schools since the end of the last century.⁷ Arguably the dominant scientific paradigm of modern clinical medicine, EBM is characterized by specific beliefs, values, techniques, and views about

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what counts as relevant empirical data. For example, studies of clinical outcomes (eg, myocardial infarction) are regarded as evidence, whereas narratives of patient experience or studies of preferences commonly are not. In the EBM paradigm, preferences arise in the context of the discussion between an individual physician and patient and are seen as something that must be negotiated in the application of evidence. Recent restatements of EBM have elevated the role of preferences, but preferences have not historically been at the heart of the EBM enterprise.

Patient-Centered Medicine

Bensing has argued that modern medicine is dominated by 2 paradigms, EBM and patient-centered medicine.⁸ The trend toward patient-centered medicine is characterized by an increased emphasis on patient experience rather than the patient's disease, and an increased role for patients in decision making. The primacy of patients' experiences is a common contemporary theme of the social sciences, nursing, and primary care⁹ literature. Within clinical decision analysis and health economics, patients' utilities or preferences represent the value statements characterizing health outcomes. Because patients are taking a more active role in making decisions, it is increasingly the clinician's responsibility to find out what patients want, help them find the right information, and support them in the decision-making process. The move to patient empowerment is sometimes expressed in the language of the marketplace (eg, "consumer" decision support) but need not be (eg, "patient" empowerment). This powerful social trend has been expressed in the increasing number and role of consumer decision support tools (eg, pamphlets, videos, Web sites) that incorporate patients' values in decision making,¹⁰ and it has also been codified in the laws of several developed countries.¹¹

Some Suggestions

To incorporate patients' perspectives, experiences, and choices more fully into CPGs, preferences should be considered at every stage of the guideline development and implementation process.

Finding Preference-Related Evidence. First, the search strategy for a CPG should include a search for preference-related evidence. Preference-related evidence includes decision analyses or cost-effectiveness analyses in which preferences are explicitly represented using health utilities. It also includes studies of patients' preferences for health outcomes using health-related quality of life measures, utility-based measures, or qualitative studies of patients' experiences. Preference-related evidence also includes studies of patients' actual decisions, whether supported by consumer decision aids or not. Preference-related evidence can also include studies of social values, including conjoint-based methods, one-on-one interviews, focus groups, and interviews of citizen juries.¹²

Integrating Preference-Related Evidence Into Recommendations. Guideline developers consider preference-related evidence when making practice recommendations. Guideline developers should, in particular, indicate whether their recommendations are preference sensitive. This indication of preference sensitive would distinguish between recommendations that nearly all patients will accept and recommendations that are likely to vary depending on an individual patient's preferences for outcome, process, or choice. An example of a less-preference sensitive decision would be the use of antibiotics for community-acquired pneumonia. Few fully informed patients would choose not to be treated.

There are several reasons a decision may be preference sensitive. The evidence about benefit may be unclear or conflicting, or there may be tradeoffs between risks and benefits. Patients' values for process or outcome, including financial considerations such as out-of-pocket costs, may vary widely. Some decisions are preference sensitive for multiple reasons.

Using Guidelines in Individual Decision Making. When recommendations are preference sensitive, CPGs should encourage discussion and should specifically endorse the acceptability, rationality, and desirability of basing treatment decisions on patient preferences. Guideline developers must, and increasingly do, recognize the importance of tailoring treatment choice not only to clinical characteristics but also to individual preferences. This means something more than the blanket disclaimer, "these are just guidelines . . . of course we encourage discussion." It means a clear understanding that preferences have the same weight in choosing the right treatment for an individual as other evidence when decisions are preference sensitive.

Including Patients in the Guideline Development Process. Only 25% of guideline developers regularly involve patients in the process.¹³ Bringing patients into the process of guidelines development is an important part of making the process less physician centric and ensuring that patient perspectives inform the guideline process.

Evaluating Guidelines With Preferences in Mind. Instruments used to evaluate guideline quality such as the AGREE instrument¹⁴ should be modified to include the extent to which patient preference perspectives are systematically incorporated into the process of evidence review and into CPGs.

An Example: Prostate Cancer Screening

The following example illustrates how patient preferences can be incorporated into CPGs. Screening for prostate cancer using prostate-specific antigen (PSA) would appear to be a preference-sensitive decision. The mortality benefit of screening is uncertain, and patients place different values on assurance that they are free from cancer and treatment adverse effects such as sexual dysfunction and urinary incontinence. A search for preference-related evidence on

MEDLINE using search terms related to prostate cancer screening and patient preferences yielded 7514 references, including 23 studies of patient utilities for prostate cancer outcomes, narrative reviews of patient and clinician experiences, decision-analytic and cost-effectiveness studies of PSA screening, and 18 randomized controlled trials of shared decision making. Insights from this literature include the following: (1) PSA screening appears to prolong life expectancy but shortens quality-adjusted life expectancy (a formal confirmation that this is a preference-sensitive decision); (2) men who receive decision support are more knowledgeable, have less decisional conflict, and are less inclined to undergo PSA screening; (3) sexual and urinary dysfunction after treatment have modest effects on global quality of life; (4) men with low literacy do not understand many prostate cancer terms; and (5) black men have specific concerns in participating in discussions around screening and providing informed consent. A guideline formulated with this evidence in mind would state explicitly that patient preferences for screening and health outcomes are an important part of the screening decision, that a careful discussion, possibly using a decision support tool, is essential, and that the discussion should be shaped by the health literacy and ethnic background of the patient.

Exploring these suggestions will be challenging. One of the challenges will be to integrate new types of data into an already difficult process. Bringing patients into guideline development raises concerns about advocacy trumping science. Elevating the role of individual preference may constrain attempts to close practice gaps.

However, this direction is worth following. Clinical practice guidelines are becoming more widely used as a method for standardizing clinical practice and building pay-for-performance programs.¹⁵ By not getting guidelines right for patients, perverse incentives may be introduced for clinicians to advocate treatments that are counter to what patients want and value; physicians may also be incentivized to deselect patients with low literacy or ethnic backgrounds whose health preferences are at odds with guidelines. Getting guidelines right means not only rolling out

science but also taking seriously what matters to patients, in finding evidence, making recommendations, and integrating these recommendations into clinical decisions.

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