

## VIEWPOINT

# The Optimal Practice of Evidence-Based Medicine Incorporating Patient Preferences in Practice Guidelines

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**Research evidence** is necessary but insufficient for making patient care decisions. An effective but toxic chemotherapeutic regimen is the treatment one patient with cancer can and will take, another patient can take but will not, and yet another patient could not take even if wanted. Careful attention to the biopsychosocial context of patients and to their informed preferences when crafting treatments requires expertise and practical wisdom. This represents the optimal practice of evidence-based medicine.

Patient preferences refer to patient perspectives, beliefs, expectations, and goals for health and life, and to the processes that individuals use in considering the potential benefits, harms, costs, and inconveniences of the management options in relation to one another.<sup>1</sup> Patients may have preferences when it comes to defining the problem, identifying the range of management options, selecting the outcomes used to compare these options, and ranking these outcomes by importance.

Informed patients may choose not to follow a guideline that does not incorporate their preferences. The ATP III guideline (Adult Treatment Panel III), for example, recommended statins for all patients with diabetes. Patients with diabetes at low cardiovascular risk were 70% less likely to opt for a statin after

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receiving information about the small absolute reduction in coronary risk statins could afford them than patients receiving guideline-directed care.<sup>2</sup> Where the use of statins in patients with diabetes is linked to quality measures or performance incentives, clinicians face the conflict of following either the guideline or the informed patient.

### Challenges in the Incorporation of Preferences in Guidelines

Access to patients' preferences is complex. Individuals form their preferences when they have to make a decision, in a context replete with emotional and social influences.<sup>3</sup> This context is often absent when volunteers, not facing a decision, report preferences.

Hindsight bias, cognitive dissonance, and regret can reduce the validity of surveys of preferences in patients who are living with the consequences of a prior decision. Indeed, a systematic review of patient preference literature for the antithrombotic guidelines of the American College of Chest Physicians found only heterogeneous and low-confidence evidence.<sup>4</sup> Direct patient consultation requires decisions about who should be invited (eg, general public, those with the disease or their caregivers, or those facing or who have recently faced the decision of interest), how they would provide input (eg, members of the panel, deliberative democracy), and how to balance their perspectives with those of other panelists. Lack of time, resources, and expertise may hinder incorporation of patient preferences or only produce tokenistic patient involvement, false inclusion, and devalued input.<sup>5</sup>

These challenges could be considered opportunities to develop new and better methods. This optimism is somewhat tempered by the stubbornly poor quality of contemporary guidelines. Getting the evidence right—the right options, outcomes, and outcome data—is an obligatory prerequisite for considering informed patient preferences. For instance, in a survey of more than 2000 patients with diabetes living in Min-

nesota, 1 in 4 respondents considered hemoglobin A<sub>1c</sub>, a measure of glycemic control, to be as important as death or major morbidity.<sup>6</sup> For decades, experts, diabetes organizations, and industry have indoctrinated patients and physicians to believe that hemoglobin A<sub>1c</sub> captures the beneficial effects of diabetes care, a view not supported by large randomized trials. If panels were to con-

sider the preferences from these patients, in this context of inaccurate information, guidelines would probably look just like the ones produced by similarly misguided diabetes experts.

This example illustrates a key insight: the challenges intrinsic to incorporating patient preferences are the same as those involved in incorporating expert views into guidelines. These include advocacy and activism of a particular position; lack of appreciation for evidence-based medicine and its methods for the selection, appraisal, summary, and presentation of the evidence; complicated power, language, goal,<sup>7</sup> and experience differences across panelists; and lack of respect for the rigorous methods of guideline formulation.

## Moving Forward

Guideline panels should perhaps comprise representatives of its target users: frontline patients and clinicians. These user panels could define the issue about which guidance should be provided, iteratively improving on it through consultation with expert clinicians and patients, and invite methodologists to summarize and present the pertinent evidence. Clinical experts could then provide testimony about caveats in the interpretation of this evidence and its application to specific patients and contexts, and about best practices when research evidence is of limited value or scarce. The panel could also commission and receive reports of the existing evidence about pertinent patient preferences and seek testimony from individuals who are experts in patient preferences, patients, and caregivers. The panel should have no financial, intellectual, or personal ties with parties interested in a particular outcome of their deliberation because these relationships offer an alternative explanation for their recommendations and thus, reduce users' trust in their work.

Patient input should drive consideration of the full range of outcomes patients experience and consider critical in deciding what to do, rather than the limited set of outcomes researchers often chose for their studies. For each question, patient input is key in determining the relative importance of these outcomes. For example, treatment burden may not be a critical outcome in the initial approach to a young person with a lethal cancer in a curable stage—survival is. Whereas, treatment burden, quality of life, and role function are critical outcomes in the management of mild diabetes in a patient who is frail and elderly—survival may not be.

Furthermore, panels should avoid making a strong recommendation when the best course of action heavily depends on the patient's context, goals, values, and preferences.<sup>8</sup> Strong recommendations translate into clinical pathways and quality-of-

care targets, and as a result, exclude consideration of the preferences of individual patients. Rather, when patient preferences are important, guideline panels should indicate so and produce a conditional or weak recommendation, a suggestion. The conditional recommendations should explicitly describe how patient preferences and context may affect the choice between the relevant options. Guidelines could present the features of the options in ways that support shared decision making. Decision aids linked to the guideline, for instance, could support the construction of informed preferences in patients who face this dilemma with their clinician.

## Conclusion

Guideline panelists must recognize, with humility, the challenges they face in working often without access to informed patient preferences and acknowledge that their recommendations should rarely assume uniform patient values and contexts in favor of a particular course of action. Guideline panels, therefore, should rarely formulate strong recommendations. Panels should become much more comfortable with ambiguity, both in the tradeoffs involved and in the recommendations given, and explicitly report how patient preferences and context were considered in formulating the panels' recommendations. Clinicians need guidance and clear guidance helps and supports efficient practices. Yet, panels must be wise in recognizing when this expediency is appropriate for patient care and when it hinders patient-centered care. Clinicians should remember that taking care of patients is supposed to be difficult. Although guidelines may simplify this task, when patient preferences and context matter, guidelines must not replace clinicians' compassionate and mindful engagement of the patient in making decisions together. This is the optimal practice of evidence-based medicine.

## ARTICLE INFORMATION

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