When guidelines recommend shared decision-making

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VIEWPOINT

When Guidelines Recommend Shared Decision-making

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Author Audio Interview

Clinicians and patients may develop care plans from clinical practice guidelines. To be trustworthy, guidelines should result from a rigorous, inclusive, and transparent process, informed by the best available research evidence and safeguarded against biases and conflicts of interest.[1] Their guidance should be clear, specific, graded by likelihood of benefit and harm, and actionable. Guidelines are increasingly recommending shared decision-making (SDM),[2] an approach in which patients and clinicians work together to develop a shared appreciation of the patient's situation and decide how to respond well to it.[3] The increasing recommendation of SDM in guidelines is problematic insofar as the extent to which the guideline recommendations are reliable, useful, usable, and desirable remains unclear.

For clinicians and patients seeking clear and direct guidance—ie, strong recommendations that "just tell me what to do"—a recommendation that advises further discussion between patients and clinicians may not seem particularly useful. A recommendation for SDM, however, signals the need for clinicians to work collaboratively with patients to understand what aspect of their clinical problem or situation demands action and to uncover what action that situation demands. A strong recommendation for a specific action, often turned into a measure of the quality of care or a target for a pay-for-performance scheme, can inhibit a patient-centered approach to care. Therefore, a recommendation for SDM can create the opportunity for clinicians to notice and respond to a patient's situation, the complexity of which demands judicious co-creation of a plan of care.

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Strong recommendations should indicate high confidence that almost all patients with a particular problem will benefit from following their guidance.[4] Yet strong recommendations may be overused. For instance, the American College of Cardiology/American Heart Association 2017 Guideline for the Prevention, Detection, Evaluation, and Management of High Blood Pressure in Adults strongly recommends that high-risk adults should be treated to a blood pressure target of less than 130/80 mm Hg. Practically, this requires many patients to use more than 2 antihypertensive medications, monitor their blood pressure at home, complete frequent blood work to survey for electrolyte or renal function abnormalities, and attend regular clinic appointments. When the target population for this recommendation is older and increasingly challenged by having multiple chronic conditions and other issues, for example difficulties with financial resources and living arrangements, these strong recommendations may be misguided. The cumulative multidimensional complexity and the overwhelming burden of treatment that affects patients living with chronic multimorbidity make such strong recommendations and invariable standards impractical, if not potentially harmful.

Yet guideline panels frequently insist on formulating unjustifiably strong recommendations, perhaps motivated by the need to offer definitive guidance, reduce practice variation, demonstrate the value of the organizations producing the guidelines, or guarantee outcomes given health care investments (ie, to improve "value"). These recommendations, however, may paradoxically fail to improve the quality of care by reducing its patient-centeredness, increasing waste (through the inability to implement the recommendation with high fidelity), and promoting harm (through drug-drug or drug-disease interactions). A better approach would guide clinicians and their complex patients through the development of a common understanding of the nature, magnitude, and relevance of the cardiovascular risk and through the joint discovery of a way to address this risk that is sensible and feasible given the particular situation of each patient. To this end, clinicians may find a conditional recommendation that invites the use of SDM more helpful.

A conditional recommendation indicates that the best action may differ from patient to patient (it depends on each patient's circumstances, values, preferences, or goals), such that alternative approaches may also be reasonable.[4] Such a guidance calls for patients and clinicians to collaborate on determining how to proceed, which may be implied or explicitly recommended. Yet to the extent that clinicians and patients lack the opportunity, time, skills, and experience to collaborate, recommendations to incorporate SDM in formulating the clinical care plan may not translate into successful SDM in practice (as has been documented for lung cancer screening with low-dose computed tomography[5]). The work of SDM is not easy. Patients and clinicians must arrive at a clear and useful understanding of the patient's situation and discover, through conversation, which of the evidence-based options makes sufficient intellectual, practical, and emotional sense as a way to advance that situation. Offering evidence summaries and easy-to-use SDM

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tools along with recommendations to support the work of SDM may be helpful, but few guideline producers do so routinely.[2,6]

Guideline panels can also support SDM by identifying options that should not be considered because the risk of adverse effects exceeds any potential benefit for almost all patients. Guideline panelists, however, may prefer to avoid the consequences of recommending against a test or intervention for a given indication because doing so may result in payers denying coverage for similar indications not considered within the guideline. They may also have a vested interest in a particular diagnostic and therapeutic approach. Also, it may be difficult for experts who have recommended a course of action to reverse course, particularly when new evidence finds that this course of action leads to a smaller-than-expected benefit or a larger-than-expected harm. Panelists—either for legitimate reasons (eg, concerns about the trustworthiness of the evidence to determine the balance of potential benefits and burdens and harms across alternatives in particular patient subgroups; closeness of that balance; and direct and opportunity costs associated with alternative options) or to defend professional or financial positions—may insist on keeping an option "on the table" to give "choice" to patients and clinicians.

Perhaps these reasons contribute to guideline recommendations for SDM for breast cancer screening in average-risk women younger than 50 years,[7] coronary revascularization to alleviate stable angina,[8] levothyroxine to improve quality of life in persons with subclinical hypothyroidism,[9] and achieving near-normoglycemia to prevent complications in patients with type 2 diabetes.[10] In these instances, a recommendation for SDM may mislead users, instead of guiding them, by including options that are unlikely to yield benefit that patients will value. To avoid being misled, the user needs a clear presentation of the evidence and explicit disclosure of panel members' rationale for including low-value options. A review of prior guidelines (ie, to see if the recommendation went from favorable to SDM) or of guidelines produced by other expert groups, ideally with different interests, may also be informative, but few users will have the time or skills to conduct such critical appraisals.

By recommending SDM, experts recognize the critical role that factors other than research evidence have in forming plans of care, including the experience and expertise of patients, their priorities, and the particulars of their situation, such as comorbidities, existing burdens of illness and treatment, social support, and personal capacity to safely enact the care plan. The recommendation for SDM also may signal, with uncommon humility, that important guidance can come from patients, and that equity in the therapeutic decision-making process matters. That legitimate recommendations for SDM, however, increasingly coexist with virtue signaling, misuse, and abuse of SDM recommendations calls for the development of rigorous methods to develop this type of recommendation. A recommendation for SDM is a recommendation for a method to co-create a course of action with the patient. Therefore, a well-developed recommendation for SDM must consider known barriers and costs of implementing SDM, such as the availability of encounter time, skills, and tools. A method to help guideline panels understand when it is most pertinent and useful to recommend SDM should then be applied in a systematic, transparent, and deliberate fashion. Simply inserting SDM recommendations into guidelines undermines the credibility and usefulness of these recommendations and, to a certain degree, reduces the value of SDM in patient care.

ARTICLE INFORMATION

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Conflict of Interest Disclosures: Dr Montori reported serving as chair of the board of The Patient Revolution, a nonprofit organization focused on advancing careful and kind care for all (this organization holds intellectual property in shared decision-making but does not derive profit from it); contributing to the GRADE approach to guidelines and to the Evidence Ecosystem but that he is not active in these groups; and leading the Knowledge and Evaluation Research Unit which, among other projects, designs, implements, and evaluates shared decision-making interventions that, when they prove valuable, become available in the public domain. No other authors reported disclosures.

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