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The ethical imperative for shared decision-making

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Abstract

The promotion of shared decision-making is a central policy initiative in the Patient Protection and Affordable Care Act and a key component of person-centered medicine. Yet, as interest increases, disturbing distortions of shared decision-making have occurred. Fueled by a desire to reduce healthcare costs, reduce litigation and improve cost-effectiveness, the underlying rationale for shared decision-making risks being overshadowed. Some portray shared decision-making as a method to bend the cost curve, but opponents claim it is a ploy to ration care to patients [1]. Both these positions misrepresent the underpinning principles.

The imperative for shared decision-making rests on the principles of good clinical practice, respecting patients' right to know that their informed preferences should be the basis for professional actions. Technologic advances have led to the proliferation of multiple treatment options while evidence-based medicine has contributed to our understanding that many therapies have marginal benefits. Shared decision-making aims to make the trade-offs between harms and benefits evident to patients rather than ration care. Overutilization arguably arises out of undue corporate influence on the promotion of marginally efficacious therapies with distorted claims of benefit. Other methods should be used to tackle these wider challenges, while the practice of shared decision-making would help medical professionals re-align themselves with patients' informed preferences and, in so doing, place patients, not making or saving money, at the center of care.

Keywords

Controversy, ethics, healthcare reform, individual patient, patient involvement, patient preference, person-centered medicine, shared decision-making

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Introduction

The promotion of shared decision-making (SDM) is a central policy initiative in the Patient Protection and Affordable Care Act of the US Federal Government [2]. Shared decision-making came about to counter the concern that professionals might over-reach their roles as agents: it respects self-determination, the rights of individuals to make their own decisions. Yet as interest has surged, some disturbing distortions of shared decision-making have occurred. Some advocates portray shared decision-making as a method to bend the cost curve. Opponents claim it is a ploy to deny care to patients [1]. Both positions misrepresent the underpinning principles. To argue, as some now do, that shared decision-making erodes individual rights is incompatible with its origins and principles.

Shared decision-making has emerged out of a long-established movement to respect individual patients. It

stresses an approach to practice where clinicians and patients make decisions together using the best available evidence. The patient receives information about the available screening and treatment options and their relevant differences, including the associated benefits and harms. The clinicians and patient then consider these options in light of the patient's circumstances, goals and preferences. Working together, they then select the best course of action.

Shared decision-making has achieved prominence over the last decade, to support individual patients to arrive at informed preferences [3] while preserving the stewardship role of the profession. Our aim is to counter the charge that shared decision-making is another name for rationing: the accusation is so far removed from the underpinning principles and, despite it having no substance, there is a danger that it could be amplified and used to de-rail one of the most important recent developments in medicine. Multiple arguments can be made in support of shared

decision-making. The Institute of Medicine defined patient-centered care as a core component of a high quality healthcare system. Wennberg has argued that shared decision-making could correct some of the supply-induced demand that explains small-area practice variation [4]. Evidence-based medicine now requires shared decision-making to ensure that the application of research evidence fits the patient's values and circumstances. But these arguments appeared after the foundational one.

Misrepresentation of the identity of SDM

Shared decision-making has recently been presented as a servant of healthcare efficiency. Fueled by a widespread and urgent desire to reduce healthcare costs, reduce litigation and improve the cost-effectiveness of care, the underlying rationale for shared decision-making risks being overshadowed. There is a risk that its identity as a respectful, empathic and patient-focused approach may become less visible to policymakers, professionals and the populace, much in the same way that the end-of-life discussions became derailed by accusations of "death panels" during the healthcare reform debate in the United States.

The recent polemical attacks on the shared decision-making initiatives included in the Affordable Care Act [2], although seemingly alarmist [1], do pick up on a real and seductive shift in how SDM has come to be justified and even marketed in policy and practice circles. Some advocates have justified SDM as a strategy to improve the value of care, believing that a more cost-effective healthcare system meets an obligation of medicine to distribute the goods of society more fairly. For others, promoting SDM on the promise of reducing costs indicates that the original ethical rationale has been lost altogether. In sum, the efficiency argument denigrates the intrinsic respect for individual patients and uses them as "means", rather than as "ends in themselves". For political advantage, politically right-wing groups have equated SDM as 'rationing'; indeed, as "exhibit A" in their case against so-called "Obamacare". This extreme portrayal, albeit incorrect, may find support among health professionals and patients who may come to regard SDM as no more than a covert strategy to shift the responsibility for making difficult decisions away from health professionals and onto sick and vulnerable patients.

Reclaiming the ethical imperative of SDM

Although it was perhaps predictable that shared decision-making would be painted into this 'rationing' corner, such portrayals need to be unequivocally quashed. Whether SDM can systematically provide efficiency gains is, in fact, unclear. Randomized trials of SDM tools fail to show a consistent effect on costs. Despite this, a Lewin Group

analysis that the Commonwealth Fund commissioned and disseminated [5] and which undoubtedly influenced the healthcare reform debate, suggested savings in the order of billions of dollars. Certainly, randomized trials do show that use of SDM tools often reduce the uptake of some elective procedures [6], but whether these can be translated into cost-reductions in routine care has not been established. Even if we were to accept the tantalizing promise of cost-reduction - because, more often than not, informed patients make more conservative choices - justifying shared decision-making in this way, is unnecessary, divisive and counterproductive. Reducing healthcare utilization is not, and *ought not to be*, a sufficient rationale: any reduction in utilization should be viewed as a *consequence* of achieving shared decision-making - not the imperative itself.

The imperative for SDM must rest on the principles of good clinical practice, respecting patients' right to know: that their informed preferences should be the basis for professional actions. Evidence-based medicine has contributed to our understanding that many therapies have marginal benefits. Shared decision-making aims primarily to make the inevitable trade-offs between harms and benefits evident to patients rather than to impose restrictions on the distribution of resources. Over-utilization arguably arises out of undue corporate influence on the profession, supplying expensive and marginally efficacious therapies with distorted claims of benefit. Rather than using SDM to curb these trends, we should tackle the corruption of healthcare head on. To that end, the practice of SDM helps medical professionals re-align themselves with patients' informed preferences and, in so doing, place patients, not making or saving money, at the center of care.

Conclusion

The benefits of shared decision-making to Society will accrue by the accumulated trust that the profession engenders through daily interactions that demonstrate unequivocal fidelity to the dignity and values of informed patients. We do not advocate the abrogation of professional roles: it will remain necessary for physicians to disagree, even argue, respectfully, with patients, provided patients views are taken seriously. But, as clinicians invite and welcome patient involvement, it is also essential to share in the work of making difficult decisions, not to abandon patients at the fork in the road. This give-and-take scenario, sensitive to individual patient needs, calls for skillful and empathic clinicians. Staking a claim to this ethical imperative, the high moral ground, is the only viable professional strategy in a politically charged and polarized healthcare environment. We cannot and must not allow shared decision-making to be portrayed as rationing, when the true aim is to place the patient at the heart of every decision and at the very center of care itself.

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