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Patient-Centered Care and Preference-Sensitive Decision Making

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Over the past 20 years or so, there has been a rise of 2 parallel movements, one toward the explicit use of clinical trial data to guide clinical practice (evidence-based medicine) and the other toward patient empowerment through explicit informed consent, shared decision making, and patient-centered care. Both components have been integrated into models of quality clinical care, but sometimes there are conflicts between evidence- and guideline-driven care and patient-centered care.

In most situations, patients value prevention of disease and disability and increased length of life, so patient-centered care and application of evidence-based medicine present no conflict. Despite general preferences for health over disease, however, individuals make trade-offs every day by working in dangerous or stressful jobs, driving too fast, eating too much, smoking, and taking dozens of other risks, large and small. These everyday compromises are also seen in clinical practice. Patients may choose a less expensive medication even if that medication is not quite as effective. They may choose a more limited operation for cancer, explicitly trading off survival for quality of life. They may decline chemotherapy because they feel the adverse effects are not worth the small chance of success.

When the choices are about technologies at the end of life, it has now been accepted in the United States and much of the world that patients who value quality of life over length of life are making a reasonable and justifiable decision. Shared decision making is also a common feature of more straightforward medical decisions, but because the immediate stakes are lower, the quality of these negotiations has been subject to less scrutiny. Even the everyday decisions about which blood pressure medicine to choose, how to manage diabetes, when to start dialysis, and what is needed to prevent or treat heart disease present these compromises between increased survival and reduced complication and other goals patients may have including cost, time, and control over their lives.[1]

Guideline-Directed Care and Pay for Performance

Pay-for-performance programs have highlighted long-standing but largely unarticulated differences in handling conflicts between patients' goals and preferences and clinical recommendations. Pay for performance also risks increasing the stakes in conflict between clinicians and patients, pushing clinicians toward a "take it or leave it" stance with "nonadherent" patients or dismissing them from their practices lest they decrease quality measures. The challenges in implementation of pay for performance, including failure to adequately account for patients' baseline health status,[2] have been debated elsewhere[3,4]; here the focus is on potential conflicts between performance measures and patient-centered care. Pay-for-performance standards rarely account for patients' preferences regarding management intensity, adverse effects, and overall self-management burden.[5]

When Patient-Centered Care Conflicts With Quality Standards

Patients' preferences increasingly factor into decisions between surgery, chemotherapy, and radiation for various cancers. On the other hand, there has been a countervailing push toward stricter standards in the management of chronic diseases, because of increasing evidence of benefit. But such recommendations also need to account for heterogeneity of benefit: treating a 30-year-old diabetic patient to reach a goal hemoglobin A_{1C} level of less than 7% probably provides substantial benefit realized over decades of reduced complications and offers a reasonable risk profile, whereas aggressively treating an 80-year-old diabetic patient provides relatively little benefit and substantial risk of harm due to adverse effects and complications of therapy.[6]

Physician recommendations should always include the rationale, expected outcome, and alternatives. If a patient refuses care that has a high likelihood of changing his or her personal risk for mortality or serious complications—not just average risk across a population—this decision needs to be explored. What are the patient's goals in life and health?

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Does the patient understand the trade-off he or she is making? Is the decision due to cost, adverse effects, experience of a friend or family member? Is the patient depressed and therefore not making decisions consistent with his or her long-term values and interests? Sometimes it may be appropriate to try persuading a reluctant patient or to address obstacles such as cost or adverse effects; at other times the patient's reason may be compelling or unlikely to change.

Accepting the Patient's Decision

Patients may have many priorities in addition to improving their health, such as making a living, caring for family, and engaging in leisure activities, and these life activities frequently involve trade-offs between health, comfort, relationships, and financial well-being. Patient-centered care requires that physicians try to understand patient goals and priorities, incorporate clinical and patient priorities, and address obstacles to care. Clinical care needs to promote patients' health priorities in light of the rest of their lives. Further, professional ethics unequivocally supports competent adult patients' right to accept or decline any medical intervention, even at risk of death.

When patients decline recommended treatments, research suggests patients and physicians often differ in their beliefs about disease,[7] goals of treatment,[8] and desire for control.[9] Cost, forgetfulness, adverse effects, or comorbidities, as well as unstated disagreement, influence patient behavior. Patients also bring their own agenda to a visit; treatment of pain, mental illness, or improved function can compete with the agenda of guideline-directed care of chronic diseases. It is incumbent on clinicians to be sure that patients understand the short- and long-term consequences of their choices and then to negotiate the best compromise to optimize outcomes consistent with the patient's goals.

Physician Payment Formulas Can Hinder Individualized Care

Both fee-for-service payment formulas and pay-for-performance programs may penalize clinicians for providing patient-centered care. If patients decline additional medication because of adverse effects or treatment burden and their blood pressure is near but not at optimal targets, physicians in pay for performance may be penalized for failing to meet treatment targets. Dialysis centers are currently paid for each treatment session, so a center that accommodates a different schedule for one patient would only be paid for the number of sessions completed under current fee-for-service arrangements. In the future under pay for performance, nephrologists could face penalties for failing to meet quality standards for dialysis "dose" even if fewer doses could be justified on the basis of residual renal function or patient treatment goals.

Since clinicians may have relatively small sample sizes on which performance is measured,[10] even 1 patient whose shared decision making results in "poor care" can have a marked influence on a physician's or facility's overall quality ratings. Physicians might then refuse to accept some patients or refuse to tailor care to patients' needs and preferences.

Recommendations

Every patient should be offered sound advice based on the best available evidence. Physician recommendations should always include the expected outcome; alternatives, including doing nothing; and expected outcomes for those alternatives. Patient-centered care can improve trust, communication, and adherence to therapy, thereby improving quality benchmarks and clinical outcomes. But competent adult patients also have the right to decline to follow that advice and to negotiate with physicians a plan of care that better meets their own goals. To make care patient-centered and consent truly informed, and to build longitudinal relationships of trust between patients and the physicians who care for them, patients' goals and preferences need to be incorporated into treatment plans, and a patient's firm, unambiguous, reasoned "no thanks" also needs to be honored.

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