Aortic valve replacement surgery is the only available treatment option able to improve survival in patients with symptomatic and severe aortic valve stenosis. Without surgical intervention, patients with symptomatic dyspnea and severe aortic valve stenosis have a median survival less than 2 years. In an ideal, patient-centered healthcare system, the decision whether to undergo risky yet potentially life-prolonging surgery should not only reflect judicious application of the evidence of safety and efficacy of the surgery, but it also should be consistent with the patient’s clinical and personal contexts, and their goals, values, and preferences for life and healthcare.

The shared decision-making process can only take place when clinicians and patients are able and willing to engage in the process and respect its outcome. To be able, clinicians and patients may benefit from tools that estimate and effectively communicate the potential benefits and risks of treatment options. In the case of aortic valve replacement, the individualized risk of death without surgery and perioperative risk of death and morbidity are examples of information that need to be shared with the patient. To be willing, at a minimum patients must be activated to express their goals and preferences and clinicians must listen and respect them.

The state of the art in risk communication uses natural frequencies and graphical displays that show the population and how many will be affected and, importantly, not affected by the outcome. Such displays make explicit the denominator, and limit the impact of framing that could occur when the communication focuses only on the numerator. In communicating risk to an individual patient, as compared to a population, it is important to realize that the patient will be either alive or dead in 2 years, rather than having a 50% chance of being dead. It is therefore helpful to talk about “individualized risk estimation” and absolute risk reduction, rather than about “your risk” and relative risk reduction. The clinician would use a pictograph (Figure) and the following phrases when communicating risk to the patient: “Of 100 people like you, 50 will die and 50 will not in the next 2 years without surgery; if all 100 people like you decide to have surgery, then 20 will die and 80 will not die in the next 2 years.” This avoids both the problem of “your risk of dying is 50%” and of framing (by avoiding “your probability of surviving is 80%”). Furthermore, a pictograph conveying the risks before and after intervention helps users avoid the temptation of promoting uptake of the treatment being offered by using relative rather than absolute risk reduction expressions.

For such risk communication tools to exist, clinicians need to have access to risk calculators at the point of care. Bach et al go to the extent of calling this estimated risk “objective” and the clinical impression of the clinicians “subjective.” The lack of role modeling and training in using—and lack of ready access to—existing risk calculators at the point of care leaves clinicians using their uninformed gist to shape risk and benefits regarding important decisions. Clinicians may shape such decisions by not presenting the options they consider inferior to the patient or by presenting those options in a negative light only to dismiss them without further consideration. Going back to Bach et al, it is highly unlikely that patients who reportedly refused the aortic valve replacement received an accurate presentation of risk in ways that they could understand and use to make an informed choice. The
same could be said of the clinicians who considered the surgical risk prohibitively high. In other words, in usual practice, clinicians and patients are making an important decision in the dark; at best, clinicians are making decisions unilaterally. This is a major gap between usual practice and ideal patient-centered care.

Although not every patient is ready to participate in shared decision making, most want to have information. Decision aids need to transfer knowledge not only about risk but also about the experience and cost of treatment. In this case, how does it feel to go through the surgery, how long does the recovery period take, what would my quality of life be after the surgery, and what may be my out-of-pocket costs. A decision aid that promotes rich conversations across all these dimensions cannot usually be created ad hoc within the time constraints of a typical clinical encounter and the skill constraints of the typical clinician. Because most patients want to receive information, and because the information needs to be tailored and designed to promote informed deliberations, having well-designed and tested decision aids embedded in the clinical workflow is critical to promote shared decision making and improve quality of care.

Although some patients may not be interested in participating in the deliberation and shared decision making processes, effective decision aids should enable more patients to do so effectively. To this extent, the decision to refer patients for surgery should result from a careful and explicit consideration of the patient’s risks, values and preferences, and context. The latter issues are not usually documented in medical records and thus remain unavailable to health services researchers using these as data sources. For example, Bach et al showed that 1 in 3 patients with symptomatic severe aortic stenosis did not undergo aortic valve replacement surgery—this may represent underuse of a life-saving treatment or appropriate use if patients made an informed decision to decline surgery. Patients may prefer to avoid surgery because of a prior experience or because they fear a specific outcome, even if unlikely (eg, postoperative delirium, dementia, or loss of independence), such that they rather be dead than demented or dependent. These aspects, which may arise in a careful deliberation with the patient, offer the clinician an opportunity to moderate expectations and fears and offer support and services that may address these concerns.

Although some judge that such patient-centered approaches are opposite to the practice of evidence-based medicine, it is important to note that the latest writings contradict these judgments. The philosophy of evidence-based medicine requires that clinicians incorporate not only the best available evidence but also the patient’s values, preferences, and circumstances in the decision making process. Thus, tailoring of care not only to the patient’s risk but to the patient’s circumstances and preferences through careful shared deliberation represents the ideal realization in practice of the philosophy of evidence-based medicine.

For patients and clinicians to engage in shared decision making they should be free of pressures to act in favor of one or another alternative course of action. Clinical practice guidelines that do not take into account the role of patient preferences and misplaced financial incentives may put pressure on clinicians to favor a particular course of action. That the clinician interacting with the patient only has that patient’s best interest in mind is key for the environment of trust and partnership necessary for shared decision making. Thus, we must consider the effect on patient’s trust that could result from funding of research and of risk communication tools by for-profit pharmaceutical or medical device companies that stand to gain from the patient choosing a particular option. Any perception of financial gain may undermine trust and sabotage shared decision making and, by extension, evidence-based healthcare.

Failure to practice evidence-based medicine appears as a reasonable explanation for the observed rate of use of aortic valve replacement surgery shown by Bach et al. This observation has been characterized as a risk-treatment paradox by which patients at apparent highest risk of adverse outcomes and perhaps most likely to benefit from treatment are perceived as too risky and not offered the beneficial treatment. Efforts to improve apparent underuse and quality of care should not seek to simply increase the rate of aortic valve replacement surgery among patients with an indication for it; rather, the quality-of-care goals should be (1) to accurately identify all patients who may benefit from aortic valve replacement surgery and (2) to ensure that 100% of these patients receive comparative information about the risks and benefits of surgery and of no surgery and engage in a shared decision making process to decide whether to undergo or forego surgery. Such meaningful conversations should achieve a rate of aortic valve surgery that reflects the clinical and personal contexts of the patient as well as the patients’ goals, values, and preferences.
Disclosures

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References


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