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Better Conversations for Better Informed Consent

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Abstract

For more than 60 years surgeons have used bioethical strategies to promote patient self-determination, collectively described as informed consent. Yet the core framework—understanding, risks, benefits, and alternatives—fails to support patients in deliberation about treatment. We find that surgeons translate this framework into an overly complicated technical explanation of disease and treatment, and an overly simplified narrative that surgery will "fix" the problem. They omit critical information about the goals and downsides of surgery and present untenable options as a matter of patient choice. We propose a novel framework called "Better Conversations." Herein, surgeons provide context about clinical norms, establish the goals of surgery, and comprehensively delineate the downsides of surgery to generate a deliberative space for patients to consider whether surgery is right for them. This paradigm shift meets the standards for informed consent, supports deliberation, and allows patients to anticipate and prepare for the experience of treatment.

Better Conversations for Better Informed Consent

In the mid-twentieth century, bioethicists and policy makers developed strategies to promote patient self-determination now collectively described as informed consent. Standards for informed consent require that patients understand their disease and the proffered treatment, its risks, benefits, and alternatives. Surgeons can name these requirements with fluidity

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while non-surgeons follow the same standards for interventions outside the operating room. Despite refinements over time, [1; 2] this core framework has endured along with an unyielding requirement to “get consent” before proceeding.

Still, a half-century later, patients and families struggle to recall what their surgeon told them,[3; 4] are overwhelmed by the experience of surgery, and endorse regret postoperatively.[5; 6] Surgeons similarly lament a process that leaves patients less than prepared,[7] while policymakers and researchers worry these conversations lead to over-treatment.[8; 9] Improvements have targeted implementation, aiming to elevate patient engagement with stronger information transfer[10; 11; 12] and promotion of shared decision-making,[13] but the process remains unsatisfactory. These efforts presume the problem is surgeon performance without considering whether the underlying core framework—understanding, risks, benefits, and alternatives—might be flawed.

We submit the problem is rooted in the core framework, not surgeon performance. To interrogate how the framework and associated theories of autonomy, legal requirements, and enthusiasm for shared decision-making are translated clinically, we examined more than 500-recorded conversations[14; 15; 16] between adult patients and surgeons throughout the United States and Canada discussing major surgery including vascular, cardiac, oncologic, gynecologic, urologic, and neurosurgical procedures. Although these conversations consistently reflect the framework for informed consent and elements of shared decision-making, they are encumbered by technical information about the patient’s disease and treatment, fail to mention the goal(s) of surgery, disclose risk but omit much of the downsides of surgery, and present untenable options as a matter of patient choice. A new core framework is needed to better support patients and families as they consider whether intervention is right for them.

Patient understanding of disease and treatment

Presently, surgeons start with a lengthy explanation of the patient’s disease and the operation to “fix it.” They provide extensive technical details, draw anatomical pictures, and navigate radiographs of tumors, aneurysms, or other pathology. The conversation continues with the specifics of surgical intervention: intricate descriptions of graft placement, suture technique, and reconfiguration of native anatomy.[17] Surgeons act as though patient understanding requires comprehension of their clinical reasoning through presentation of medical facts, spending more than half of their discussion about surgery in a mini-medical school lecture.[18] These patterns are consistent across consultations, but the utility of this technical information for patients and families is limited.[19] Yet understanding anatomy, physiology, and surgical technique is not necessary for patients to determine whether surgery is the right treatment, any more than understanding auto mechanics is requisite for car owners to determine whether their transmission should be replaced.

Benefits and risks

Universally, surgeons explain how surgery removes, repairs, replaces or, simply fixes the identified problem.[20] This is often the only benefit mentioned as the core framework lacks clarity about what constitutes benefit and there is an unstated presumption that intervention

will return the patient to "normal" when the problem is fixed.[21] When benefits are conflated with an intermediate outcome—the technical aim of surgery—surgeons don't discuss what surgery can and cannot do to improve the patient's life. This narrative both neglects the patient's goal for surgery and can lead to misunderstanding. Patients will attach their own (often-implausible) goals to the operation, assuming that what is bothering them will be improved once the problem is fixed.[22]

Our data show that surgeons routinely disclose risk but miss important information about other downsides of surgery. Surgeons focus on reportable complications, but the experience of surgery includes bad or unpleasant things that happen to patients simply because they have surgery—an incision, effort and time to recover, a scar, and for many a permanent functional change.[23] Furthermore, there are bad things that might happen that don't rise to the level of "risk disclosure" because they aren't professionally characterized as complications, e.g., urinary retention, long-term change in bowel habits, or failure to achieve the goal of surgery due to disease progression. Surgeons satisfy the legal requirements for consent by listing complications but their omissions blindside patients who experience surgery.[24; 25]

Alternatives and choices

Notions of shared decision-making and patient choice play out in ways that are unlikely to support self-determination. Possibly out of respect for patient autonomy or an oversimplification of the requirements for shared decision-making, surgeons feign neutrality about the patient's choice or present ineffectual options, even when there are clear advantages or disadvantages to surgery.[26] When they are reluctant to operate, surgeons note they can do the operation then surreptitiously push patients towards non-operative treatment, without explicitly voicing their concern that surgery is unlikely to help the patient.[27]

Reconsidering the core framework: Better conversations

To heed requirements for informed consent and support shared decision-making, surgeons translate the core framework into an overly complicated technical understanding of the patient's disease and treatment, and an overly simplified narrative that surgery will fix the patient's problem. They omit critical information about the goals and downsides of surgery and have lost how to actualize the patient's role in medical decisions, while concealing clinical norms and professional expertise. A better approach starts with surgeons providing their initial inclination about surgery, followed by a clear description of what surgery might accomplish for the patient. Presenting the downsides of surgery in close juxtaposition to its goals creates a deliberative space for patients to consider whether surgery is worth it for them. (Figure)

Preamble

Patients see a surgeon because someone, another clinician, or the patient, has identified a problem that might be treated with surgery. Surgeons often review imaging in advance, and then ask patients about symptoms, their overall health, and conduct a physical exam. Next, they transition to a discussion about what is right for this patient.

Step 1: Show your cards.

Up front, surgeons can state their initial inclination about surgery expressed as a professional norm “We usually do surgery for this” or their professional opinion “I think surgery can help you.”[28] With similar candor about their starting point, surgeons can express hesitation to pursue surgery “I am worried surgery is not a good idea” or emphasize that this is a moment to choose between two reasonable treatment options “I’m on the fence, there are two ways to treat this.” Importantly, this is not a recommendation; it is simply a starting point, an opportunity for transparency so patients who are scared and sick don’t need to guess what the surgeon is thinking. It also removes the problem of presenting an unreasonable option, a non-choice choice, with the same status as usual care.

Step 2: Clearly describe the goals of surgery.

Surgery can accomplish four goals: help patients live longer, feel better (improve function), prevent disability (preserve function), or make a diagnosis. When the surgeon explicitly states at least one of these goals, they can precisely convey what surgery might accomplish for this patient, rather than describing the benefits of surgery as a designated fix for an identified problem. For example, “The goal of surgery is to help you feel better. Your varicose veins aren’t going to shorten your life, and they won’t lead to amputation.” Naturally, patients generate their own fears about how this problem might affect their life and hopes about how correction of the problem could make them feel or function better. To counteract these forces and ground the reasoning for their assessment, surgeons should explicitly state the goal(s) of surgery and draw clear boundaries around what surgery can and cannot do.

Likewise, this approach applies when surgeons are worried surgery will produce more harm than good. Consider a patient with life-limiting comorbidities and a 6-cm asymptomatic abdominal aortic aneurysm with difficult anatomy. Presently, surgeons note there is an aneurysm, they have an operation to fix it, but it is very risky. Many patients will push to have surgery, anxious about their aneurysm, hoping it can be fixed. This set up makes it difficult for patients to recognize the surgeon’s concern that surgery will result in premature death and the patient’s remaining life is short, so they are unlikely to benefit. If the surgeon starts with an explicit statement that the goal of surgery is “to prolong life” and surgery is unlikely to meet this goal, there will be more clarity about what is at stake.

Step 3: Describe all the downsides of surgery.

After showing their cards and noting the goal(s) of surgery, surgeons can acknowledge that surgery is something to endure, and some may find it unendurable. To help patients deliberate, they need a comprehensive and consolidated approach that captures the downsides of surgery, as they might experience it. The downsides come in three forms: (1) bad things that happen to everyone who has this surgery, (2) bad things that could happen to people who have this surgery and (3) this surgery falls short of accomplishing its goals.[29] Everyone who has surgery will need to go through it; even small incisions hurt, and minor recoveries require time and effort. Major operations hurt more, take 2–3 months for recovery, and can leave the patient with permanent changes, e.g., end ileostomy or insertion of prosthetics (mesh, intramedullary rods). Bad things that could happen

include reportable surgical complications, bumps in the road like urinary retention or post-laparoscopy shoulder pain, major functional or cognitive changes, and wholly unanticipated events. Although many of these events are not reportable, they are things patients need to hear so they can consider and prepare for the experience of surgery. Patients who experience a major unwanted change postoperatively, like chronic loose stools, may believe this is worth a goal like life prolongation, but it is easier to accommodate this outcome when they appreciate the reciprocity between goals and downsides in advance.

Step 4: Deliberate.

Instead of asking patients to reconcile a disarticulated list of risks with assumptions about how the technical repair will achieve their goals, better conversations can help patients consider what they might gain and lose with surgery. To focus patients on the work of deliberation surgeons might ask, “What do you think?” When surgeons have noted an inclination to operate, they might say, “Is it worth it to you?” For settings where there are two reasonable options, the surgeon can coach patients to compare the downsides of each treatment side by side. When the surgeon is reluctant to operate, they might say, “Does this reasoning make sense to you?” Patients can reflect on what they have learned and talk about how they see the tradeoffs between the downsides and the chance to achieve the goals of surgery.

Step 5: Make an agreement and a plan.

Patients who believe the goals of surgery are valuable and the downsides of surgery are tolerable will likely judge surgery to be worth it, even if unwanted outcomes occur. This position helps form an alliance with the surgeon; particularly important for patients with a difficult postoperative course who recall their personal deliberation and note “you told me something like this might happen.” Others will judge the goals of surgery as not valuable to them or the treatment burdens too high. When the surgeon is reluctant to operate, patients might disagree, believing the goals are achievable, or the downsides are not too great. Both circumstances present an opportunity to support patient self-determination with an agreement to disagree, acknowledging uncertainty and variation in judgment about which strategy will make the patient better off.

Changing for the better

When surgery is the agreed upon plan, some patients may want to engage with technical details, and some surgeons may enjoy relaying their technical prowess or feel this information is important to demonstrate expertise. Sharing technical details can satisfy curiosity or further generate rapport through provision of supplemental material, but it is not a requirement for being informed.

Change will take more than our description of a better conversation. It is difficult to undo entrenched clinical practices, particularly those rooted in genuine (albeit flawed) belief that presentation of technical details will support autonomy, is legally required for informed consent, and facilitates shared decision-making. Others will perceive these changes as minor or say, “I already do that,” yet the data do not support this claim. There is also potential for surgeon misunderstanding “show your cards.” This step is designed to promote transparency

but works only when surgeons hold their cards loosely. Overpowering patients could leave them without space to reflect on what they have learned or the ability to discuss their disagreement with the surgeon's views.

Current conversations about surgery fail to support patients, families, and surgeons in deliberation. With better conversations, surgeons provide context about clinical norms, clearly establish the goals of surgery—what surgery can and cannot do—and comprehensively delineate the downsides of surgery as experienced by the patient to generate a deliberative space for patients to consider whether surgery is right for them.

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