American Association for Thoracic Surgery 2016 ethics forum: Preoperative disclosure: In all honesty, my results…

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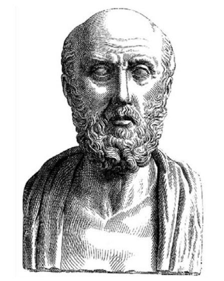

“Life is short, and the Art long; experience fallacious, and judgment difficult.”—Hippocrates

Central Message

Respect for patient autonomy requires having an honest discussion of the risks, benefits, and alternatives to the treatment we propose. Honesty about our personal experience and outcomes is paramount.

You are providing information to a patient during the consent process for an esophagectomy. What is your obligation to recite your personal experience and results with this procedure? What if you perform 60 esophagectomies per year? What if you perform only 5 esophagectomies per year and there is a high-volume center 10 miles away?

Clinical outcomes for hospitals, practices, and individual physicians are increasingly coming under scrutiny. Cardiothoracic surgery has been at the forefront of this with public reporting of hospital and individual surgeon performance data in several states.

Controversy certainly surrounds reporting of performance data, but what about the surgeon’s responsibility to disclose his or her results to patients? Disclosure of personal performance data is really an issue of informed consent, specifically how much information is needed for a truly informed decision.

LEGAL REQUIREMENT

The necessity of even obtaining patient consent is highlighted in *Schloendorff v The Society of the New York Hospital*[1] in the early 1900s, in which a patient consented to an examination under anesthesia. With the patient under anesthesia, the surgeon removed a tumor, a procedure for which she did not consent. In his famous ruling, Justice Benjamin Cardozo states that “every human being…has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient’s consent, commits an assault for which he is liable in damages.”[1] Over the next several decades, consent evolved into informed consent; the key elements in most states are a description of the nature and purpose of the procedure, benefits of the procedure, reasonably known risks, and alternatives. How much and what specific information must be disclosed are not well defined, and the standard of informed consent varies by state. The professional standard, the earliest model, relies on what most physicians would disclose in a similar situation. The reasonable patient standard is based on what a reasonable patient would want to know under similar circumstances. The subjective standard is defined by what a specific patient would want to know on the basis of their individual values and goals. There are obvious shortcomings of each of these standards. Childers and colleagues[2] proposed a balanced model between the reasonable patient and the subjective model. For example, when discussing the risks and benefits of a higher-risk procedure in an older patient whose primary concern is maintaining independence, a surgeon should include a discussion about the need for discharge to a nursing home. This model improves patient autonomy in making informed choices and can enhance the physician–patient relationship without being overly burdensome.

Although a large number of cases surround the legal issues of informed consent, few cases address the legal requirements of disclosing personal performance data and those that do often reach conflicting conclusions. *Whiteside v Lukson*[3] involved a case of a bile duct injury during a surgeon’s first few laparoscopic cholecystectomies. The fact that the surgeon had done only a few of these procedures was not disclosed to the patient. The Court of Appeals of Washington ruled that the surgeon had no duty to disclose his inexperience with the procedure. The Court further warned that broadening disclosure requirements could lead to a slippery slope in which even a physician’s medical school grades or financial situation could be considered material under the reasonable patient standard. In *Johnson v Kokemoor*,[4] the Supreme Court of Wisconsin ruled that a physician did have the duty to disclose individual

TABLE 1. Benefits and risks of disclosure of individual performance data during informed consent

Benefits	Risks
Enhanced patient autonomy	Inaccuracy of data
Improved decision making	Increased anxiety about surgery
Enhanced physician–patient trust	Compromised physician–patient trust

experience. In this case, a surgeon performed a complex aneurysm clipping for which he had little experience, resulting in partial paralysis. The Court ruled that the surgeon should have provided the patient the extent of his experience, compared the mortality and morbidity rates of experienced versus inexperienced surgeons, and offered referral to a more experienced center. They further stated that this ruling was specific to this case in which there is a vast body of literature regarding the impact of experience on outcomes.[4]

ETHICAL OBLIGATION

No clear legal standard addresses the issue of disclosure of personal performance data. Let's now look at the ethics of disclosure of personal performance data. The risks and benefits of disclosure are outlined by Burger and colleagues[5] and are summarized in Table 1.

Benefits of Disclosure

The benefits of disclosure focus on respect for patient autonomy, one of the fundamental principles of bioethics. Respect for autonomy is not only allowing patients to make their own decisions about treatment but also ensuring that they are making truly informed decisions. In many cases, individual surgeon performance data are a factor in the risk of a particular procedure. Using the reasonable patient standard, one can assume that a reasonable patient would want to know this information. Schneider and Epstein[6] explored the question of whether patients want performance data. They surveyed 474 patients who had undergone a coronary artery bypass operation in Pennsylvania. Only 12% of patients knew of the *Consumer Guide*, which reports the risk-adjusted mortality of all cardiac surgeons and hospitals in the state, before their surgery. Less than 2% of patients were aware of their specific surgeon's results and less than 1% said that the surgeon rating had a significant influence on their decision. However, after patients were told of the *Consumer Guide*, 55% were very/somewhat interested in the information and 58% of patients would definitely/probably change surgeons if their surgeon's mortality rates were higher than expected. It is interesting that these numbers aren't higher, and I wonder if they would be if the survey was taken before their operation.

Risks of Disclosure

One of the main risks of disclosure relates to availability and accuracy of individual performance data. Not all surgeons have access to their individual data, especially risk-adjusted data. If a surgeon does have access to their data, what is the reliability of these data? Who is collecting the data is certainly a large factor. The quality of the data abstraction is a critical factor in the accuracy of the data. Although there is a conflict of interest against surgeons collecting their own data, surgeons should have some oversight of the process to ensure that the data collection is accurate. The database that the individual or hospital is using also is a factor. Risk-adjusted comparisons are the gold standard; however, risk-adjusted models are far from perfect. Sample size for less common procedures is limited, and including every factor that might be important is impossible. Many databases include only a fraction of cases. The dataset that a surgeon uses to compare his/her results against is important. Mortality rates in the Society of Thoracic Surgeons (STS) general thoracic database are generally lower than in broader databases. For example, a surgeon with a postoperative esophagectomy mortality rate of 6% compares favorably with national data using the Nationwide Inpatient Sample (reported mortality 6.1%); however, this is approximately twice the mortality rate using the STS database (reported mortality 3.1%).[7] The impact of performance data on junior surgeons also is a consideration because it takes several years to establish enough of a volume for fair comparison. This is also true of uncommon procedures, in which outcomes among small sample sizes are meaningless. Robert Sade[8] summarizes this concept in a case commentary involving informed consent for a percutaneous valve trial: "This complication rate alone says nothing about (the surgeon's) competence…or the benefits of percutaneous valve replacement, so to provide (the patient) with the (surgeon's results) would be misleading at best, and could lead to a poorly informed – and therefore unwarranted – decision…." Although respect for patient autonomy by providing important and accurate information is critical, supplying inaccurate and flawed information is a disservice and potentially harmful to our patients. Although having accurate and relevant information is critical, it is also equally important to be able to convey the information in a way that is clear and understandable to our patients. While this can be challenging, a particular patient's risk is often best explained relative to the average. Asking patients to summarize their understanding of the potential risks is one way of confirming comprehension.

A recent article highlights the inconsistencies seen among different databases. Allen and colleagues[9] compared the results of the American College of Surgeons National Surgical Quality Improvement Program (NSQIP) and the STS databases for general thoracic surgical procedures in a single year at a single institution. A common database