Entering the Era of Shared Decision Making

By Lael Duncan, MD

It is much more important to know what sort of a patient has a disease than what sort of a disease a patient has.

—William Osler

Patient X was transferred to my service just days ago. She was a 78-year-old female with COPD and type 2 diabetes who suffered an acute non-ST elevation MI at an outside facility (name and details have been changed). She underwent cardiac catheterization, was found to have multivessel disease and subsequently received a 5-vessel bypass. Her course was complicated by intraoperative arrest due to ventricular tachycardia, need for reopening of the chest and cardiac massage, and prolonged bypass time. As a result she suffered global cerebral ischemia, a large right parietal CVA and acute renal failure.

Patient X was transferred to a long-term acute care facility for medical management, ventilator weaning and stroke rehabilitation on post-op day 14. She was a widow, and her next of kin, a son, was completely unaware of any wishes or health goals she might have had. Subsequent care was delivered in the usual fashion: when wishes are not known, do everything.

Can’t we as physicians do better than that for our patients, ourselves and our nation’s financial future? I believe so, and the government does too. There are many clauses in the new health care legislation that mandate “shared” or “informed” medical decision making. The premise is that when we make decisions with our patients or their surrogates, rather than for our patients in a vacuum, we achieve more value-driven results.

We make decisions with our patients daily with the goal of providing good, evidence-based care for them. Yet in its pure form, especially in a primary care setting, evidence-based care may not be what is right for your patient. In the words of Dr. S. Pauker, “Evidence-based standardization and patient centeredness have been on collision courses.”

How can two such sound concepts in medicine be seemingly at odds? Witness the mammography controversy, still raging, or the ongoing debate over PSA. A lot of what you get for an answer depends on how you ask the question. Implementing shared decision making into daily practice will undoubtedly bring us closer to patient-centered care but may reveal the inherent weaknesses in the broad applications of standardized guidelines developed from evidence-based care data.

The recent nationwide DECISIONS study gathered generalizable data on how clinical decisions are made, so that the typical American patient experience of making medical decisions could be characterized. The study confirmed that clinicians do a poor job of inviting patient participation in decision making. We rarely present sufficient, clear and balanced information. More disturbingly, information is sometimes presented differently to different groups of patients. The study demonstrates that we are far from matching our best intentions with our practices. Like first-year medical students, we seem to understand the concept of informed consent but are somehow unable to carry out the task.

We all know the major barriers to implementing shared decision making: time constraints, logistics and reimbursement. A recent systematic review identified health professionals’ most commonly perceived barriers to implementing shared decision making. These included: lack of applicability because of patient characteristics; lack of applicability due to the clinical situation...
(for example, emergency situations); and perceived patient preferences.

Despite these problems, shared decision making will be seen in the future as a potential quality measure. It is already a hallmark of the patient-centered practice and the medical home, terms we commonly use to describe the direction in which health care is moving. The recent Patient Protection and Affordable Care Act, for example, says that an accountable care organization “shall demonstrate to the Secretary that it meets patient-centeredness criteria [and] the use of individualized care plans.”

Care plans that are truly individualized, however, are not necessarily going to meet criteria for standard guidelines, hence Dr. Pauker’s comment above. Should an 80-year-old female with chronic lung disease continue to get yearly mammograms? Is a late-stage lupus patient a candidate for standard treatment for stage 3 breast cancer? Should a 70-year-old man with heart disease and diabetes sign a DNR before bypass surgery? These are tough decisions that require active participation from an informed patient.

The utility of decision aids for addressing issues in which patient individuality plays a role has been demonstrated in several clinical settings. Decision aids (DAs) range in form from simple printed or audiovisual materials (which can be viewed with a decision “coach” or privately), to integrated booklet/DVD sets that can be used in a variety of settings. DAs are available for such clinical conundrums as how to treat early breast cancer, evaluating cancer screening tests, discussing surgical interventions, managing chronic advanced illness and facing end-of-life care. Many other DAs are also available, and still others are being tested.

Patient centeredness, patient preference, preference sensitive, patient engagement . . . these are the medical terms of our near future. We all care for and about our patients, but now we need to demonstrate tangibly how we involve them in their own care. How we provide education and health management skills will become the central ideals around which their care plan is built.

The use of specialized decision aids and detailed advanced directives should become part of every practice. Directives on patient centeredness, now written into law, coupled with the grass roots movements of “empowered patients” and the new age of technology, will change how we regularly engage our patients. What is at stake is not only the financial future of medicine, but also the quality of care available to the patients we serve. Let us not forget that ultimately, we ourselves, and those we care about, will be among those patients.

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References