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Informed Patient Choice: Patient-Centered Valuing of Surgical Risks & Benefits

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Shared decision-making and patient decision aids: making the case for *informed choice*

With any surgery, consent must be obtained from each patient, and valid consent is based on knowledge of the options, the risks and benefits of each option, and the likelihood that these will occur for the individual patient. The legal doctrine and requirements of informed consent are well knownⁱ. In theory, informed consent is a process, not a moment in time. In reality, it has occurred when a clinician requests a signature from a patient to authorize that a specific treatment or procedure take place, and the patient signs. In current practice, there is no requirement that shared decision-making occur before the signing of the consent form.

Not all surgery decisions lend themselves equally to the elicitation of values and preferences. For treatment recommendations that are based on guidelines or standards of care, where there is strong evidence of effectiveness of a treatment and strong agreement among patients that these are valued interventions (e.g. surgery for hip fracture), the patient tends to agree to a recommendation rather than engage in a shared decision-making process. However, many surgeries are elective, and fall under the category of preference- and values-sensitive treatment decisions. Assessing the risk/benefit tradeoffs in such decisions is best done using a shared decision-making model.

The shared decision-making process is a collaboration between clinician and patient, using a decision aid as an adjunct to the process.ⁱⁱ The incorporation of shared decision-making tools and elicitation of patient values and preferences into the traditional but obsolete surgery consent process is *informed choice*. The essential components of this process are: the clinician perspective, the patient perspective, and a decision aid that provides objective information about all treatment options and engages the patient (by making clear that there is a decision to be made and that the person undergoing the treatment can choose to be the locus of decision making). The decision aid presents the risks and benefits of each treatment option in a way that is designed to help patients understand the likelihood of benefits or harms occurring, and to consider what benefits and risks matter most to them.

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Current thinking (by some surgeons, ethicists, lawyers, and policy makers, among othersⁱⁱⁱ), supports replacing informed consent with explicit documentation of the informed choice process:

1. provision of balanced, evidence-based information (or lack thereof) on all options, using decision aids as an adjunct where they exist;
2. discussion of benefits and risks of each option and the likelihood that they will occur, using framing and language understandable to the patient;
3. elicitation and clarification of patient values and preferred role in decision-making; and
4. a treatment decision arrived at through discussion between clinician and patient.

Shared decision-making is especially useful when there is no clear “best” treatment option (e.g. elective musculoskeletal surgeries for hip, knee and spine). For cases in which there are several choices and the evidence about them is less than clear, shared decision-making helps patients to become more educated about treatment options and allows them to recognize that a decision can be based on their values.^{iv} This also applies in cases where the evidence for all options is available and each decision-maker may value the risk/benefit profiles for each option differently.

Decision aids

Research has shown the added value of using decision aids when making treatment choices. Decision aids are “interventions designed to help people make specific and deliberative choices among options (including the status quo) by providing (at the minimum) information on the options and outcomes relevant to a person’s health status.”^v High quality decision aids exist^{vi}, and contain balanced, evidence-based information about the surgical and non-surgical options for several high volume musculoskeletal procedures: lumbar herniated disc, lumbar spinal stenosis, knee osteoarthritis and hip osteoarthritis. Analysis of 34 randomized trials has shown that decision aids improve decision-making by:

- Increasing knowledge of the options, benefits and risks
- Creating more realistic expectations
- Lowering decisional conflict
- Reducing uncertainty about what to choose
- Enhancing active participation in decision-making
- Decreasing the proportion of people who are undecided
- Improving agreement between values and choices^{vii}

In addition to underpinning an ethical and legal process of informed choice, the widespread use of decision aids and shared decision-making tools in values-driven care offers an opportunity to address unwarranted variations in such care. Using an informed choice process and tools should produce the “right” rate of surgery, the rate at which patients’ values align with the surgery option.

In 2001, Hawker et al did a phone and mail survey in Ontario, Canada to find out how strongly patients’ preferences for hip and knee arthroplasty correlate with clinical eligibility for surgery. The study found that only 15% of people deemed clinically eligible – by self-reported pain and x-ray images – would consent to surgery if offered. They found that “...how individuals balance the potential benefits and risks of surgery in relieving their complaints (i.e., patients’ preferences or willingness to have surgery) has been shown to

influence the decision-making process.”^{viii} Thus it is essential that the micro-systems which operate within clinical environments actively support patients’ valuing process.

Surgeons’ attitudes toward shared decision-makinga

To assess the attitudes of orthopaedic surgeons toward the use of decision support tools and processes in the treatment of patients with hip and knee osteoarthritis, Llewellyn-Thomas et al. carried out a survey of hip and knee surgeons in 2004.^{ix} 44% of eligible members of the American Academy of Hip & Knee Surgeons responded to the survey, which found that shared decision-making was highly rated as a good or excellent idea. A majority gave high ratings to both the *importance* and *helpfulness* of decision aids that teach patients about the surgical and non-surgical options, benefits and risks, reveal patient preferences for treatment, and develop a care plan. The top reason to use decision aids was “increased patient comprehension” and the top barrier to their use was “interference with office work.” The American Academy of Orthopaedic Surgeons (AAOS) has endorsed the concept of decision support by offering a streaming video version of the *FIMDM Treatment Choices for Knee Osteoarthritis* decision aid on its web site (<http://orthoinfo.aaos.org/category.cfm?topcategory=Knee>). Llewellyn-Thomas et al also conducted a similar survey to learn about attitudes of AAOS member back surgeons. The findings were similar in terms of valuing decision aids for their patients.^x This group identified the possibility of reducing malpractice insurance premiums and litigation as potential incentives to their use.

These surveys concluded that although there is broad support from surgeons, there is little movement toward expanded use throughout the healthcare system. Implementation strategies are lacking and traditional incentives and policies to support such strategies need more advocates. A web-based toolkit for integrating decision support into specialty care is under development, based on the Dartmouth framework.^{xi} It aims to facilitate more widespread use of the tools and processes that have been piloted and found to be both feasible and acceptable to clinicians and patients.

Informed choice at Dartmouth-Hitchcock Medical Center (DHMC)

Specialty Care Model

Both the Spine Center and the Adult Reconstruction (joint replacement surgery) sections of the Department of Orthopaedics at DHMC have been collaborating with the Center for Shared Decision-making (CSDM) at DHMC to integrate shared decision-making tools into usual care. We use a post-visit model, referring patients with surgery-eligible lumbar herniated disc, spinal stenosis, and knee or hip osteoarthritis to the CSDM to borrow the video/DVD (with accompanying booklet and symptom rating worksheet) for viewing at home. Patient knowledge and values are ascertained to measure decision quality and to ensure their values/preferences are incorporated into the decision they are about to make.^{xii} Decisional conflict is also measured as part of this process. This helps the clinician understand the complexity of the decision their patients are facing, and allows the clinician to address sources of decisional conflict.

In both the Adult Reconstruction Clinic and the Spine Center, usual care includes a mechanism for closing the decision loop. Spine patients typically return for more conversation with the surgeon prior to surgery while knee and hip patients are instructed about how to proceed once they have made a decision (phone call, email, appointment). In both cases self-reported health status measures are collected at each visit. This enables the units to follow their patients’ clinical progress over time, tracking their individual treatment decisions. If indicated and protocol calls for, it also allows for cost-effectiveness to be assessed, an important component in healthcare today.^{xiii}

Conclusions

There appears to be strong support of surgeons for the concept of *informed choice* in theory but systems and processes for widespread incorporation into clinical practice remain challenging. Lack of familiarity with the concept and tools available is the first challenge. Physicians who are familiar with these concepts and tools may feel they already “do shared decision-making” in their current practice, or they may resist adopting this model because of concerns about time and resources. Concerns about lack of time to spend with patients engaged in shared decision-making can be balanced by the time savings that use of decision aids in preparation for the clinical encounter will yield. Some media, particularly video, are unwieldy but will likely be available as web-based tools in the future. Both the cost of the tools and the potential loss of income if fewer patients choose surgery are perceived as significant barriers. Without a clinical champion advocating for and facilitating change, many healthcare systems will stay as they are. In addition, these tools must be made available for patients for whom language and literacy barriers otherwise exclude them from the process.

We propose that Medicare and other insurers offer financial incentives to clinicians for engaging in informed choice with their patients, using quality measures of how well patient knowledge and values align with treatment choice.^{xiv} Healthcare accrediting organizations, as leaders advocating for patient-centered care, should reward use of decision support tools and processes. Groups such as IHI, NCQA, NQF, IOM, specialty societies, and the like, need to both support the concept and offer specific mechanisms for disseminating it widely. Patients are seeking a “trusted navigator”, and likely will consider these decision tools as a valued partner in their often tortuous path through a complicated healthcare system. Medical schools should include decision support training in their curricula, and nurses can enhance their leadership role as patient advocates with these unique patient decision tools.

It is important that we recognize *informed choice* as an approach that can help transform the healthcare system. We must mobilize the necessary talent, and focus our diverse interests to meet the larger task of improving the scientific basis of everyday practice. Evidence-based medicine is all about providing effective care. As a nation we have failed in this task by not providing what we know works (e.g. HgA1c testing, diabetic eye exams, beta blockers post MI, etc.). Pay for performance is now being tested around effective care. For preference sensitive care e.g., spine, joint replacement or other elective procedures, we need to incorporate informed choice tools and processes into routine care throughout the healthcare system. These tools allow us to place before our patients the information they need on what is known about the supporting evidence regarding the many choices often available in elective procedures, in order to make choices that align with their values.

The perceived barriers to understanding patient preferences and values around elective surgical procedures are not insurmountable. Overcoming these barriers requires the active participation of all of us – government, industry, academia, private practice and the public. If we are to truly transform healthcare delivery and if we truly wish to practice patient-centered care, we need to put the necessary tools in our patients’ hands so they can partner with their doctors to rationalize the delivery of healthcare before it becomes irrationally rationed.

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