

Confronting Evidence: Individualised care and the case for Shared Decision-Making

Abstract:

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Abstract

In many clinical scenarios there exists more than one clinically appropriate intervention strategy. When these involve subjective trade-offs between potential benefits and harms, patients' preferences should inform decision-making. Shared decision-making is a collaborative process, where clinician and patient reconcile the best available evidence with respect for patients' individualized care preferences. In practice, clinicians may be poorly equipped to participate in this process. Shared decision-making is applicable to many conditions including stable coronary artery disease, end-of-life care, and numerous small decisions in chronic disease management. There is evidence of more clinically appropriate care patterns, improved patient understanding and sense of empowerment. Many trials reported a 20% reduction in major surgery in favour of conservative treatment, although demand tends to increase for some interventions. The generalizability of international evidence to Ireland is unclear. Considering the potential benefits, there is a case for implementing and evaluating shared decision-making pilot projects in Ireland.

Introduction

The traditional hallmark of high quality clinical care was accurate medical diagnosis, and formulation and execution of a treatment plan based on that diagnosis. But the frequent ambiguity of medical evidence and the changing expectations of patients demand other attributes. For some conditions (for example, a fractured femur) there is only one accepted treatment, and patient preferences have little relevance. But for many conditions there exists more than one acceptable path, and each choice entails distinct benefits, side effects and subjective trade-offs. In these preference-sensitive contexts, which may account for a quarter of all health care spending, patients' preferences and values can guide the intervention strategy. Shared decision making (SDM) is a process that allows patients and providers to make health care decisions collaboratively, taking into account the best available scientific evidence, as well as patients' values and preferences. This can enhance clinical appropriateness, and improve communication, patients' knowledge, and involvement in decision-making. A study of 1,000 out-patient visits where more than 3,500 decisions were made found that fewer than 10% of decisions fulfilled minimum standards for informed decision making, and the importance of improved decision-making is underscored by large variation in treatment patterns within health systems, unrelated to the availability of resources¹.

Methods

We conducted a literature search on the topic of shared decision making in the PubMed database, using the following search term: (((("shared decision making"[Title/Abstract]) OR "informed decision making"[Title/Abstract]) OR "informed medical decision making"[Title/Abstract])) AND ((quality[Title/Abstract]) OR evidence[Title/Abstract]) OR effectiveness[Title/Abstract])). The search was restricted to papers published from 2008 to 15th December 2013. A total of 843 papers were found. We included recent systematic and non-systematic literature reviews that summarize evidence and implementation challenges relating to SDM. We identified additional papers and books by searching the bibliographies of references, and the website of the Informed Medical Decisions Foundation.

Results

Examples of shared decision-making

SDM is relevant for numerous clinical conditions associated with preference-sensitive care, such as bothersome lower urinary tract symptoms in men with benign prostatic hyperplasia. If a patient judges the surgical risks of incontinence and sexual dysfunction to outweigh the potential gains, there may be no need for surgery, despite capacity for clinical benefit. In a Canadian orthopaedic study, expert physicians identified patients in potential need of joint replacement based on symptoms and radiographic findings. Only 8-15% of these patients were definitely willing to undergo the intervention when informed of its evidence base, illustrating the need to balance patients' preferences with evidence. Table 1 presents a selection of relevant clinical scenarios and associated treatment options.

SDM is also applicable to many types of care not traditionally considered preference-sensitive, including end-of-life care and the array of small decisions in chronic disease management. An elderly patient with Parkinson's Disease may prioritise certain forms of functionality such as the ability to communicate with relatives over the internet, whereas a physician may define treatment success in narrow terms of biomedical metrics such as presence of tremor. Aggressively optimising particular clinical targets may compromise overall quality of life. In such situations it is sensible to elicit and account for the patient's specific values and goals.

Tools for shared decision-making

SDM should convey up-to-date scientific evidence to patients in a comprehensible manner. One strategy is to train clinicians in communication skills and facilitation of SDM. Systematic reviews show this may improve communication, patients' understanding, and satisfaction, but there is no firm evidence of altered clinical outcomes and utilisation patterns². Another approach is adoption of decision aid tools, which inform patients on the risks and benefits of diagnostic and treatment strategies. For example, the Prostate Interactive Education System presents information on prostate cancer treatment in an interactive format. Patients can access the decision aid freely online and examine texts and videos on the rationale for treatment options such as external beam radiation, robotic surgery, and watchful waiting (active surveillance). It holistically deals with family and relationship issues arising from prostate cancer. For example, a section for women offers written advice and videos of women discussing methods for dealing with a spouse's illness, medical decision-making, social interactions with family and friends, and side effects of treatment. On the topic of radical prostatectomy, there are video simulations of physician counselling for topics such as pain, relative effectiveness, and interaction with medicines.

What does the evidence say?

A recent Cochrane review summarises much of the evidence for decision aids addressing treatment or screening decisions. It showed improved patient-clinician communication, superior patient enthusiasm, knowledge, understanding of trade-offs, and involvement in decision-making. The effects on consultation length were inconsistent. There appeared to be no adverse effects on patient satisfaction or clinical outcomes¹⁰. Adoption of decision aids was associated with a 20% reduction in utilisation of major surgery in favour of conservative treatment, reduced use of PSA screening, and reduced use of post-menopausal hormones. A study found that women in the United Kingdom suffering from abnormal uterine bleeding, when informed properly of the risks and benefits chose surgery significantly less often (relative reduction of 20%). Patients with back pain and herniated disks were 30% less likely to choose surgery when fully informed¹⁰. Some demand may be postponed rather than obviated. The economic consequences are unclear. Reduced utilization may not translate into reduced net costs, as this is influenced by implementation costs and the sensitivity of cost structures to reduced demand. The generalizability of utilization reductions is unclear. Much evidence is from the predominantly market-oriented US system, and some comes from settings such as Canada and the United Kingdom¹⁰. The effects may vary across settings depending on baseline provision rates. The goal is to avoid both overuse and underuse rather than to uniformly temper demand. SDM tends to increase demand for some interventions such as spinal stenosis surgery

Caveats and limitations

Do patients truly want the added responsibility of SDM? Some patients may prefer to delegate the burden of decision-making to a clinician, and SDM may be incongruent with patients' psychosocial needs, especially in the face of far-reaching uncertainty, fear and distress. If patients (or their families) choose a treatment that culminates in poor outcomes, the ensuing guilt may amplify anguish and regret. Nonetheless evidence suggests SDM has high levels of acceptability with patients and can improve the care experience. In one provider organisation, 76% of patients over 65 years would strongly recommend use of a decision aid prior to deciding on a surgical procedure¹. In a study of 20 women with suspected recurrent ovarian cancer, 95% would recommend the use of a decision aid, despite its association with high anxiety levels².

SDM may impose a cognitive burden unsuitable for some patients. People are prone to inconsistent and irrational decision-making, and framing the same evidence in different ways can alter perceptions of effectiveness, for example patients and physicians may perceive a 10% mortality rate differently from a 90% survival rate¹³. Studies suggest that physicians and patients frequently misinterpret statistical evidence. Mammography screening for breast cancer has a miss rate of around 10%, and its false positive rate is only slightly lower, but in a German study 46% of women (and 42% of men) reported it as absolutely certain¹⁴. SDM must be carefully structured to overcome such misunderstanding.

Discussion

Implementation of SDM touches on cultural issues, and it can be difficult to alter established work practices. In a Veterans Administration hospital, a decision aid for benign prostatic hyperplasia lowered the demand for surgical procedures and maintained patient satisfaction, but its use was terminated after the volume of surgeries became insufficient for urology residents to attain board certification¹⁵. In a study of SDM in end-of-life care, treatment intensity persistently exceeded patients' recorded preferences¹⁵. It is unclear if clinicians disregarded patients' preferences, or whether unmeasured changes in patients' preferences occurred as death approached. The prevailing medical culture urges clinicians to do their utmost to heal, and this may inadvertently deter tempering of treatment intensity in accordance with patient preferences. SDM may prove a key tool for Irish clinicians to reconcile evidence-based medicine with individualized care. Successful implementation could substantially influence patterns of clinical care, and this demands multi-stakeholder commitment to improvement.

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Acknowledgement

Thanks to MJ Barry of Harvard Medical School for helpful comments.

References

1. Wennberg D, editor *Opportunities to Reduce Unwarranted Care Differences. The Healthcare Imperative: Lowering Costs and Improving Outcomes: Workshop Series Summary*; 2010: National Academies Press.
2. Braddock III CH, Edwards KA, Hasenberg NM, Laidley TL, Levinson W. Informed decision making in outpatient practice. *JAMA*; 1999;282:2313-20.
3. Hawker GA, Wright JG, Coyte PC, Williams JI, Harvey B, Glazier R, Wilkins A, Badley EM. Determining the need for hip and knee arthroplasty: the role of clinical severity and patients' preferences. *Medical care*. 2001;39:206-16.
4. Volandes AE, Paasche-Orlow MK, Barry MJ, Gillick MR, Minaker KL, Chang Y, Cook EF, Abbo ED, El-Jawahri A, Mitchell SL. Video decision support tool for advance care planning in dementia: randomised controlled trial. *BMJ*; 2009;338.
5. Wilson SR, Strub P, Buist AS, Knowles SB, Lavori PW, Lapidus J, Vollmer WM, Better Outcomes of Asthma Treatment (BOAT) Study Group. Shared treatment decision making improves adherence and outcomes in poorly controlled asthma. *American journal of respiratory and critical care medicine*. 2010;181:566.
6. Gigerenzer G, Gray JM. *Better Doctors, Better Patients, Better Decisions: Envisioning Health Care 2020* [Forum Held in Frankfurt Am Main, Germany, Oct. 25-30, 2009]: Mit Press; 2011.
7. Reuben DB, Tinetti ME. Goal-oriented patient care: an alternative health outcomes paradigm. *NEJM*. 2012;366:777-9.
8. Coulter A, Ellins J, Swain D, Clarke A, Heron P, Rasul F, Magee H, Sheldon H. Assessing the quality of information to support people in making decisions about their health and healthcare: Citeseer; 2006.
9. Temple University. Prostate Interactive Education System 2012 [28th January 2014]. Available from: <http://www.temple.edu/imits/piesweb/>.
10. Stacey D, Bennett CL, Barry MJ, Col NF, Eden KB, Holmes-Rovner M, Llewellyn-Thomas H, Lyddiatt A, Legare F, Thomson R. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev*. 2011;10.
11. Fowler F. Shared decision-making: Who Benefits the Most May Surprise You 2012 [16th November 2013]. Available from: <http://informedmedicaldecisions.org/2012/04/27/shared-decision-making-who-benefits-the-most-may-surprise-you/>.
12. Anderson C, Carter J, Nattress K, Beale P, Philp S, Harrison J, Juraskova I. "The Booklet Helped Me Not to Panic": A Pilot of a Decision Aid for Asymptomatic Women With Ovarian Cancer and With Rising CA-125 Levels. *International Journal of Gynecological Cancer*. 2011;21:737-43.
13. Ahmed H, Naik G, Willoughby H, Edwards A. Communicating risk. *BMJ*. 2012;344:40-4.
14. Wennberg JE. *Tracking medicine: a researcher's quest to understand health care*: Oxford University Press; 2010.
15. Kryworuchko J, Hill E, Murray MA, Stacey D, Fergusson DA. Interventions for Shared Decision-Making About Life Support in the Intensive Care Unit: A Systematic Review. *Worldviews on Evidence-Based Nursing*. 2012.