

Shared decision making: really putting patients at the centre of healthcare

Although many clinicians feel they already use shared decision making, research shows a perception-reality gap. **A M Stiggelbout and colleagues** discuss why it is important and highlight some best practices

Imagine yourself as a parent who is worried that your child is missing school because of repeated attacks of tonsillitis. You think tonsillectomy will solve the problem but learn from your general practitioner that there is a risk of severe bleeding that you were unaware of. You have second thoughts about surgery as you learn more about the balance of potential benefits and harms (box 1). This is an example of shared decision making—clinicians and patients make decisions together using the best available evidence. In partnership with their clinician, patients are encouraged to consider available screening, treatment, or

management options and the likely benefits and harms of each, to communicate their preferences, and help select the course of action that best fits these.¹

Shared decision making should be the norm in most medical practice for several reasons, the most important of which is an ethical imperative under the widely accepted four principles.³ Not only is it essential for respecting autonomy (enabling individuals to make reasoned informed choices), but it is also needed for beneficence (the balancing of benefits of treatment against the risks and costs) and non-maleficence (avoiding harm). To

judge whether the benefits and risks of treatment are balanced from a patient's perspective and to avoid procedures patients would rather not have if they were well informed (and which thus may harm them), clinicians must determine their patients' preferences. Abundant evidence of a reduction in the use of tests (such as prostate specific antigen) and elective procedures⁴ shows that patients tend to make more conservative judgments than their doctors. Shared decision making may thus also reduce unwarranted practice variation (both overuse and underuse) and in some situations, by extrapolation, costs. The fourth principle, justice (distributing benefits, risks, and costs fairly) might also be enhanced if patients elect to have fewer procedures. Equity may also increase if less educated people are involved to the same extent as those who are more educated. Finally, shared decision making may lead to better health outcomes and lower litigation rates, although the evidence remains limited.^{5 6}

Despite these benefits, shared decision making is not routine. However, best practices are gradually emerging, and below we provide examples—tactics and strategies that clinicians and their organisations can use to support patients to become involved in decision making.

Best practices for implementation

Several countries, including the United States and Canada, have used multifaceted interventions targeted at systems or practices to implement shared decision making.^{7 8} Many involve the dissemination of patient decision aids for situations where there is no single “best” choice.⁴ The decision aids may be pamphlets, videos, or web based tools that describe the options available and help patients to



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understand these options as well as the possible benefits and harms (see <http://decision-aid.ohri.ca/AZinvent.php> for an inventory of patient decision aids). These tools help patients consider options from a personal viewpoint, preparing them for participation in decision making.⁴

In Canada, the province of Saskatchewan promotes the use of decision aids in surgical specialties. Outcome data, such as decision quality are collected for monitoring purposes.⁸ But dissemination of decision aids alone is not enough. Although decision aids are designed to empower patients, they have been developed for independent use outside the clinical encounter and shared decision making does not necessarily follow.

Shared decision making is more likely if the decision support tools have been developed for use in face to face clinical encounters. Examples of these tools are the Wiser Choices tools developed at the Mayo Clinic in the US (<http://shareddecisions.mayoclinic.org>), and option grids (www.optiongrid.co.uk/) developed in Cardiff. Wiser Choices tools are structured graphical displays of risks that help clinicians convey information to patients, enabling decisions that are consistent with both the best available evidence and the values and preferences of the patient (figure). Option grids are one page summaries that provide answers to patients' frequently asked questions when considering treatment choices (such as whether to have amniocentesis). Using these kinds of tools in clinical encounters facilitates shared decisions without substantially increasing consultation times.^{9 10}

Although helpful, patient decision aids and short decision support tools are currently available for only a limited number of conditions. A broader approach is therefore required to implementing shared decision making. The Center for Shared Decision Making at Dartmouth Hitchcock Medical Center in the US provides service and training to patients and clinicians (http://patients.dartmouth-hitchcock.org/shared_decision_making.html). In the UK the MAGIC programme (Making Good decisions in Collaboration), funded by the Health Foundation, aims to embed shared decision making in daily practice in a range of clinical settings, stimulating skills development and behavioural change. Simple changes to clinical pathways create opportunities for more shared decision

Box 1 | Typical shared decision making consultation using a tonsillectomy option grid²

Mother: I was hoping tonsillectomy would stop Anna missing so much school.
 Doctor: It may do that of course—though exactly how much is really difficult to know. Anna is now 12 years old, and in many children the attacks of tonsillitis get less frequent around this time. So not having surgery is an option too.
 Mother: But it's a simple operation isn't it?
 Doctor: Have a look at this information (gives her the option grid to read).
 Mother: Oh... what's this about the risk of bleeding?
 Doctor: Let's check the numbers. 1 in 100 risk of immediate bleeding and 3 in a 100 risk of serious bleeding in the two weeks after the operation.
 Mother: I did not know that at all. I'm not sure I want to take that chance, to be honest.
 Doctor: How about you take this information home to share with your husband. I'm happy to refer your daughter at any time, but it's best you consider this information before you make that decision.
 Mother: Thank you.

Adapted tonsillectomy pathway (Cardiff ear, nose, and throat department)

Standard pathway	Adapted pathway (using option grid)
Parent and child attend outpatient clinic for assessment of recurrent tonsillitis	Parent and child given tonsillectomy option grid to read whilst waiting for outpatient consultation ²
Specialist nurse reviews referral letter and reviews the problem with the parent(s) and child	Specialist nurse reviews referral letter and reviews the problem with the parent(s) and child
Specialist nurse checks whether criteria for tonsillectomy are met. Discussion about listing for tonsillectomy	Specialist nurse checks whether criteria for tonsillectomy are met as well as reviewing the information in the option grid with parent(s) and child. Then uses a decision quality measure to check understanding
Proceed (or not) to tonsillectomy surgical list	Proceed (or not) to tonsillectomy surgical list

making—for example, an adapted pathway for children referred for an opinion regarding tonsillectomy (table).

Many patients do not expect to be involved in decision making and so need to be made aware that their preferences, when well informed, may determine the most appropriate choice of treatment. Simple changes in doctor-patient communication can lead to striking improvements in shared decision making. A short instruction to patients to ask three simple questions has been shown to lead to more shared decision making.¹⁰ In the MAGIC programme, posters displayed in waiting rooms urge patients to ask these three questions (“What are my options?” “What are the benefits and harms?” “And how likely are these?”). Increasing patients' self efficacy will increase their intention to share in decision making.¹¹ The arrival of so called e-patients (equipped, enabled, empowered, and engaged in healthcare decisions) fits these ideas.¹²

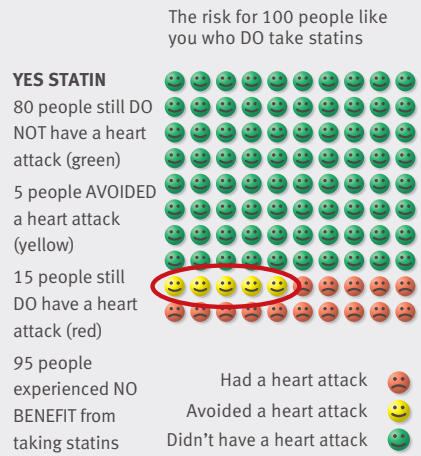
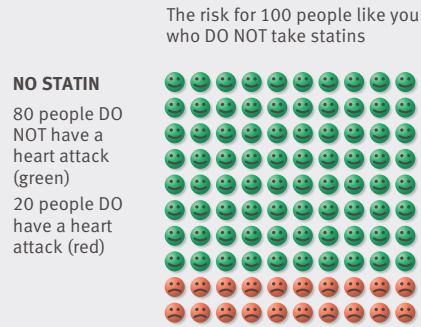
In many of the initiatives described above, patients participate in developing indicators for quality of care, in the education of health professionals, and in the development of patient centred services. Similar demonstra-

tion projects by the Foundation for Informed Medical Decision Making are under way in the US—for example, at the Palo Alto Medical Foundation.⁷

Simple strategies for individual clinicians

The first and most important step in shared decision making in preference sensitive decisions¹³ is creating awareness of equipoise—that is, explaining to the patient that there is no best choice, that a decision has to be made, and that doing nothing or keeping the status quo is also an option.^{14 15} After having laid out the options, the next step is to discuss the benefits and harms of each, as well as their respective probabilities. Exact probabilities are not always needed, but in most preference sensitive decisions¹³ the patient will need numbers to be able to weigh the pros and cons. A patient will have difficulty in deciding between surgery and watchful waiting for an aortic aneurysm if he does not know the approximate chances of a rupture or of operative mortality and other complications. Here the mentioned decision tools become valuable. If these are unavailable, simply communicating what will happen to 100 or 1000

1. What is my risk of having a heart attack in the next 10 years?



2. What are the downsides of taking statins (cholesterol pill)?

- Statins need to be taken every day for a long time (maybe forever)
- Statins cost money (to you or your drug plan)
- Common side effects: nausea, diarrhoea, constipation (most patients can tolerate)
- Muscle aching/stiffness: 5 in 100 patients (some need to stop statins because of this)
- Liver blood test goes up (no pain, no permanent liver damage): 2 in 100 patients (some need to stop statins because of this)
- Muscle and kidney damage: 1 in 20 000 patients (requires patients to stop statins)

3. What do you want to do now?

- Take (or continue to take) statins
- Not take (or stop taking) statins
- Prefer to decide at some other time

Decision aid for choosing statin in a diabetes patient with a 20% risk of myocardial infarction (http://mayoresearch.mayo.edu/mayo/research/ker_unit/upload/StatinDecAid_ELEV_Mayo.pdf)

similar patients in case of either option (that is, giving absolute not relative risks) will help the patient weigh the benefits and risks.

Next, patients' ideas, concerns, and expectations about the options, their benefits, and their harms should be elicited, and the patient should be supported in the process of deliberation (box 2).

For shared decision making to occur, a form of partnership should be built that goes beyond rapport and involves sharing responsibility.¹⁵ More responsibility can be a burden, however, so professionals should encourage and support the process, explaining that it preferably is a *shared* process, to prevent patients from feeling abandoned and that they have to decide on their own.

The patient's preferred role should be explored,¹⁴ but not until the information has been provided. Research shows that patients who initially may be reluctant to participate in the decision often change their mind after the options have been laid out.¹⁶ Thus, after sharing information, clinicians should empathically invite patients to engage to the maximum extent they desire in making this decision at this time. Some patients are afraid of being assertive, fearful that this will jeopardise a good doctor-patient relationship and lead to lower quality care.¹⁷ Therefore, clinicians should invite patients to participate, assess what patients need to make a decision, provide appropriate support, and help make decisions when patients prefer to defer to them. It would be inappropriate to force decision making responsibilities on people who genuinely defer this role, for this may cause harm and distress. Though shared decision making needs input from and interaction with a clinician, it need not occur entirely in the consultation or under time pressure.¹⁸ Indeed, most patients value the opportunity to involve others,¹⁹ and so supporting and allowing time for this process is also required.

What can the profession do?

Clinical practice guidelines could promote shared decision making by highlighting decision points and suggesting what information to communicate about reasonable options and how to involve patients.²⁰ Postgraduate training and accreditation can also support implementation of shared decision making. Skills training can change the extent to which clinicians practise shared decision making.²¹

Box 2 | Questions to support deliberation

- What do you expect from treatment for your condition?
- Do you have all the information you think you need to weigh up these two options?
- Thinking about this decision, what is the most important aspect for you to consider?
- What aspects of surgery are you most concerned about?
- How do the benefits of both options compare? And how do the harms compare?
- Are there important other people that you want to talk to in making this decision?

Because clinicians have to be able to discuss evidence based information and elicit patient preferences, linking courses on shared decision making with those on evidence based medicine could also be beneficial. Risk communication and eliciting patient preferences remain a neglected part of evidence based medicine.²² Integrating shared decision making into the evidence based medicine framework will cut both ways, helping clinicians to communicate evidence and ask patients for their preference as well as promoting shared decisions.

Debate

Despite the push to implement shared decision making, some questions remain. We need more data on whether it requires significant amounts of extra time. If so, will re-engineering clinical pathways to provide decision support at the right times solve this problem, and, if not, will better adherence, less overtreatment, and improved quality of care from the patient's perspective be sufficient gain to justify more time spent in the clinical encounter?

The use of guidelines may counteract the implementation of shared decision making if patient preferences are at odds with guideline recommendations and possibly with clinician preferences. When using guidelines patient preferences are generally not elicited or are over-ruled.²³ It is not clear whether professionals are willing to change this situation.

Finally, it has been argued that shared decision making is relevant only for well educated middle class patients and a luxury for high income countries. There is evidence, however, that if patients with lower literacy are provided with well designed information and given appropriate support they participate equally well and stand to benefit the most

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by becoming more aware of the evidence.²⁴ Although most research has occurred in high and middle income countries,²⁵ the concept of shared decision making is entirely consistent with the priorities of low income settings—that is, to improve health literacy, improve patient provider communication, and empower individuals to be more involved in their healthcare.²⁶ Healthcare in low income countries is often constrained by limited human and physical resources. Literacy levels among patients may be low and cultural factors may require communication strategies that are more inclusive of family and friends. New innovations using mobile phone technologies have recently become more common in low resource settings, although most have been unidirectional—either collecting data or issuing reminders or health promotional material.²⁷ There is real potential for these to become more interactive and provide a platform for shared decision making in low income countries.

Where to go from here?

Shared decision making is a complex intervention, and its implementation in healthcare will need multifaceted strategies coupled with culture change among professionals, their organisations, and patients. This shift starts with increased awareness at all levels of society, as expressed in the Salzburg statement.¹⁸ It is important to monitor which of the many practices described above are the most successful in promoting shared decision making and disrupt the clinical workflow no more than necessary. The ultimate goal is that it is not seen as a tedious added extra but as the core of good clinical practice, with patients placed fully at the centre of all decisions.

A M Stiggelbout professor of medical decision making, Department of Medical Decision Making, Leiden University Medical Centre, PO Box 9600, 2300 RC Leiden, Netherlands

T Van der Weijden professor of implementation of evidence, Maastricht University Department of General Practice, CAPHRI School of Public Health and Primary Care, Maastricht, Netherlands

M P T De Wit patient representative, Dutch League of Arthritis Patients, Zaltbommel, Netherlands

D Frosch associate investigator, Palo Alto Medical Foundation Research Institute, Palo Alto, CA, USA

F Légaré Canada research chair in implementation of shared decision making in primary care, Knowledge Transfer and Health Technology Assessment Research Group, Hôpital St-François D'Assise, Québec QC, Canada

V M Montori director of healthcare delivery research programme, Center for the Science of Healthcare Delivery, Mayo Clinic, Rochester, MN, USA

L Trevena associate professor, Sydney School of Public Health, University of Sydney, NSW, Australia

G Elwyn professor of primary care, Institute of Primary Care and Public Health, School of Medicine, Cardiff University Cardiff, UK

Correspondence to: A M Stiggelbout
a.m.stiggelbout@lumc.nl

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Contributors and sources: This paper originated in debates at the sixth international shared decision making conference in Maastricht, Netherlands, June 2011 (www.ISDM2011.org). AMS is president of the Society for Medical Decision Making. TVDW was chair of ISDM2011, MPTDW is patient representative of the Dutch League of Arthritis Patients, DF is associate professor of medicine at UCLA, FL leads research into implementing shared decision making in primary care, VMM designs and conducts trials of patient decision aids in routine clinical settings and is chair of ISDM2013 in Peru (www.isdm2013.org). LT is associate professor at the Sydney School of Public Health, GE works to implement shared decision making at Cardiff, Nijmegen, and Maastricht, Netherlands, and Dartmouth College, USA. AMS drafted the manuscript, and all authors worked collaboratively to contribute, edit, and agree the final version. AMS is guarantor. The authors acknowledge three external reviewers for their comments.

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