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Shared decision making and decision aids

A literature review

Shared decision making (SDM) is a process within a patient centred consultation that involves both the patient and doctor discussing management options and agreeing on management decisions in partnership. Decision aids are designed to help patients understand the options relating to management for certain conditions and their possible benefits and potential adverse effects. We discuss the evolution and rationale behind SDM and the evidence relating to outcomes, the types of decision aids available, and research relating to their use.

In order to appreciate the significance of shared decision making as a process within the doctor-patient consultation, it is important to consider models of the consultation that either facilitate or hinder this process. While we tend to discuss the tasks of the consultation as a series of steps and divide the interaction into two parts, starting with information gathering and finishing with information sharing/management, in practice there is often not such a clear divide.¹ Shared decision making is only possible within a framework in which the patient's ideas and expectations are considered through the continuum of the consultation.

Models of the doctor-patient relationship affecting management

This sharing partnership between doctor and patient is only one model of the doctor-patient relationship. Szasz and Hollander² provide an early discussion of three theoretical models of the doctor-patient relationship and suggest that which one of these is uppermost at any particular time depends on the nature of the patient's problem and the setting of the consultation.² The models are graded from the doctor being active while the patient is passive (activity-passivity), via the patient having limited power while being expected to cooperate with the doctor's advice (guidance-cooperation), to there being a state of mutual participation. This last model is the most difficult to sustain. Doctor and patient must be aware of the other's needs, wishes and individuality. Roter and Hall³ wrote about the locus of control between doctor and patient. High doctor control combined with low patient control

leads to a consultation in which the doctor dominates and makes decisions: paternalism.

Paternalism relies on the concept of the doctor as an authority figure. Brody⁴ defines three types of medical power based on the writings of Max Weber (German sociologist, 1864–1920): aesculapian, charismatic and social. Aesculapian power is that which doctors have by virtue of training and the body of professional knowledge they possess. Charismatic power is due to the personality of the doctor and the way they interact with patients. Social power comes from the doctor's position within society. Paternalism reflects the once dominant disease centred approach to consultations.

The main tasks of the disease centred consultation are to diagnose illness from a biological perspective and to treat it, hopefully effecting a cure.⁵ The patient is not involved in management decisions and may not take any prescribed treatment correctly, if at all. The prescribing of medicines is the most common intervention in health care, yet it is estimated that around 50% of patients do not take their medicines as intended.⁶ Misunderstandings about prescriptions between doctor and patient often relate to failure of communication about the doctor's decisions, leading to nonadherence.⁷

At the opposite end of the spectrum from paternalism, there is a danger in the physician adopting a completely neutral stance and giving the patient a range of options without expressing any preference, the 'informed model'.⁸ This model has been seen as a move toward increased patient autonomy but has been criticised as sacrificing competence for control as physicians withhold their own experience and recommendations to avoid overly influencing

PROFESSIONAL PRACTICE

Doctor-patient relationship



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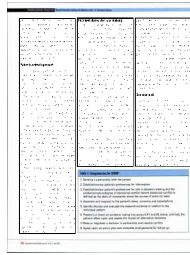
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patients.⁹ Therefore the shared model (the patient as partner, management by negotiation) is now in the ascendancy. However, it should be noted that there is often difficulty in distinguishing between shared decision making and informed choice and that separating the two models is not always justified¹⁰: sharing decisions cannot take place without the sharing of information and the approach may therefore be renamed informed shared decision making (ISDM).

Patient centred approach

Increased patient participation and decision making is part of the patient centred approach. Balint¹¹ explored the nature of the doctor-patient relationship and ways of understanding patients' illnesses. He first used the term 'patient centred medicine' in 1970, a reference to the client centred therapy of psychologist Carl Rogers.¹² Byrne and Long¹³ compared the patient centred style with what they called the doctor centred style of consulting. In a patient centred consultation the doctor and patient consider the patient's condition and diagnosis in partnership and the management or treatment plan is negotiated between doctor and patient. The doctor needs to explore the reason for the patient seeking medical advice and the patient's ideas, concerns and expectations. McWhinney et al¹⁴ proposed a model for the consultation that they also called 'the patient centred clinical method'. One of the five components of patient centredness as defined in the literature is 'sharing power and responsibility'.¹⁵

The increasing knowledge base for patient centredness mirrors the growing consensus that patients should be more involved in decisions about their health care, which has arisen from political trends, ethics and health service research.¹⁶ The shared decision making model is of particular benefit for clinicians intervening to reduce the risk of disease in their patients, where individualised calculations of risks and benefits are used and where choices about treatment are made.¹⁷ However, current training in consultation skills tends to concentrate on the first part of the consultation (achieving rapport, matching agendas, problem solving) rather than

management and negotiation.¹⁸

Informed shared decision making

Charles et al¹⁹ have defined one model of ISDM. The commitment of both doctor and patient to engage in the process is crucial although the extent of involvement may vary. Towle²⁰ has also suggested a series of steps that should occur in consultations that would enable doctors and patients to share in the decision making process, including information transfer and the doctor's affirmation of the patient's treatment preference (*Table 1*). Kassirer²² has listed the situations in which shared decision making is most appropriate as being those in which big differences exist between the potential outcomes of the available options, when a patient is particularly opposed to taking risks, or when the patient fixes great importance to particular potential outcomes.

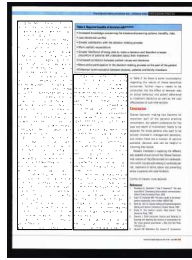
Patients actively involved in decisions about their health care may have improved health outcomes,²³ but the evidence is inconsistent.²⁴ Improvement may be due to a number of factors including adherence to treatment decisions. However, one barrier to ISDM is the amount of time the process takes in consultations, therefore it is important to continue to research the effects of ISDM on patient outcomes and satisfaction.

Patient centred care does not mean sharing all information and decisions about care, rather it means taking into account the patient's wish for information and preference for sharing decisions or not.²⁵ Some patients will not wish to share decisions, preferring the doctor to choose the management.²⁶ Certain characteristics of patients make them more or less likely to want to be involved. Younger patients and those with a higher education level are more likely to want to share decisions.²⁷ However, as it is difficult for doctors to judge which patients prefer a nonparticipatory role,²⁸ it is important for the doctor to explore individual patient preferences regarding decision making,²⁹ even if the patient does not wish to make the final decision. Doctors should not assume whether a particular patient wishes to share in the decision making process. Patients who previously have asked their doctors to choose their treatment ('what would you do doctor?') are more likely to wish

to be involved in making a decision once they have experienced the process in a consultation for the first time.³⁰

Decision aids

One of the limitations of the shared decision making process is that doctors may choose the amount and type of information they give in order to influence patient choices.³¹ The options may also be limited by the doctor's lack of knowledge in a particular field,³² or by previous experience of a treatment causing an adverse reaction in a patient. Even when options are presented, the doctor may already have decided on his or her personal recommendation, and therefore how the choices are presented is affected by this opinion. However, there will be times when the approaches to management are completely open with the doctor having no firm opinions as to which is preferable. Elwyn et al³³ have named this situation clinical



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'equipose', defining it as when the doctor admits there are two or more approaches to management and he or she does not have a strong view toward any of them.³³

Decision aids are one means of helping both the doctor and patient work through a full range of options for a particular condition. Decision aids are 'interventions designed to help people make specific and deliberate choices among options by providing information about the options and outcomes relevant to a person's health status';³⁴ and '... interactive products that... present information, options and guidance through the decision process'.³⁵ A distinguishing feature is the inclusion of exercises designed to promote clarification of the patient's values regarding what is at stake and what it is they are trying to achieve as a result of treatment.³⁶ Generally, the objective of decision aids is to provide information for patients to facilitate participation in the decision making process if this is their preference.³⁷ This may include specific aspects of helping patients to understand the treatment options available to them and the consequences of the various options (both positive and negative) and to prepare patients for active participation in health care decisions.³⁸

Many studies have described the use and development of decision aids. For patients with atrial fibrillation who had participated in a major clinical trial, the use of an audiobooklet improved their understanding of the benefits and risks associated with different treatment options and helped them make definitive choices about therapies.³⁹ Less expensive decision boards (mixture of written information and visual aids) help to assist breast cancer patients decide which treatment option they would prefer based on the best available evidence.⁴⁰ Other formats include paper based charts, booklets, tapes, videos or interactive computer programs.

Although there is some conjecture

about the importance of the decision aid medium,^{37,41} it is important to note that the better aids are those in which the information is personalised to the individual patient. Therefore web based or computer programs can have an advantage. They can be programmed to enhance interactivity and contain the potential for personalising information such as individual risk factors based on each patient's risk profile.³⁷ A recent study based at the University of Sydney found that a web based aid significantly improved parents' attitudes to MMR vaccination.⁴² The number of parents leaning toward having their children vaccinated increased from 39 to 55%. After using the decision aid respondents were more likely to feel that they knew their options and that they had enough information to make a decision.

Decision aids are categorised according to whether they are educational (informative) or decision analysis tools (aid in structuring decision making process), and if they are prescriptive (aimed at arriving at a treatment decision) or descriptive (clarifying options and improving insight into decision making process).⁴³ They can be classified according to whether they are used before, during or after the consultation and with or without the presence of the doctor for guidance. Some may be used as a resource for patients to work through on their own and others may be used during consultations to structure or prompt discussion of treatment options.³⁸ In the ISDM model, decision aids are used to facilitate joint decision making between the patient and doctor. Therefore, it is not desirable for doctors to suggest decision aids to patients only as a way to share information and subsequently neglect their obligation to work with the patient to arrive at a decision.

There are mixed findings regarding the impact of decision aids on treatment decisions.⁴³ Reported benefits are shown

in *Table 2*. As there is some inconsistency regarding the nature of these beneficial outcomes, further inquiry needs to be conducted into the effect of decision aids on actual behaviour and patient adherence to treatment decisions as well as the cost effectiveness of such interventions.

Conclusion

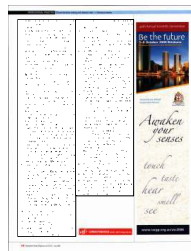
Shared decision making has become an important part of the general practice consultation, but patient preference for the type and depth of involvement needs to be explored. For those patients who want to be actively involved in management decisions, and where there are a number of options available, decision aids can be helpful in informing their choice.

Readers interested in exploring the different aids available should consult the Ottawa Decision Aids website at <http://decisionaid.ohri.ca/dec aids.html> which includes aids relating to cardiovascular risk, treatment of tennis elbow and preventing stroke in patients with atrial fibrillation.

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References

1. Pendleton D, Schofield T, Tate P, Havelock P. The new consultation. Developing doctor-patient communication. Oxford: Oxford University Press, 2003.
2. Szasz TS, Hollander MH. The basic model of the doctor-patient relationship. *Arch Int Med* 1956;97:585.
3. Roter DL, Hall JA. Doctors talking with patients/patients talking with doctors. Connecticut: Auburn House, 1992.
4. Brody H. The healer's power. New Haven: Yale University Press, 1992.
5. Stevens J. Brief encounter. Factors and fallacies in learning and teaching the science of consultation for the future general practitioner. *J Roy Coll Gen Pract* 1974;24:5-22.
5. Haynes RB, McKibbon KA, Kanani R. Systematic



- review of randomised trials of interventions to assist patients to follow prescriptions for medications. *Lancet* 1996;348:383-6.
7. Britten N, Stevenson FA, Barry CA, Barber N, Bradley CP. Misunderstandings in prescribing decisions in general practice: qualitative study. *BMJ* 2000;320:484-8.
 8. Tomlinson T. The physician's influence on patient's choices. *Theor Med* 1986;7:105-21.
 9. Quill TE, Brody H. Physician recommendations and patient autonomy: finding a balance between physician power and patient choice. *Anns Int Med* 1996;125:763-9.
 10. Edwards A, Evans R, Elwyn G. Manufactured but not imported: new direction for research in shared decision making support and skills. *Patient Educ Couns* 2003;50:33-8.
 11. Balint M. *The doctor, his patient and the illness*. London: Tavistock Publications, 1957.
 12. Rogers CR. *Client centred therapy: its current practice, implications and theory*. Boston: Houghton Mifflin, 1951.
 13. Byrne PS, Long BEL. *Doctors talking to patients*. London: HMSO, 1967.
 14. Levenstein JH, McCracken EC, McWhinney IR, et al. The patient centred clinical method. 1. A model for the doctor-patient interaction in family medicine. *Fam Pract* 1986;3:24-30.
 15. Mead N, Bower P. Patient centredness: a conceptual framework and review of the empirical literature. *Soc Sci Med* 2000;51:1087-100.
 16. Kravitz RL, Melnikow J. Engaging patients in medical decision making. *BMJ* 2001;323:584-5.
 17. Edwards AGK, Barker J, Bloor M, et al. A systematic review of risk communication: improving effective clinical practice and research in primary care. Cardiff: University of Wales College of Medicine, Department of General Practice, 1998.
 18. Elwyn G, Edwards A, Kinnersley P. Shared decision making in primary care: the neglected second half of the consultation. *Br J Gen Pract* 1999;49:477-82.
 19. Charles C, Gafni A, Whelan T. Shared decision making in the medical encounter: what does it mean? (or it takes two to tango). *Soc Sci Med* 1997;44:681-92.
 20. Towle A. *Physician and patient communication skills: competencies for informed shared decision making*. [Informed Shared Decision Making Project]. Vancouver: University of British Columbia, 1997.
 21. Towle A, Godolphin W, Richardson A. *Competencies for informed shared decision making (ISDM): Report on interviews with physicians, patients and patient educators and focus group meetings with patients*. Vancouver: University of British Columbia, 1997.
 22. Kassirer JP. Incorporating patients' preferences into medical decisions. *N Engl J Med* 1994;330:1895-6.
 23. Stewart MA. Effective physician-patient communication and health outcomes. *Can Med Assoc J* 1995;152:1423-33.
 24. Stewart M, Brown JB, Donner A, et al. The impact of patient centred care on outcomes. *J Fam Pract* 2000;49:796-804.
 25. Stewart M. Towards a global definition of patient centred care. *BMJ* 2001;322:444-5.
 26. Guagnoli E, Ward P. Patient participation in decision making. *Soc Sci Med* 1998;47:329-39.
 27. Blanchard C, Labrecque MS, Ruckdeschel JC, et al. Information and decision making preferences of hospitalised adult cancer patients. *Soc Sci Med* 1988;27:1139-45.
 28. Strull WM, Lo B, Charles G. Do patients want to participate in medical decision making? *JAMA* 1984;252:2990-4.
 29. Levinson W, Koo A, Kuby A, et al. Not all patients want to participate in decision making. *J Gen Intern Med* 2005;20:531-5.
 30. Longo MF, Cohen DR, Hood K, et al. Involving patients in primary care consultations: assessing preferences using discrete choice experiments. *Br J Gen Pract* 2006;56:35-42.
 31. Lelie A. Decision making in nephrology: shared decision making? *Patient Educ Couns* 2000;42:81-90.
 32. Wirtz V, Cribb A, Barber N. Patient-doctor decision making about treatment within the consultation: a critical analysis of models. *Soc Sci Med* 2006;62:116-24.
 33. Elwyn G, Edwards A, Kinnersley P, Grol R. Shared decision making and the concept of equipoise: defining the competences of involving patients in health care choices. *Br J Gen Pract* 2000;50:892-9.
 34. O'Connor A, Stacey D, Entwistle V, et al. Decision aids for people facing health treatment or screening decisions. *The Cochrane Database of Systematic Reviews* 2003(1): Art. No.: CD001431.
 35. Epstein RM, Alper BS, Quill TE. Communicating evidence for participatory decision making. *JAMA* 2004;291:2359-66.
 36. Llewellyn-Thomas HA. Patients' health care decision making: a framework for descriptive and experimental investigations. *Med Decis Making* 1995;15:101-6.
 37. Edwards A, Elwyn G. The potential benefits of decision aids in clinical medicine. *JAMA* 1999;282:779-80.
 38. O'Connor A, Edwards A. The role of decision aids in promoting evidence based patient choice. In: Edwards A, Elwyn G, editors. *Evidence based patient choice: inevitable or impossible?* New York: Oxford University Press, 2001;220-42.
 39. Man-Son-Hing M, Laupacis A, O'Connor AM, et al. A patient decision aid regarding antithrombotic therapy for stroke prevention in atrial fibrillation: a randomised controlled trial. *JAMA* 1999;282:737-43.
 40. Whelan T, Levine M, Willan A, et al. Effect of a decision aid on knowledge and treatment decision making for breast cancer surgery. *JAMA* 2004;292:435-41.
 41. McNutt RA. Shared medical decision making: problems, process and progress. *JAMA* 2004;292:2516-18.
 42. Wallace C, Leask J, Trevena LJ. Effects of a web-based decision aid on parental attitudes to MMR vaccination: a before and after study. *BMJ* 2006;332:146-9.
 43. Volk RJ, Spann SJ. Decision aids for prostate cancer screening. *J Fam Pract* 2000;49:425-7.



Table 1. Competencies for ISDM²¹

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1. Develop a partnership with the patient
 2. Establish/review patient's preferences for information
 3. Establish/review patient's preferences for role in decision making and the existence/nature/degree of decisional conflict (where decisional conflict is defined as the state of uncertainty about the course of action to take)
 4. Ascertain and respond to the patient's ideas, concerns and expectations
 5. Identify choices and evaluate the research evidence in relation to the individual patient
 6. Present (or direct to) evidence, taking into account #1 and #2 above, and help the patient reflect upon and assess the impact of alternative decisions
 7. Make or negotiate a decision in partnership and resolve conflict
 8. Agree upon an action plan and complete arrangements for follow up

Table 2. Reported benefits of decision aids^{21,22,4,6}

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- Increased knowledge concerning the treatment/screening options, benefits, risks
 - Less decisional conflict
 - Greater satisfaction with the decision making process
 - More realistic expectations
 - Greater likelihood of being able to make a decision and therefore a lesser proportion of patients left undecided about their treatment
 - Increased correlation between patient values and decisions
 - More active participation in the decision making process on the part of the patient
 - Enhanced communication between doctors, patients and family members