Clinical review

The importance of patient preferences in treatment decisions—challenges for doctors

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The expectation that patients will become increasingly involved in making treatment decisions poses new challenges for doctors. This article discusses what these are and how doctors might face them

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Health professionals are increasingly encouraged to involve patients in treatment decisions, recognising patients as experts with a unique knowledge of their own health and their preferences for treatments, health states, and outcomes.[1, 2] Increased patient involvement, a result of various sociopolitical changes,[w1] is an important part of quality improvement since it has been associated with improved health outcomes[3, w1–w9] and enables doctors to be more accountable to the public.

However, this poses challenges for doctors. We discuss these in relation to the competences for shared decision making that have been proposed.[4, w10]

Summary points

Doctors are encouraged to involve patients in making treatment decisions, but this poses challenges for doctors

Practical concerns include the extra time needed and the difficulties in eliciting patients' preferences, exacerbated by limited appropriate information to support patient involvement

Doctors may not have the appropriate competences, with risk communication particularly challenging, and patients' preferences may differ from those of their doctors or evidence based guidelines

Some doctors may wish to retain the imbalance of power between themselves and their patients, and patients may be reluctant to share their preferences if they consider their doctor as more powerful and knowledgeable

Innovative research and appropriate professional training is needed to find solutions to these problems to support doctors committed to involving their patients in decision making

Methods

We made literature searches using Medline, Web of Science, PsychINFO, CINAHL, the Cochrane Library, and HMIC (key words "consumer participation," "patient participation," "decision making," "patient preferences," "shared decision making," "patient involvement in decision making"). We also searched references of articles, indexes of key journals, important texts about patient involvement, and key reviews.

We conducted informal interviews with doctors from a range of specialties (general practice, orthopaedics, stroke medicine, accident and emergency, and vascular surgery) and recorded their opinions to provide a focus to this discussion (quotes in italics).

Establishing a partnership

For patients' views about treatment options to be valued and necessary, there must be a partnership between doctor and patient, but establishing one requires both time and certain skills.

"There's not enough time"—The pressure of time is a perpetual challenge; doctors are particularly concerned about the implications of informing patients without allowing extra time for this.[5] However, involving patients more in treatment decisions may have no significant effect on consultation length[3]: adequate discussion at an early stage may allow more succinct discussion later and ultimately save time.[6] Nevertheless, it may be difficult to overcome doctors' perceptions of the extra time required.

Doctors may not have the appropriate communication skills to elicit patients' preferences and involve them in treatment decisions[w10]; for example, general practice registrars would welcome further training in involving patients in decision making.[7]

"You need to build a relationship up over time"—Doctors may find it easier to share decision making with patients they know well.[8, w11] However, a patient may not see the same doctor at every consultation, and care may be multidisciplinary. Doctors seeing a patient for the first, or a single, time may have to be particularly skilful at gaining the patient's trust and eliciting his or her preferences, which are likely to be affected by the patient's experience of other doctors.[9]

Extra references (w1-w26) are listed on bmj.com

Emergency scene; image removed at request of agency

Doctors need to build a partnership with patients and gain their trust in order to elicit their preferences

Eliciting patients' preferences

"It's difficult to generalise about what role patients prefer in treatment decisions"—Doctors may have a poor understanding of their patients' preferences for involvement in decision making.[10] In one study doctors wrongly estimated hypertensive patients' preferences for discussion about treatment 40% of the time, underestimating this and their desire for information, while overestimating their desire to participate in decisions.[11] Finding ways to elicit patients' preferences is therefore a considerable challenge. Furthermore, preferences may be influenced by the way that they are elicited,[12] and doctors may elicit preferences from certain groups of patients more readily than others.

Although some patients may not wish to make the final choice of treatment, many would prefer more information.[w12-w14] Deber suggested there may be two components of treatment decisions—problem solving ("identifying the one right answer") and decision making ("selecting the most desired bundle of outcomes")—and hypothesised that, whereas patients may prefer doctors to perform the problem solving component (which requires clinical expertise), patients would want to be involved in decision making.[13] This was supported in a survey of patients undergoing angiography.[w15]

"Some patients just don't want to be involved"—Some patients may not want to participate in decision making.[w16] This may be because they feel they lack the knowledge and experience to develop informed preferences and are afraid of making the wrong decision.[w17 w18] Nevertheless, it is thought that most patients want doctors to understand their preferences even if they do not wish to make the final decision.[14] Furthermore, patients' role preferences may change over time and through the course of an illness,[15] so doctors have to be sensitive to such changes.

Giving patients information

Patients must be given technical information that is clear and unbiased to ensure that their preferences are based on fact and not misconception.

"People don't retain information"—Even when patients are given such information they may not recall it. In a study of patients' recall of the risks associated with endarterectomy, patients recalled risks ranging from 0 to 65% for a communicated risk of 2%.[16]

"You have to be able to give the right information at the right time"—Doctors feel that a lack of suitable information, or of access to it, is a barrier to shared decision making,[7] while there seems to be too little information designed specifically to support patient involvement.[17]

Presenting risk

"You can always present information so they select the treatment you want them to"—A study of nephrologists revealed that doctors used information to influence patients' treatment choices.[18] Presenting "logically equivalent" information in different ways has a substantial effect on treatment preferences.[19 w19] For example, relative risk is more persuasive than absolute risk.[6]

Enabling patients to understand risks is crucial before considering different treatment options. Yet risk is a complex phenomenon that many patients (and doctors) find difficult to understand. Common errors include compression bias (the tendency to overestimate small risks and underestimate large ones), miscalibration bias (overestimation of the level and accuracy of one's knowledge), availability bias (overestimation of notorious risks[20]), and optimism-pessimism bias (the tendency of patients to believe that they are at less risk of an adverse outcome than people similar to them[14]).

Patients may understand different methods of presenting risk to varying extents. Numerical information is often poorly understood,[6 w20] so doctors may need to determine how to present risk in a way that is helpful for an individual patient, or at least be able to present it

Patients' views of being involved in decision making

Involvement of patients is something that is fundamental to patient experience, as shown by the following two interview extracts (unpublished data from authors).

53 year old woman

"I had one particular problem, when I thought alcohol was affecting my . . . irritable bowel. She gave me a book to read. She didn't say, 'We'll do this or the other,' she said, 'Look, read this,' and that is the kind of involvement that I think is great . . . you can decide almost for yourself or go back to her and say, 'Look it says this, shall we do the other?'

"I think shared decision making is really hard because [doctors] have so much more knowledge. So it can't be totally shared unless we are totally informed, and we can't be totally informed because we can't go and do a crash course on whatever disease we have got. When there are alternatives they need to inform people."

51 year old man

"Actually talk to them, treat them like human beings, it's the bedside manner it comes down to at the end of the day. I'm not saying you've got to sit there for days talking to people but actually say, 'I'm going to do this operation, and you need it because . . . and we can't find any alternatives to doing it, are you happy with that?' Some conversation like that would have been sufficient, but we didn't have a choice.

"If someone sits down and says, 'You've got cancer,' you just hear 'I've got cancer.' . . . That's when they should say, 'Right, we will stop there, and we'll give you this information to read or this website.' But they don't tell you about it, and so you're so far down the path that all the decisions have been made. If something needs to be done very quickly it's knowing which are the important bits of information. One assumes that . . . doctors are in the best position to give you that information, but they're not always the best person at giving information."

in different ways. Differences in education and experience may also affect patients' understanding of risk; methods of increasing comprehension among people with poor literacy and numeracy will be essential.[21]

Individualised risk information—that is, based on each patient's clinical characteristics—is available for only a few conditions, such as the Framingham equation for stroke or cardiovascular disease.[w21] Even this information is probabilistic in nature and requires skilful communication.

Furthermore, there may be ambiguity associated with the language of risk. Doctors and patient may have different perceptions of what is "low risk," "unlikely," or "rare."[6 w22] There may also be variation in acceptability of risk, so doctors need to ascertain the degree of risk that a patient is comfortable with to ensure discussion is relevant. In addition, people's conceptions of a condition and its implications may vary.[6]

Expressing uncertainty

"Some people will feel insecure if you appear to be in doubt about which treatment is best"—Doctors and patients may respond to uncertainty in different ways. Edwards and Prior state that doctors must address how they respond to uncertainty and should recognise that sharing it with patients may decrease the anxiety patients have if uncertainty about treatment options is not made explicit.[22]

Decision analysis may facilitate communication of complex risks.[w23] However, it has not yet been routinely used in clinical practice, and methodological limitations, such as only expressing outcomes in numerical terms, may limit its usefulness.[w23]

Dealing with alternative information sources

"If they are going to the internet then I am not meeting their information needs"—Doctors may be resistant to patients seeking alternative sources of information, which may place strains on the relationship,[w1] particularly since much health information is of poor quality.[w24] Patients may not have the skills to evaluate this, and doctors may find it difficult to counter flawed evidence presented in a persuasive way.

Additional educational resources

Websites

DIPEx (www.dipex.org). Audio and video interviews with people describing their personal experiences of various medical problems

Centre for Health Information Quality (www.hfht.org/chiq/). Development agency working to raise standards in health information for the public

Hi Quality (www.hiquality.org.uk/). Set up by the Centre for Health Information Quality to support those looking for or producing health information

Discern (www.discern.org.uk/). Brief questionnaire that allows users to assess the quality of information on treatment choices for health problems

Medicines Partnership (www.concordance.org/). Two year initiative supported by the Department of Health aimed at putting the principles of concordance into practice, including professional development, projects, research, health policy, and information for and from patients and the public

Foundation for Informed Medical Decision Making (www.fimdm.org/). US group that, as a result of concerns about variations in medical intervention rates, encourages patients to play a greater role in choosing treatments. Produces web based and video decision aids

Ottawa Health Decision Centre (www.ohri.ca/programs/clinical_epidemiology/OHDEC/default.asp). Part of the Clinical Epidemiology Unit of the Loeb Health Research Institute at Ottawa Hospital. Undertakes research into support for patient decision making

Reviews

Engaging patients in decisions: a challenge to health care delivery and public health. *Qual Health Care* 2001;10(suppl 1):i1-66 (http://qhc.bmjjournals.com/content/vol10/suppl_1/). Collection of papers that provide an excellent overview of the subject

Elwyn G, Edwards A. *Evidence based patient choice.* Oxford: Oxford University Press, 2001. Superb overview of the subject

Relevant journals

Health Expectations, Patient Education and Counselling, Medical Decision Making, Quality and Safety in Health Care

Negotiating a decision in partnership with the patient

In many cases a shared decision that is acceptable for both patient and doctor will arise from discussion, but sometimes this is more problematic.

"It's hard to integrate patients' preferences if they have unreasonable expectations"—Reaching consensus is difficult if patients' preferences do not match those of doctors. Differences between patients and doctors have been shown in many clinical settings, including cardiovascular disease, cancer, obstetrics and gynaecology, and acute respiratory illness.[23] Patients' preferences may also disagree with clinical guidelines,[w25] which may have implications for concordance and poses a challenge to doctors to resolve such discrepancies.

Some doctors are concerned that patients will demand treatments that offer little benefit but which may be expensive. The conflict between individual and societal needs is particularly important in the publicly funded NHS,[w26] and strategies will have to be developed to deal with inequitable demands.

Inequalities in patient choice

A further concern is that residual racial and sex discrimination, along with socioeconomic and educational inequality, may cause groups of patients to have systematic variation in their preferences and in their capacity to articulate them.[24] Black patients with HIV were less likely to have discussed their treatment preferences with their doctor than white HIV positive patients.[25] Access to services is affected by sex, race, and socioeconomic status,[24] which may affect expectations and perceptions of risk. In women with menstrual disorders, educated women were much less likely to agree to hysterectomy.[10] This may produce further widening of inequalities, particularly if certain groups of patients are more vocal about their preferences and demanding of particular treatments.

Conclusions

To improve the quality of care they provide, doctors should understand their patients' preferences. However, this raises many challenges for doctors. Practical concerns include time pressures and difficulties in eliciting preferences from patients who may be hesitant to make treatment decisions. These are compounded by a deficit of appropriate information to support patients' decisions. Doctors may not have the appropriate interpersonal skills, particularly for communicating risk.

Medical uncertainty, deficiencies in individual doctors' knowledge, and the highly variable ability of patients to understand and remember clinical information mean that risk communication is often inadequate to support patients in making informed decisions.

Some doctors may wish to uphold the imbalance of power between themselves and their patients, which may make patients reluctant to share their preferences. Inequalities in health care may be perpetuated or exacerbated if these affect patients' preferences or the extent to which doctors seek to inform or understand them. There are also challenges to be overcome if patients express preferences that contradict those of their doctors or guidelines.

Despite these challenges, many doctors are committed to understanding patients' preferences. Innovative research is being undertaken to find solutions to these problems. The imaginative use of different sources of information, together with evidence based decision aids and decision analysis, are likely to be useful.

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A history lesson

I first met Joan after she was admitted to hospital for investigation of a persistently raised serum creatine kinase concentration. Provisional arrangements had been made for electromyography and muscle biopsy, in case she had polymyositis. Joan was grateful for the medical attention, but somewhat surprised at the urgency of admission. She had suffered from exertional muscle pain and weakness for as long as she could remember. Ever since childhood, she had experienced mobility problems: after walking only short distances, she would have to stop and rest because of the aching in her legs. These intrusive symptoms had affected many aspects of her life.

Joan's father had worked on the railways, so they had enjoyed free rail travel. On their annual trips to see her grandmother in Lochgilphead they needed to catch a train and then a ferry, and were often on a tight schedule. They had to run to get from the ferry terminal at Gourock to catch the train. She was always unable to keep up with the rest of the family, and she remembered her father frowning beneath his bowler hat, looking back in despair as she tried to run. At school, she was always last to be picked for teams. During winter she would dread the walk to school if it had been snowing as she was unable to dodge out of the way of flying snowballs. Like most young people, she enjoyed going to dances in her teens and 20s. However, she was only able to make it round the floor once and found the experience much easier if she could start with a waltz rather than a foxtrot. Some people thought she was seeking attention when she stopped to rest after walking only a short distance. Given that most people of this generation met their future spouses at these dances, I asked Joan about her husband. "I did eventually find a husband," she explained, "but he never liked dancing."

Over the years her friends, relatives, and medical attendants had grown accustomed to her rather odd gait; indeed, she had worked for years at her general practice as a bookkeeper. Her mobility gradually deteriorated, but surprisingly she did not seek formal medical attention until 1999, by which time she could only walk about 50 yards before her legs "seemed to stop." Spinal stenosis was suspected, but no imaging was performed as Joan was not keen on surgery.

The next year she developed chest pains and was found to have a raised creatine kinase concentration (1900 U/l). Subsequent coronary angiography showed severe triple vessel disease. Joan underwent a successful triple bypass the following year, although the operation was delayed after a further admission with chest pain and a raised creatine kinase level, without changes on her electrocardiogram. Her creatine kinase levels had never returned to normal, which eventually prompted her referral to us.

Joan's history strongly suggested a metabolic myopathy, and McArdle's syndrome (myophosphorylase deficiency) was eventually confirmed on muscle biopsy. I telephoned her to discuss the diagnosis and tell her that there was no effective treatment for her condition. To my surprise, she said it had been a "very satisfactory result." After years of being ridiculed, she was just glad to have an explanation.

Joan's story reminded me how important history taking is, and simply listening to patients will often provide vital clues to their diagnosis. It was also enlightening to realise that sometimes simply a diagnosis can be a satisfactory outcome for patients, especially if they have endured years of unexplained symptoms.

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