

Sharing decisions with patients: is the information good enough?

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Shared decision making, in which patients and health professionals join in both the process of decision making and ownership of the decision made, is attracting considerable interest as a means by which patients' preferences can be incorporated into clinical decisions.¹ When there are several treatment options which may have different effects on the patient's quality of life, there is a strong case for offering patients choice. Their active involvement in decision making may increase the effectiveness of the treatment.

Trials are currently under way to test this hypothesis formally, but there are good grounds for optimism. Patients with hypertension benefit if they are allowed to adopt an active rather than a passive role in treatment,^{2,3} patients with breast cancer suffer less depression and anxiety if they are treated by doctors who adopt a participative consultation style,⁴ and patients who are more actively involved in discussions about the management of their diabetes achieve better blood sugar control.⁵ Patients whose doctors are ignorant of their values and preferences may receive treatment that is inappropriate to their needs.⁶⁻⁸

Patients cannot express informed preferences unless they are given sufficient and appropriate information, including detailed explanations about their condition and the likely outcomes with and without treatment. Yet many report considerable difficulties in obtaining relevant information.⁹ There are various reasons for this. Health professionals frequently underestimate patients' desire for and ability to cope with information. Consultation times are limited—there is often insufficient time to explain fully the condition and the treatment choices. Health professionals may themselves lack knowledge of treatment options and their effects. A solution to this problem is to ensure that patients have access to written or audiovisual material, to inform themselves and to use in discussion with health professionals.

Evaluating information materials

If information materials are to be used to support treatment decisions, they must contain scientifically reliable information and be presented in a form that is acceptable and useful to patients. We have recently completed a study evaluating patient information for 10 common conditions or treatments. The methods have been described elsewhere.¹⁰ All 10 topics (back pain, cataract, depression, glue ear, high cholesterol,

Summary points

If information materials are to be used to support patients' involvement in treatment decisions, they must contain relevant, research based data in a form that is acceptable and useful to patients

Current information materials for patients omit relevant data, fail to give a balanced view of the effectiveness of different treatments, and ignore uncertainties

Many information materials adopt a patronising tone—few actively promote a participative approach to decision making

Groups producing information materials must start with needs defined by patients, give treatment information based on rigorous systematic reviews, and involve multidisciplinary teams (including patients) in developing and testing the materials

hip replacement, infertility, menorrhagia, prostate enlargement, stroke rehabilitation) had been the subject of systematic reviews providing a yardstick against which to judge the clinical content of the material available.

Identification of materials

We surveyed self help groups, consumer and voluntary organisations, professional bodies, health authorities and NHS trusts, drug companies, private health insurers, and other commercial organisations to identify relevant materials. The survey elicited positive responses from 78 organisations, which, between them, provided copies of 128 printed materials, eight audiotapes or prerecorded telephone helplines, and four videos (see appendix). Materials were selected for review if they referred to more than one treatment option and included some reference to treatment outcomes.

Review

We organised reviews of 54 materials (42% of those received) by 62 patients with personal experience of the specific health problems and by 28 clinical or aca-

demographic specialists who were familiar with the available research evidence. The patients were recruited via newspaper advertisements and self help groups. All had recent experience of one of the health problems chosen for study. They participated in 10 focus groups (one for each health problem), in which they discussed their information needs and their opinions about the specific materials. The focus group discussions were audiotaped, transcribed, and analysed using the framework method.¹¹ Themes were identified and charted independently by two of us (VE and DG). The clinical specialists reviewed the materials independently using a structured checklist. A questionnaire which was sent to the developers of the materials elicited responses from publishers of 26 of the materials reviewed (48%).

General views

Patient focus groups reported considerable dissatisfaction with their experiences of communication with health professionals. Most had wanted much more information about their condition and treatment than they had been given. Many did not feel they had been offered any choices about their treatment, and some had not realised that there were other options until they received the information materials we sent them for review. Initial reactions to these materials were enthusiastic—any information was better than nothing—but on closer examination the patients became more critical. The specialists tended to be more critical of the materials than the patients. The study revealed many deficiencies in the information available; it also provided suggestions on how patient information might be improved. We highlight selected themes here.

Topics of relevance to patients

The patients identified a wide range of information needs and had some clear ideas about the kinds of information that were needed at particular times during the course of illness and treatment (box). Very few of the materials reviewed met all these needs adequately. For example, while many materials contained reasonably clear descriptions of the disease and common symptoms, the causes and consequences of conditions were much less well covered and information about prevalence was often missing. These were serious omissions because focus group participants were clear that they needed to understand the natural history of the condition from which they were suffering in order to help them cope with it. Many of these important omissions could have been avoided if patients had been consulted about their information needs before the materials were developed. All but four of the publishers who returned our questionnaire claimed to have involved patients or potential users in the development of the materials, but for the most part this was restricted to asking individual lay readers or consumer group representatives to comment on the design and content of an existing draft. Very few had researched patients' information needs before they started, and few had evaluated materials formally before making them publicly available.

Patients need information to:

- Understand what is wrong
- Gain a realistic idea of prognosis
- Make the most of consultations
- Understand the processes and likely outcomes of possible tests and treatments
- Assist in self care
- Learn about available services and sources of help
- Provide reassurance and help to cope
- Help others understand
- Legitimise seeking help and their concerns
- Learn how to prevent further illness
- Identify further information and self help groups
- Identify the "best" healthcare providers

Information about effectiveness

The specialists identified many inaccuracies and misleading statements in the materials reviewed which could give a false impression of the likely effectiveness of treatments. The most common fault was to give an overoptimistic view, emphasising benefits and glossing over risks and side effects. Quantitative information about recovery time and outcome probabilities was absent from most materials. The assumption on the part of many information producers that patients do not want to know about side effects was not borne out by the views expressed in the focus groups. Most participants were adamant that they did want to know the full picture, as long as it was presented in a non-alarmist fashion. They indicated a preference for information that is balanced and includes a careful and honest assessment of the pros and cons of treatment. If outcome probabilities are unknown because relevant research has not been carried out, it is best to be frank about this rather than provide reassurance that may turn out to be false.

Treatment options and self care

There is a fine balance between providing too little information in a leaflet and too much. Focus group



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participants considered many materials too introductory and basic to be helpful, but one or two contained a great deal of technical detail that reviewers considered unnecessary. The patients were clear that they wanted information about the full range of treatment possibilities, including complementary therapies or counselling. Some otherwise good quality materials failed to provide information about certain treatments or management strategies, presumably because they were not supported by evidence of efficacy. Patients who had heard about these treatments found the omissions frustrating and were keen to learn more. They would prefer that the information was included together with an honest assessment of whether or not the treatments are known to be effective. The patients wanted to be told about things they could do themselves to manage the problem or to avoid risks, but self care and prevention were not always well covered in the materials we reviewed.

Dealing with uncertainty

Many materials included prescriptive statements and lists of “do’s” and “don’ts” that were not supported by evidence. It was very uncommon for materials to admit to scientific uncertainty or variations in clinical opinion. Very few contained any information about the primary sources on which they were based, and it was rare to find a discussion of the strength of research evidence for the claims made. The survey of publishers showed an alarming vagueness about the sources of evidence from which the information was drawn. Only two of the materials we reviewed were explicitly based on systematic reviews of research into treatment efficacy. It is very important that patient information is based on the best and most up to date information available. Reliance on the knowledge of individual doctors is not sufficient as a guarantee of reliability. The best way to ensure that information on treatment efficacy is scientifically based and accurate is to conduct a systematic review of published reports or to base it on a review contained in a quality assured database such as the *Cochrane Library*.

Currency

Nearly a third of the materials we reviewed did not include a publication date, so it was not possible for readers to judge whether they were likely to contain out of date information. Some had been in circulation for many years, and specialist reviewers pointed out that many were indeed out of date and failed to include information about new treatments or recent research evidence. The development of patient information materials should not be seen as a one off exercise. It requires a long term commitment to produce regular updates and to withdraw out of date materials from circulation. It is helpful if materials indicate a “shelf life,” beyond which date readers should be warned to seek alternative sources of information.

Language, tone, and presentation

Several materials were criticised for being patronising, victim blaming, dismissive, or promoting an attitude

of “doctor knows best.” Focus group participants indicated a preference for information that was facilitative rather than prescriptive, honestly optimistic rather than frightening or gloomy, and which related to them personally. The use of pictures and diagrams was appreciated, but the patients did not like “gory” or “scary” pictures. They preferred materials that were structured and concise, with clear headings, important sections highlighted, short blocks of text and a good index. No clear preferences were identified for video, audio, computer based, or printed materials. Focus group participants were more concerned with the information content than with media, and all types were appreciated if they contained useful information.

Participation in decision making

While few of the materials included explicit statements of their aims and who they were designed for, responses to the publishers’ questionnaire showed that most were intended to educate patients or to prepare them for specific treatments or surgical procedures. Only two of the materials reviewed were explicitly designed to support informed treatment choice. The didactic style of many of the materials was not popular with the focus group participants. They were more enthusiastic about materials which gave them a sense

Checklist for patient information materials

The process:

- (1) Involve patients throughout the process
- (2) Involve a wide range of clinical experts
- (3) Be specific about the purpose of the information and the target audience
- (4) Consider the information needs of minority groups
- (5) Review the clinical research evidence and use systematic reviews wherever possible
- (6) Plan how the materials can be used within a wider programme promoting shared decision making
- (7) Consider cost and feasibility of distribution and updating when choosing media
- (8) Develop a strategy for distribution
- (9) Evaluate the materials and their use
- (10) Make arrangements for periodic review and updating
- (11) Publicise the availability of the information materials

The content:

- (1) Use patients’ questions as the starting point
- (2) Ensure that common concerns and misconceptions are addressed
- (3) Refer to all relevant treatment or management options
- (4) Include honest information about benefits and risks
- (5) Include quantitative information where possible
- (6) Include checklists and questions to ask the doctor
- (7) Include sources of further information
- (8) Use non-alarmist, non-patronising language in active rather than passive voice
- (9) Design should be structured and concise with good illustrations
- (10) Be explicit about authorship and sponsorship
- (11) Include reference to sources and strength of evidence
- (12) Include the publication date

of empowerment. These included materials which reassured them that they were not alone in experiencing the symptoms, gave them ideas for self help, and suggested questions they could ask the doctor. Participants appreciated features that actively engaged them and helped them to record relevant information for discussion in a clinical consultation, such as symptom diaries or space to write down questions or points to remember.

Improving quality

These findings show that there is a great deal more to the production of good quality patient information than is commonly assumed. Patients should be involved throughout the process, reliable sources of evidence must be used, and careful thought must be given to the purpose of the information and the needs of the target audience.¹² The box gives a checklist of points for consideration by developers of patient information materials.

Our survey showed that there was a dearth of information designed specifically to support patient involvement in treatment decisions, despite the fact that many patients want to play a more active role and patient involvement has been on the policy agenda for some years now. The box outlines a series of questions that patients may want answers to if they are to express informed preferences. It should be possible to design information packages which address these questions honestly, accurately, and in a form that is acceptable to patients.

Task for the NHS Executive

The goals of the government's patient partnership strategy, which aims to promote shared decision making,¹³ will not be met unless patients are provided with good quality information about diseases and treatments. We call on the NHS Executive to:

- Fund the development and evaluation of high quality patient information materials covering common clinical problems
- Commission patient information materials to accompany each of the evidence based guidelines to be commissioned by the National Institute of Clinical Excellence¹⁴
- Establish a system for accrediting patient information materials and websites to help patients and health professionals identify reliable information
- Establish a system for disseminating good quality materials to patients, where appropriate making them available in general practitioners' surgeries, hospital departments, community pharmacies, consumer health information services, healthy living centres, public libraries, etc
- Ensure that each NHS Trust and primary care group has a designated senior member of staff responsible for ensuring that patient information meets high quality standards
- Ensure that all clinicians receive training in communication skills and techniques to promote shared decision making.

Questions commonly asked by patients

What is causing the problem?
 Am I alone? How does my experience compare with that of other patients?
 Is there anything I can do myself to ameliorate the problem?
 What is the purpose of the tests and investigations?
 What are the different treatment options?
 What are the benefits of the treatment(s)?
 What are the risks of the treatment(s)?
 Is it essential to have treatment for this problem?
 Will the treatment(s) relieve the symptoms?
 How long will it take to recover?
 What are the possible side effects?
 What effect will the treatment(s) have on my feelings and emotions?
 What effect will the treatment(s) have on my sex life?
 How will it affect my risk of disease in the future?
 How can I prepare myself for the treatment?
 What procedures will be followed if I go to hospital?
 When can I go home?
 What do my carers need to know?
 What can I do to speed recovery?
 What are the options for rehabilitation?
 How can I prevent recurrence or future illness?
 Where can I get more information about the problem or treatments?

Appendix: Information materials obtained for the study

Asterisks indicate materials reviewed.

Commercial publishers/private health care:

Butterworth-Heinemann (back pain)
 EMIS (cataract, glue ear,* infertility, stroke rehabilitation)
 Fish Foundation (high cholesterol)
 General Practitioner (menorrhagia)
 Hadley Hutt Computing (infertility)
 Krames Communications (depression,* high cholesterol, hip replacement, infertility, menorrhagia*)
 PatientWise (back pain,* high cholesterol,* prostate enlargement*)
 Pritchett & Hull (hip replacement, stroke rehabilitation)
 PPP Healthcare (cataract, hip replacement,* infertility*)
 Scriptographic (back pain, depression,* prostate enlargement*)
 Videos for Patients (depression,* prostate enlargement*)

Consumer groups/voluntary organisations:

Arthritis Care (hip replacement)
 Australian Conductive Deafness Association (glue ear)
 British Heart Foundation (high cholesterol*)
 Chest, Heart and Stroke Association (stroke rehabilitation*)
 College of Health (depression,* glue ear,* hip replacement,* infertility, prostate enlargement*)
 Depression Alliance (depression)
 Family Heart Association (high cholesterol)
 Mind (depression*)
 National Back Pain Association (back pain*)
 National Deaf Children's Society (glue ear)
 Royal National Institute for the Blind (cataract*)
 Stroke Association (stroke rehabilitation*)
 Women's Health (infertility,* menorrhagia*)
 Women's Health Concern (infertility,* menorrhagia*)

Drug and equipment manufacturers:

Bencard (prostate enlargement)
 Bridge Pharmaceuticals (prostate enlargement)
 Ciba-Geigy (back pain)
 Coloplast Foundation (prostate enlargement)
 DePuy (hip replacement*)
 Duphar Laboratories (depression)
 Invicta Pharmaceuticals (prostate enlargement*)
 Johnson & Johnson (hip replacement)
 Lundbeck (depression*)
 Merck, Sharpe & Dohme (high cholesterol,* prostate enlargement)
 Nurofen (back pain*)
 Pharmaceutical Division, 3M Health Care (back pain)
 Richborough Pharmaceuticals (glue ear)
 Serono Laboratories (infertility*)
 Smith & Nephew (prostate enlargement)
 SmithKline Beecham (depression*)
 Tambrands (menorrhagia)
 Zeneca Pharmaceuticals (glue ear)

NHS organisations:

Bedfordshire Health Authority (glue ear*)
 Blackburn, Hyndburn and Ribbles Valley NHS Trust (hip replacement)
 Buckinghamshire Health Authority (cataract*)
 Central Sheffield University Hospitals (infertility, menorrhagia,* prostate enlargement)
 East Lancashire Health Authority (back pain*)
 Gloucester Day Case Cataract Unit (cataract*)
 Health Promotion Wales (high cholesterol*)
 Hertfordshire Health Authorities (glue ear*)
 North Ayrshire and Arran NHS Trust (infertility)
 Plymouth Community Services NHS Trust (prostate enlargement)
 Portsmouth Health Care NHS Trust (stroke rehabilitation)
 Royal Free Hospital, London (glue ear)
 South Manchester University Hospitals NHS Trust (hip replacement, stroke rehabilitation*)
 The Royal Hospitals, Belfast (cataract, hip replacement, infertility)
 United Bristol Healthcare NHS Trust (cataract*)
 University Hospital, Nottingham (menorrhagia)
 Walsgrave Hospital, Coventry (cataract,* high cholesterol, prostate enlargement)
 Whittington Hospital, London (back pain)

Professional/academic bodies:

Action Research (back pain)
 American Academy of Family Physicians (high cholesterol)
 Arthritis and Rheumatism Research Council (back pain, hip replacement*)
 Association of Health Care Policy and Research, US Department of Health and Human Services, (back pain, cataract, depression, stroke rehabilitation*)
 British Medical Association (glue ear, high cholesterol*)
 Chartered Society of Physiotherapists (back pain)
 Hearing Research Trust (glue ear*)
 Institute of Hearing Research (glue ear)
 Nottingham University Research and Treatment Unit in Reproduction (infertility*)
 Organisation of Chartered Physiotherapists in Private Practice (back pain)

Pain Research Institute (back pain)
 Royal College of General Practitioners (depression)
 Royal College of Obstetricians and Gynaecologists (menorrhagia*)
 Royal College of Psychiatrists (depression*)
 Royal College of Surgeons of England (hip replacement,* prostate enlargement*)
 The Stationery Office (back pain*)

Informing Patients, the full report of the study, which includes detailed reviews of the information materials, is available from the King's Fund bookshop, price £16.95.

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*Endpiece***On seeing a kangaroo**

On 29 August 1773 Johnson and Boswell were visiting Scotland and, while dining with the Reverend Alexander Grant in Inverness, Johnson mentioned the first sighting of the kangaroo in the Endeavour River area in July 1770. He is reported to have "volunteered an imitation of the animal. The company stared . . . nothing could be more ludicrous than the appearance of a tall, heavy, grave-looking man, like Dr Johnson, standing up to mimic the shape and motions of a kangaroo. He stood erect, put out his hands like feelers, and, gathering up the tails of his huge brown coat so as to resemble the pouch of the animal, made two or three vigorous bounds across the room."

James Boswell, *The Life of Dr Johnson*, Everyman Library, Dent, 1967