

similar principles should help the doctor identify a population at low risk of having a spinal fracture.

The management of patients with low risk injuries of the neck and back is now well defined. Explanation of the injury, reassurance that the injury is not serious, early mobilisation, and early return to function is the best initial strategy. Advice about physiotherapy can be given to all and formal physiotherapy arranged early for those with more severe limitation in movement.

Patients who have had an accident need to have the risks of a spinal injury assessed. A group of patients at low risk of having an unstable spinal injury can be

identified. These patients do not need spinal immobilisation. Patients with neck symptoms after minor injury meeting all the criteria for low risk are unlikely to need routine radiological evaluation.

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- 1 Ravichandran G, Silver JR. Missed injuries of spinal cord. *BMJ* 1982;284:953-6.
- 2 Poonnoose PM, Ravichandran G, McClelland MR. Missed and mismanaged injuries of spinal cord. *J Trauma* 2002;53:314-20.
- 3 Stiell IG, Wells GA, Vandemheen KL, Clement CM, Lesiuk H, De Maio VJ, et al. The Canadian C-spine rule for radiography in alert and stable trauma patients. *JAMA* 2001;286:1841-8.
- 4 Hoffman JR, Mower WR, Wolfson AB, Todd KH, Zucker MI. Validity of a set of clinical criteria to rule out injury to the cervical spine in patients

with blunt trauma. National Emergency X-Radiography Utilisation Study Group. *N Engl J Med* 2000;343:94-9.

- 5 National Institute for Clinical Excellence. *Triage, assessment, investigation and early management of head injury in infants, children and adults. Clinical guideline 4*. London: National Institute for Clinical Excellence, 2003.
- 6 British Trauma Society. Guidelines for the initial management and assessment of spinal injury. British Trauma Society, 2002. *Injury* 2003;34:405-25.

“Expert patient”—dream or nightmare?

The concept of a well informed patient is welcome, but a new name is needed

Since the chief medical officer for England first introduced the term expert patient, it has been picked up and used very widely.¹ During this time, the notion of the expert patient seems to have been criticised by doctors at least as much as it has been welcomed.² If one asks lawyers, architects, social workers, or management consultants whether they prefer clients who take an interest in the issues they face and are motivated to work in partnership to achieve successful results, the answer seems obvious. So why does the idea of expert patients provoke such antipathy within the medical profession?

We know from reading the press and listening to the debate that when doctors come across the term “expert patient” they hear different things. For the chief medical officer, expert patients are “people who have the confidence, skills, information and knowledge to play a central role in the management of life with chronic diseases.”¹ The suspicion is that for many doctors, the expert patient of the imagination is the one clutching a sheaf of printouts from the internet, demanding a particular treatment that is unproved, manifestly unsuitable, astronomically expensive, or all three. Or, possibly worst of all, a treatment the doctor has never heard of, let alone personally prescribed.

A survey by the pharmaceutical industry body reported that only 21% of doctors were in favour of the government’s proposals on the expert patient; 58% predicted an increase in the workload of general practitioners; 42% believed it would increase NHS costs; and only 12% thought it would improve relationships between doctors and patients.³ A more recent MORI survey of health professionals found that 63% of doctors think that in the long run better informed patients will require more of their time—a rather higher proportion than nurses (48%) but less than

pharmacists (76%).⁴ For these anxious and overworked medics, the expert patient is the demanding patient, the unreasonable patient, the time consuming patient, or the patient who knows it all.⁵ And who in their right minds would want one of those in the consulting room on a Monday morning, with 10 other, more deserving people waiting patiently to be seen?

Perhaps the expert patient is actually something rather different from this unappealing stereotype of the dissatisfied, middle class consumer. The goal of the expert patient programme is not to turn people with Parkinson’s disease into amateur neurologists or people with arthritis into hobby rheumatologists, setting them up to bully and compete with their doctors. The expert patient programme and other self management programmes run by patients’ organisations place more emphasis on developing the confidence and skills to improve quality of life and work in partnership with health professionals.¹ Research shows that such people make less and better use of health professional time, rather than the opposite scenario feared by many doctors. For example, in randomised controlled trials the arthritis self management course and modified versions of the programme showed consistent improvements in knowledge, self efficacy, and use of self management behaviours, notably exercise. Studies by Lorig et al at Stanford University show that a reduction in visits to doctors of 42-44% can be achieved.⁶⁻⁸

The expert patient programme has now been running for two years, and by May 2003 over 2000 people had attended the six week course. Estimates indicate that 19 000 patients could benefit if each primary care trust hosts four pilot courses with between eight and 16 people trained per course.⁹ Thus, even if these targets prove achievable, graduates of the expert patient programme and its voluntary sector cousins

will always form a minority of people with long term conditions. In a different and more important sense all patients and carers are experts, regardless of how much medical knowledge they may have. That is because of the experience of living with their condition and their personal beliefs, priorities, and attitudes to risk.

In relation to taking medicines, to pick one example, people's own beliefs about medicines are known to be the most important determinant of whether and how medicines are taken.¹⁰ Although this idea is not new to doctors, research has shown that patients' perspectives (including their desire and ability to take medicines) are seldom discussed when medicines are prescribed.¹¹ As highly educated professionals in well paid employment, doctors are not necessarily best placed to understand the realities of life for many of their patients, particularly those living with debilitating medical conditions, who are disproportionately non-working, old, and poor. In the surgery the expertise of disadvantaged people who do not share the doctor's implicit model of the disease is therefore at the highest premium, rather than that of the so called expert patient.

Doctors need to act on what they already know—that all patients are experts, however uninformed or misinformed they may be about health issues. Patients' expertise is valuable because by understanding the patient's views and situation, the doctor is better equipped to identify a solution that will lead to a successful outcome, however defined.

The minority of patients who have the resources to find out about their illness and want to take an active part in managing their own care are to be welcomed as allies and partners. Long live expert patients—but, in the interests of doctor-patient relations, let us find something else to call them. What we need is a simple, understandable phrase that is less prone to provoke hostility than "expert patient." Coulter has proposed "autonomous," seeing autonomy as the antithesis of dependency.¹² Muir Gray prefers the term "resourceful."¹³ For our money, the best term of all is "involved." Unlike the alternatives considered above, involvement clearly requires at least two parties, rather than implying that the health professional role is somehow

redundant or replaceable. Neither intimidating nor patronising, involvement is a broad church in which many if not most of us would be happy to find a home and where we hope good doctors will always feel welcome.

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- 1 Department of Health. *The expert patient: a new approach to chronic disease management in the 21st century*. London: Stationery Office, 2001.
- 2 Kennedy A, Gately C, Rogers A, EPP Evaluation Team. *National evaluation of expert patients programme: assessing the process of embedding EPP in the NHS: preliminary survey of PCT pilot sites*. Manchester: National Primary Care Research and Development Centre, 2004. www.nprdc.man.ac.uk/PublicationDetail.cfm?ID=105 (accessed 22 Mar 2004).
- 3 Association of the British Pharmaceutical Industry. *The expert patient—survey, October 1999*. London: ABPI, 1999. www.abpi.org.uk/publications/publication_details/expert_patient/survey.asp (accessed 22 Mar 2004).
- 4 Market and Opinion Research International, for Developing Patient Partnerships, formerly the Doctor Patient Partnership, DPP. *Medicines and the British*. London: MORI, 2003. www.mori.com/polls/2003/medicines.shtml (accessed 22 Mar 2004).
- 5 Dorer G. Developments in the expert patients programme. Presentation at the British Pharmaceutical Conference and Exhibition 2003, Harrogate International Centre, 15-17 September 2003.
- 6 Barlow JH, Turner AP, Wright C. A randomized controlled study of the arthritis self-management programme in the UK. *Health Educ Res* 2000;15:665-80.
- 7 Lorig KR, Sobel DS, Stewart AL, Brown BW Jr, Bandura A, Ritter P, et al. Evidence suggesting that a chronic disease self-management programme can improve health status while reducing hospitalisation. A randomized trial. *Med Care* 1999;37:5-14.
- 8 Lorig KR, Ritter P, Stewart AL, Sobel DS, Brown BW Jr, Bandura A, et al. Chronic disease self-management program: 2-year health status and health care utilisation outcomes. *Med Care* 2001;39:1217-23.
- 9 NHS. *About expert patients*. www.expertpatients.nhs.uk/about_faq.shtml (accessed 11 March 2004).
- 10 Horne R, Weinman J. Patients' beliefs about prescribed medicines and their role in adherence to treatment in chronic illness. *J Psychosom Res* 1999;47:555-67.
- 11 Makoul G, Arntson P, Schofield T. Health promotion in primary care: physician-patient communication and decision making about prescription medications. *Soc Sci Med* 1995;41:1241-54.
- 12 Coulter A. *The autonomous patient—ending paternalism in medical care*. London: Nuffield Trust, 2002.
- 13 Muir Gray JA. *The resourceful patient*. Oxford: eRosetta Press, 2002.

BMJ Publishing Group to launch new website for patients

The best way for patients and their doctors to have a meaningful partnership is if they both have access to the same evidence based information. But so often, patients are given lower quality, watered down versions of the evidence. From 29 March, BestTreatments, the website for patients developed by the BMJ Publishing Group, will be available for the first time to a UK audience through NHS Direct Online, the NHS website for England and Wales (nhsdirect.nhs.uk).

BestTreatments is based on *Clinical Evidence*, the BMJ's international source of the best evidence about treatments. It translates this evidence into simple, jargon free language for patients—it tells them what treatments work and what don't work and, importantly, it says when there is uncertainty over effectiveness. At any point on the site, patients can "click through" to see the parallel page from *Clinical Evidence*.

BestTreatments was originally developed for US patients by UnitedHealth Group, a US healthcare company.

So far the site has information on 60 common chronic conditions, including cancers, back pain, depression, diabetes, and high blood pressure. For the UK audience the BestTreatments website will also have information on 16 common elective operations and tests, including hysterectomy, hip replacement, grommets, and colonoscopy. The information tells people what happens during their operation, the evidence on the benefits and risks, other treatment options, and what they can expect afterwards. It will help patients who have been referred for an operation to decide, in partnership with their doctors, whether it is right for them.