

Well informed uncertainties about the effects of treatments

How should clinicians and patients respond?

Uncertainties about the effects of treatments are inevitable. Whatever the basis for judgments about the likely effects of treatments in individual patients, there is no escape from the reality that every such judgment initiates a clinical trial in which there can be no certainty that an individual patient will benefit. Sometimes the judgment will draw on the patient's past experience of the treatment, more usually on the clinician's experience of treating other patients. Increasingly, clinicians and patients are taking account of collective experience—the results of formal evaluations of treatments.¹ Maybe this is because they recognise that treatments can sometimes do more harm than good, sometimes on a devastating scale.

What should happen if, after weighing the best available evidence from collective experience and taking account of patients' preferences, residual uncertainty remains about which treatment options should be chosen? Should the clinician and patient simply press ahead with yet another poorly controlled clinical trial? It is surprising that such questions seem to have been addressed relatively rarely. One attempt to do so was published in this journal three years ago by a medical ethicist. "If we are uncertain about the relative intrinsic merits of [different] treatments," he wrote, "then we cannot be certain about those merits in any given use of one of them—as in treating an individual patient. So it seems irrational and unethical to insist one way or another before the completion of a suitable trial. Thus the answer to the question, "What is the best treatment for the patient?" is: "The trial." The trial is the treatment. Is this experimentation? Yes. But all we mean by that is choice under uncertainty, plus data collection. Does it matter that the choice is "random"? Logically, no. After all, what better mechanism is there for choice under uncertainty?"²

This approach to dealing with uncertainty is reflected in some of the guidance issued by the National Institute for Clinical Excellence, and it is implicit in the NHS Plan, which calls for a doubling in the numbers of cancer patients participating in clinical trials.³ The dividends that result from adopting this

response to uncertainty can be substantial: gradual and important improvements in the prognosis of children with leukaemia, for example, seem likely to reflect an expectation among paediatric oncologists that decisions about treatment should be taken within the context of controlled trials, so that uncertainties can be addressed and reduced.

Strategies for dealing with uncertainty need to be considered and debated more explicitly. For example, what does the "quality in health care" movement have to say? Has it given sufficient attention to the responsibilities of clinicians and health service managers to reduce uncertainties about the relative merits of different treatments, and thus improve the quality and cost effectiveness of services? What are the responsibilities of clinicians and managers implementing the clinical governance framework in the NHS? Should clinicians and institutions be held accountable for failing to address uncertainties systematically, as some have suggested they should be?⁴ Are strategies for dealing with uncertainty being addressed in medical schools, and by professional organisations such as the medical royal colleges, encouraging clinicians to be more open with patients about the limitations of treatments and their potential for harm? And are organisations that endeavour to represent the interests of the public—the Consumers' Association, patients' groups, and the General Medical Council, for example—taking a sufficiently active role in promoting discussion about how people should respond to well informed uncertainties about treatment choices?

As another medical ethicist has noted, "Doctors must make many practical decisions, often on the basis of inadequate information. Too finely developed a critical faculty, endeavouring disinterestedly to learn the best that may be known and thought, may positively inhibit the ability to make such decisions."⁵ But there is surely scope for dealing with inadequate information in ways that can help to identify really important uncertainties, uncertainties that are often reflected in dramatic variations in clinical practice and which cry out for coordinated efforts to improve

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knowledge. Although some of these variations reflect ignorance of existing evidence, others reflect a lack of appropriate evidence. The NHS should develop mechanisms for logging and reviewing these “informed” uncertainties, building on the experience of the NHS health technology assessment programme.⁶ Indeed, when considering the massive investment in NHS information systems, is it not a scandal that they are not yet helping clinicians and patients to record and address uncertainties within the context of usual clinical care?⁷

A prerequisite for constructive debate about uncertainties about the effects of treatments is a greater willingness among professionals and the public to admit and discuss them, combined with the humility to acknowledge that good intentions alone have not protected patients from the unintended harmful effects of treatments. Explicit admission of uncertainty by clinicians can sometimes undermine patients’ confidence⁸; it may even sometimes reduce the therapeutic effectiveness of individual encounters between clinician and patient.⁹ Finding ways to engage patients in the discussion that is needed thus poses a great challenge.¹⁰ Nevertheless, because clinicians share with patients the front lines where uncertainties are

encountered in practice, patients must obviously help define how to deal with these quandaries.¹¹

Surely, however, it is up to clinicians to initiate these discussions—with each other, with patients, with the general public, and with researchers—who should certainly be challenged to be more responsive to the needs of people working in and using health services. As one philosopher-clinician has said recently, “a cowed medical profession has conceded too much of the running in medico-ethical debates to others.”¹² We need an alliance of clinicians, patients, researchers, and managers to discuss how best to deal with well informed uncertainties about the effects of treatments.

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