

book reviews

The autonomous patient: ending paternalism in medical care

By Angela Coulter. The Stationery Office, London 2002. 128pp. £5.99.

Angela Coulter is a distinguished medical sociologist and epidemiologist whose opinions and observations are valued highly by those in the business of formulating governmental health policy and of bringing about the so-called 'modernisation' of the NHS. This monograph argues that paternalism, which she regards as a defining characteristic of medical care, 'has had its day' and that the patient of the twenty-first century, more informed and educated than ever before, will be determined to exert more self-reliance than passivity and dependence; a major move towards autonomy. Her principal target is, needless to say, the doctor and the medical profession who are allegedly reluctant to change and are thereby holding up what are perceived to be the required developments.

Her case for change is heavily influenced by the Kennedy report that followed the Bristol Royal Infirmary enquiry into paediatric cardiac surgery. Emphasis is given to the professional failing of the surgeons involved to communicate adequately in regard to informed consent, the need for openness when things do not go to plan, and the willingness to listen to the views of patients and their carers. Less attention is, however, paid to the system, and the failure of the Department of Health and its successive political masters over a 15-year period to provide proper facilities and resources. This was despite the continuous exhortation of Royal medical colleges, specialty associations and individuals ever since the famous visit to Downing Street to see Mrs Thatcher in the late Eighties by the presidents of both the Royal College of Physicians and the Royal College of Surgeons.

Dr Coulter refers to a crisis in confidence and growing public pessimism with health systems despite above-inflation expenditure and rapidly improving therapeutic efficacy. She argues that in order to solve such failings a total culture change is needed, with a major alteration in the way clinicians see their roles. My own observations and 'research' since reading her very clear and well-written work do not entirely bear this out. I hear much praise for and satisfaction with the general practitioners, surgeons, physicians, nurses and nurse practitioners who man post-operative clinics and minor trauma centres, but immense criticism of the system's delays, cancelled operations, breakdowns in apparatus, dirty wards, cramped out-of-date facilities and so on. And patients and their relatives cannot help but notice the increasing army of bureaucrats and managers, whom they perceive as wasteful and doing little that is beneficial. Paternalism is not what irritates patients most, indeed there has already been a huge swing away from the more traditional paternalism that Dr Coulter criticises – but patients do certainly and rightly want to know and understand all options available, and to have their say. What they need and so often do not get is sufficient

time with their general practitioner, their hospital doctor, senior or junior, or their nurse. In the end there is a prevailing sentiment, based on trust, that the general practitioner, physician or surgeon is the 'expert', and would he or she please recommend what he or she believes to be the best course of action? More autonomy for patients – yes, but it should not be overdone and it is not either universally asked for or appropriate. Dr Coulter concedes this.

There are some interesting statistics. Everybody now knows that the UK, until the present day, has spent significantly less on health care than most other developed countries. (In 1998 the UK's spend was approximately \$1,500 per head compared with Germany's \$2,300 – a huge discrepancy which hides another huge discrepancy not mentioned here. This is the wide range of spend within the UK. Scotland's funding per head is over 20% more than England's – and there is a wide range within England as well. Indeed, Scotland could already be spending well over the EU average.)

Dr Coulter refers to the influence the media have on expectations: apparent bad news is more likely to make the front pages than good news, and this distortion contributes significantly to the sense that the NHS is in a greater crisis than it is.

Data comparing patient satisfaction in the UK, the USA and certain European countries raises serious concern. In 1996, 40% of UK patients expressed dissatisfaction with the overall medical service provided, compared with only 5.7% in Denmark. In a recent survey of hospital patients, 30% found the *availability* of doctors and nurses not to be good compared with some much lower figures on the Continent. (Interestingly, my own enquiries into patient satisfaction with doctors in our own major private hospitals show it to be extremely high, with a 'dissatisfaction rate' of between 0.5% and 0%.)

The issue of accountability is dealt with in a somewhat blurred fashion. Accountable to whom? Well, those who pay. In this country this, by and large, is the taxpayer – hence the new plethora of performance indicators, star ratings, league tables and so on, all requiring teams of individuals, paid either directly or indirectly by the Department of Health, to collect, collate, assess and interpret the mass of data obtained. Will such an approach enhance or undermine performance or confidence? Might it not be better to put more trust in professionals, as Onora O'Neill argued in her 2001 Reith lectures? Accountability in France, Germany and a number of other European countries is, in contrast to the UK, direct to the patient, their carer or their family, with a system of direct payment (to be reimbursed to a greater or lesser degree) ensuring real choice and control. Indeed, we are now hearing the idea of providing people with more control and choice by a system of vouchers – both in health care and education – and it will be interesting to see how this develops. Still, in 2003 the principal complaint British patients and their families have is to do with the time made available for consultation in primary and hospital care and the lack of prompt, reliable availability.

This is an excellently written monograph, 120 pages crammed with data, ideas and argument providing a splendid basis for healthy

discussion, some understandable irritation and some scepticism. I recommend it warmly, particularly for those who are able to influence the direction in which the profession is moving. But I would recommend that it be read alongside Baroness O'Neill's *A question of trust*, published last year by Cambridge University Press.

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Perceptions of pain

By Deborah Padfield. Dewi Lewis Publishing, Stockport 2003. 128pp. £14.99.

There are clear limits to using language to express an individual's subjective response to severe chronic pain. Virginia Woolf wrote that '...the merest schoolgirl when she falls in love has Shakespeare and Keats to speak for her, let a sufferer try to describe the pain in his head and language at once runs dry'.¹ Furthermore what if the doctor can find nothing wrong and all the tests are negative, but the pain persists? A physician or surgeon may then dismiss the cause as emotional. How will the patient react – seek another opinion, lose faith in the profession?

Attempts by artists to depict pain have never really been entirely successful. Some have focussed on events associated with pain, for example by using Christian iconography or situations such as tooth extractions or joints being gnawed by imaginary beasts. Some have attempted to portray pain through facial expressions, as in the classical studies of Charles Bell, Duchenne de Boulogne and Charles Darwin. But these approaches have only ever been partly successful because they could never depict precisely how individuals actually felt about their pain. This book attempts to address the matter in an original and unique way.

It follows the success of the exhibition 'Perceptions of pain', sponsored by Novartis Pharma AG, and comprises a compilation of images based on photographs by Deborah Padfield, herself afflicted with chronic pain, selected by a number of pain sufferers who collaborated closely with her. Their pain results from accidents, assault, surgery or illness and has lasted between 9 and 42 years. In most cases no medical resolution has been found to their problems. At numerous workshops with individual patients the images were carefully selected and manipulated and transformed by cutting, stitching and writing on them. The result is a fascinating mix of black-and-white and colour images. Being a sufferer for some time from migrainous neuralgia (whatever that is) myself, I can certainly sympathise with all those involved in trying to depict their very personal experiences which are often beyond the reach of words. As Deborah Padfield emphasises, the works were not driven by aesthetic considerations but by a desire to '...look at aspects of ourselves, and experiences, which have hitherto been too painful to acknowledge'. But asking pain sufferers to try to explain their suffering in this way might also have other benefits. It could help students and doctors in training as well as more experienced individuals better to understand their patients' problems and thereby improve communication with them. It could also help to establish a diagnosis, for example in children to distinguish migrainous from

non-migrainous headache. And it might also provide useful information for possible treatments. Professor Brian Hurwitz in his thought-provoking introduction also hopes these images might '...galvanise clinicians into ensuring that NHS managers and planners accord the resources required for appropriate medical treatment of pain'. Clearly a picture can be worth more than a thousand words. This fascinating book certainly emphasises the point in a very elegant and convincing manner.

Reference

- 1 Woolf V, 'On being ill'. In: Woolf V. *The crowded dance of modern life: selected essays*. London: Penguin, 1993.

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The science of the placebo: toward an interdisciplinary research agenda

Edited by Engel LW, Guess HA, Kleinman A, Kusek JW. BMJ Books, London 2002. 343pp. £15.95.

The science of the placebo is the outcome of a conference held in November 2000 and attended by medical scholars, researchers, and clinicians, including those working in both conventional and complementary and alternative medicine. Conference proceedings can be disappointing reading for the clinician, but this book is an exception to that rule. It contains a wealth of clinically relevant information in addition to that on issues of research methodology and ethics which may be of more interest to researchers. The book starts with an overview, which provides a very useful summary and guide to the later chapters; this chapter alone should be read by those interested in the way patients are affected by their interaction with clinicians.

The final chapter lists six principles that were agreed at the conference. First, that the term placebo describes a 'process encompassing dynamic features of the patient-health professional interaction' and that 'placebo (or nocebo) effects operate whenever patients and practitioners interact'. Second, that 'placebo effects are a subset of mind-body effects that emerge by eliciting innate healing processes and/or enabling an amelioration of symptoms'. Third, that it is unlikely that any 'single model of placebo effects nor any single mechanism will be able to explain how placebo effects manifest as physiological changes in the body'. Fourth, that interdisciplinary research is needed for placebos research. Fifth, that 'there is a need to eliminate the pejorative connotation of the word placebo as merely a sham and deceptive process and replace it with positive meaning'. Finally, that 'studies involving placebo effects must be designed to separate actual placebo effects from various artefacts'.

This book shows, through cited research, the important impact placebos and nocebos have for health and disease. Several of these studies will be of interest to those in clinical practice. For example there is the study that investigated the link between Chinese astrology and mortality. Chinese astrology predicts health outcome as a function of year of birth, and these outcomes are reflected in the mortality statistics (disease type) of Chinese Americans, but not in those of the white controls. The author concludes: 'It is clear from