

by a different registrar on each attendance.

- 2 *The effect of the internal market.* A low budget district hospital will always be reluctant to refer a patient to a high cost specialist unit. I speak from experience. This problem must be overcome.
- 3 *The question of free prescriptions for patients with rare diseases.* The present list of those diseases which qualify is, to say the least, bizarre. I have raised this problem with every administration, either directly or through my MP, since the days of Harold Wilson, without success. If Italy can supply free prescriptions for such patients, surely the UK can too.
- 4 *The malign influence of ethics committees on clinical research.* Apparently, it now takes a 57-page questionnaire to be filled in, after reading the instruction booklet, to apply for permission to proceed. Any variation in the protocol, which may well be necessary once the work has started, has to be passed by 'a research manager'. I wonder what experience of clinical research these managers have; I only ask. I doubt if penicillamine (1955) or trientine (1969) would ever have been approved with the data available, at the time, on these compounds. I somehow avoided the ethics committee in 1984 when introducing tetrathiomolybdate. I doubt if having taken the compound myself for a week would have cut much ice with an ethics committee. In 1994 I wanted to try a new therapeutic approach for a patient with acaeruloplasminaemia but had to abandon the attempt. Hardly to the benefit of the patient.

I think these aspects of the management of rare diseases should have been discussed. They are extremely germane to various problems for both the doctor and patient and must be confronted.

#### Reference

- 1 Jones TM. Cheap at half the price? Book review. *Lancet* 2004;364:321.

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#### Influence of guidelines on CPR decisions

Editor – As a lawyer acting for the NHS, I was not surprised by the findings of Diggory *et al* in their 'Audit of clerking proforma' for cardiopulmonary resuscitation (CPR) decisions (*Clin Med* Sept/Oct 2004 pp 424–6). Their finding that the requirement to discuss a proposed Do Not Attempt Resuscitation (DNAR) order with the patient concerned was associated with a fall in DNAR orders accords with my own experience. Of the drop in the number of DNAR orders noted in Audit 5, I would like to know how many were due to patient discussions not taking place and how many to a demand by patients for CPR even where not advised? The article implies the former explanation. If so, how can the public distinguish between those clinicians who have correctly discerned an unacceptable risk to the health of their patient in having such a discussion, from those doctors who are simply too uncomfortable to broach such a difficult subject or, worse, believe they are beyond having to explain themselves?

Certainly, my interpretation of the BMA/Resuscitation Council/RCN 2001 guidelines differs significantly from that of Diggory *et al* on the question of prior consultation. One of the stated aims of the guidelines<sup>1</sup> is to promote transparent decision-making. The guidelines themselves go on to say that the emphasis on the individual's interests means that it is important that resuscitation is discussed sensitively with competent patients. This can help people to understand why treatment is given and why, in some circumstances, it may be unable to provide any benefit. There is a further paragraph in the guidelines directly on this point, which states that because the patient's own view on the level of burden or risk they consider acceptable carries considerable weight in deciding whether treatment is given, it follows that decisions about whether the likely benefits of successful CPR outweigh the burdens should be discussed with competent adults. This goes to the very heart of the decision-making process itself, casting doubt on whether the 'right' decision can ever be made for a competent patient without their involvement. The only excep-

tion to prior consultation mentioned in the guidelines is when a patient does not wish to have that discussion, ie the clinician is rebuffed on raising the issue. Surely a clinician must have an exceptionally good reason (relevant to *that* patient and not just a *category* of patient) for not even raising the issue in the first place?

The GMC's 2002 guidelines on *Withholding and withdrawal of life-prolonging treatments*,<sup>2</sup> to which the authors refer, are currently being reviewed by the Court of Appeal. Until that Court pronounces, I would suggest wider dissemination of the true success rates of CPR and more emphasis and research on the quality and not quantity of clinical decision-making in this difficult area.

#### References

- 1 The British Medical Association, the Resuscitation Council and the Royal College of Nursing. *Decisions relating to cardiopulmonary resuscitation*. A joint statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing, January 2002. ([www.bma.org.uk/ap.nsf/Content/cardioreus](http://www.bma.org.uk/ap.nsf/Content/cardioreus))
- 2 General Medical Council. *Withholding and withdrawal of life prolonging treatments*. London: GMC, 2002.

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Editor – Diggory and colleagues (*Clin Med* Sept/Oct 2004 pp 424–6) have audited documentation of cardiopulmonary resuscitation (CPR) decisions, on the assumption that good documentation reflects high quality care. This is often true, but not invariably so. They have set their own standard for the audit, rather than choosing a standard derived from national guidelines. Their standard seems to be based on a belief that all patients must have a CPR decision documented at the time of hospital admission, even if this means ignoring some parts of national guidelines from professional bodies.<sup>1</sup> They have demonstrated that the modification of their policy to reflect these guidelines led to a fall in documentation, so conclude that the guidelines must be changed (or reinterpreted). An alternative conclusion could be that their standard should be changed, as it is not compatible with best practice.

The authors use their paper to highlight their disagreement with the national guidelines but their argument is weakened by selective or inaccurate quotations from the literature. The guidelines do not say that 'no Do Not Attempt Resuscitation (DNAR) decision can be made without prior discussion with the patient'. Many acutely ill patients (nearly 50% in a recent study<sup>2</sup>) will be incompetent to make decisions about their care, but the guidelines recognise this and also acknowledge that some patients will not want to be involved in decisions. However, they do recommend that most competent patients, and the families of incompetent patients, should usually be involved in decisions in keeping with the requirements of the Human Rights Act.<sup>1</sup>

The authors repeatedly refer to situations where CPR is 'ineffective' as if this was easily determined, but 'futile' CPR is difficult to define and even more difficult to predict. We know that even experienced doctors are not very good at predicting CPR outcomes and in one study their predictions were no better than chance.<sup>3</sup> Despite this, the authors seem happy for junior doctors in their department to make these predictions and take decisions on the basis of 'futility'.

Doctors do not like discussing CPR decisions with patients; it is difficult, time consuming, there are many uncertainties and there is much potential for misunderstanding. On the other hand, patients and the public have very different expectations of us than they had a few years ago, and the Human Rights Act gives their expectations legal support. We can either accept this reality or continue to try to find reasons to ignore it.

#### References

- 1 The British Medical Association, the Resuscitation Council and the Royal College of Nursing. *Decisions relating to cardiopulmonary resuscitation. A joint statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing, January 2002* ([www.bma.org.uk/ap.nsf/Content/cardioreus](http://www.bma.org.uk/ap.nsf/Content/cardioreus))
- 2 Raymont V, Bingley W, Buchanan A, David AS *et al*. Prevalence of mental incapacity in medical inpatients and associated risk factors. *Lancet* 2004;**364**:1421–7.
- 3 Ebell M, Bergus GR, Warbasse L, Bloomer R. The inability of physicians to

predict the outcome of in-hospital resuscitation. *J Gen Intern Med* 1996;**11**:16–22.

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#### In response

Kevin Stewart's and Camilla Long's comments and the situation described by Philip Berry<sup>1</sup> illustrate the muddle arising from varied interpretations of unsatisfactory guidelines. We quote 'selectively' from the guidelines to illustrate the confusion caused by the juxtaposition of the statement: a patient's wish to receive cardiopulmonary resuscitation (CPR) should be respected but it is for the doctor to make the final decision. What should we do when wish and decision are at odds?

We agree with Long that the fall in decision rates when we introduced a policy obliging discussion on CPR before making a Do Not Attempt Resuscitation (DNAR) order was probably due to reluctance to enter into discussion.

Stewart is correct in stating that many elderly patients do not have capacity when acutely unwell, but on admission to hospital they are at 'foreseeable' risk of death. We believe the admitting doctor should make a CPR decision.

Difficulty in prediction is not a reason why a decision should not be made. We did not use the term 'futility' but made reference to situations where expectations of success were very low. Doctors must make many decisions, often with little discussion, where outcome is difficult to predict. CPR is just one.

Our approach is that the first decision is to decide what treatment is appropriate, then to discuss with the patient whether they want it. We do not feel obliged to offer treatment which we believe to be inappropriate. We agree that this situation may change once the Court of Appeal rules on the case of *Burke v the General Medical Council* concerning whether or not doctors must provide treatment (in his case, feeding) whatever his circumstances. Human rights legislation was at issue in the High Court Judgement. Like others, we await the Court of Appeal review with anxiety.<sup>2</sup> Long is concerned that patients will be unable to tell if CPR decisions,

without discussion, were made to avoid distress or because of a reluctance to discuss the issues. Our policy is that reasons for not discussing should be recorded in the notes. Our most recent (September 2004) audit of 172 inpatients found we made 164 CPR decisions within 24 hours. Of these, 116 were DNAR orders. We made 22 DNAR orders without discussion, citing a poor prognosis for survival and the need to avoid distress and/or confusion.

We are trying not to shirk discussions; our audits show we have them on a daily basis. We do not suggest good documentation means good care, but poor documentation is a likely predictor of poor discussion rates, perhaps reflecting less satisfactory care. Decision rates vary greatly; with rates of 15–98% found by a survey of 13 elderly care departments.<sup>3</sup> Our policy permitting DNAR orders to be made without discussion when patients are acutely ill is central to becoming comfortable discussing CPR. Our audits show us moving with the times to a policy that maximises patient autonomy and choice – an example of best practice.

#### References

- 1 Berry P. An audit into consultation in 'do not attempt resuscitation' decisions. *Clin Med* 2004;**4**:471–2.
- 2 Gillon R. Why the GMC is right to appeal over life-prolonging treatment. *BMJ* 2004;**329**:810–11.
- 3 Cauchi L, Diggory P, Vigus J. Implementation of cardiopulmonary resuscitation guidelines in elderly care departments. A survey of 13 hospitals shows wide variability in practice. *Resuscitation* 2004;**63**:157–60.

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#### **Hippocratic oaths: medicine and its discontents: book review**

I was interested to read Dr JM Holt's review of Raymond Tallis's new book *Hippocratic oaths: medicine and its discontents* (*Clin*