

- 6 **King N.** Defining and describing benefit appropriately in clinical trials. *J Law Med Ethics* 2000;**28**:332–43.
- 7 **Daugherty C,** Ratain MJ, Grochowski S, *et al.* Perceptions of cancer patients and their physicians involved in phase I trials. *J Clin Oncol* 1995;**9**:1062–72.
- 8 **Miller M.** Phase I cancer trials: a collusion of misunderstanding. *Hastings Cent Rep.* 2000;**30**: 34–42, at 40).
- 9 **Miller FG,** Rosenstein DL. The therapeutic orientation to clinical trials. *New Engl J Med* 2003;**348**:1383–6.
- 10 **Pentz RD,** Flamm AL, Sugarman J, *et al.* Study of the media's potential influence on prospective research participants' understanding of and motivation for participation in a high-profile phase I trial. *J Clin Oncol* 2002;**20**:3785–91.
- 11 **Flory J,** Emanuel E. Interventions to improve research participants' understanding of informed consent to research: a systemic review. *JAMA* 2004;**292**:1593–601.
- 12 **Dunn LB,** Gordon NE. Improving informed consent and enhancing recruitment for research by understanding. *JAMA* 2005;**293**:609–12.
- 13 **Grady C.** Money for research participation: does it jeopardize informed consent? *Am J Bioeth* 2001;**1**:40–4.
- 14 **Grady C.** Payment of clinical research subjects. *J Clin Invest* 2005;**115**:1681–7.

ECHO.....

Doctors decide disclosure of sudden unexplained death

Please visit the *Journal of Medical Ethics* website [www.jmedethics.com] for a link to the full text of this article.

British neurologists are guided by their judgement, not published guidelines, in telling patients about sudden unexplained death in epilepsy (SUDEP), a survey discloses.

National Institute for Health and Clinical Excellence (NICE) guidelines advocate that patients and their families and carers should be given this information. In reality, practice among neurologists differs, with only 5% complying, most (61%) telling a few patients, a quarter telling most, and 8% telling none. Neurologists with an interest in epilepsy were more likely to comply, maybe because of familiarity with the guidelines. They were less likely to report a negative reaction, maybe being more at ease about the disclosure or their patients having come across the subject before. Years as a doctor or seniority did not affect the findings. About half the respondents discussed SUDEP in just one circumstance—when patients asked—otherwise it was when patients asked or if they had risk factors for SUDEP. Almost all thought that patients did not understand relative risks for SUDEP well; nearly half (47%) did not consider that knowing about SUDEP affected patients' quality of life; but a third thought that broaching the subject caused anxiety.

The response rate was 82% for consultant neurologists and about 19% for specialist registrars.

NICE guidelines do not advise how, when, and by whom information on SUDEP should be given. The prevailing view of medical leaders and patient groups is for as much as possible, covering every contingency, to be given up front, denying patients' right not to know.

▲ Morton B, *et al.* *Journal of Neurology, Neurosurgery, and Psychiatry* 2006;**77**:199–202.