Care of dying patients in hospital

Patients' interests should be put before research

EDITOR,—I was shocked by every aspect of the paper on the care of dying patients in hospital, but perhaps most of all by the nature of observer non-participant research in this context.¹ I have no interest in attacking the researchers concerned, enmeshed as they are in a system not of their making, but this paper seems to raise issues of wider concern: it is to me a clear case of the "scientific" approach leading to grossly unethical behaviour. How could anyone in the interests of a research paper, however important, leave a dying woman begging for a glass of water on no fewer than four occasions for 30 minutes? How could this non-participating observer allow a woman dying of hepatic carcinoma to fail in attempting to drink unaided for four hours before helping her? In my opinion research of this nature needs rethinking at the highest level, and soon.

It also seems to be a matter of concern that, notwithstanding the reasons given for the delay in its preparation, this report was not published for 10 years, during which time (as the report itself indicates) similar suffering has continued in hospitals unabated.

I entirely agree, however, with the paper's gist. The Natural Death Centre believes that more NHS resources need to be put into the care of people dying at home, and we have started a nationwide Befriending Network (which any general practitioner can make use of), whereby trained volunteers will sit at the home of a critically ill person to assist the carer.

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1 Mills M, Davies HTO, Macrae WA. Care of dying patients in hospital. *BMJ* 1994;309:583-6. (3 September.)

Authors' reply

EDITOR,—The main issue raised by Nicholas Albery is an age old ethical dilemma. It faces any journalist or aid agency worker when reporting or assessing the dreadful consequences of war or famine. Which is the more ethical behaviour: to intervene and help the few or to stand back and try to develop more general solutions with the potential to help many? We have no ready answer to this common dilemma but wish to make a few comments on the specifics of our study.

Firstly, without evidence of a serious problem, serious solutions are unlikely to be forthcoming. Our work was aimed at uncovering defects in the care of dying patients, which might then be addressed to the benefit of future patients. The principal investigator (MM) was aware of the dilemmas facing a non-participant observer, especially one with nurse training and extensive ward experience. In fact, she abandoned her non-participant role on several occasions when she intervened to prevent further suffering. She was, however, committed to gathering the evidence to galvanise general improvements in care for this most disadvantaged group of patients.

Secondly, the presence of the non-participant

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observer in no way hampered the care of the patients under observation. This observational research was different from studies that intervene to patients' possible detriment. Care of the patients in the study would not have been improved if the research had not been carried out.

Thirdly, it is indeed a matter of concern that these findings took so long to be published. The death of both of the project's supervisors and a lack of local support to analyse and write up the findings were important factors in the delay. Of greater concern are the pockets of antipathy towards the findings that frustrated initial attempts at their dissemination and are still encountered now that they have been published. It seems that many of the incidents observed are so unsettling that some people would rather they were not widely aired.

Our findings show the desperate need for improvements in the care of dying patients. Use of patient advocates, either drawn from staff care or trained volunteers, may go some way to ensuring that patients' care (as opposed to monitoring or treatment) is not neglected. To this end, the Befriending Network described by Albery may be a useful way of overcoming some of the problems we observed, albeit for a small proportion of patients. Studies such as the one reported can be used to assist the design of much needed improvements for the majority.

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Why care of the dying is still poor

EDITOR,—Mina Mills and colleagues' descriptive analysis of the care of dying patients in four Scottish teaching hospitals highlights an area of medical ignorance or avoidance that still exists 11 years after the study.¹ I believe that there are several reasons for this.

Firstly, palliative care is not generally taught in the undergraduate medical curriculum. Like many of their seniors who trained before palliative care became established as a specialty, junior doctors are often unaware of what can be offered to dying patients. This subject is also omitted from most standard medical texts.

Secondly, understandable psychological barriers must be overcome in dealing with dying patients. Doctors often use distancing tactics to alleviate their discomfort and embarrassment to preserve their emotional wellbeing.² Interviewing, assessment, and counselling skills are needed to enable these patients to be treated openly and sensitively.

Thirdly, when patients do not have cancer the diagnosis of "dying" is often made by exclusion after the failure of standard medical treatment. Thus staff often have little time to alter their mode of care.³

Finally, three fifths of patients who die in hospital in Britain are over the age of 75 (Department of Health, personal communication). Elderly patients pose additional difficulties with regard to good terminal care. Whereas in Mills and colleagues' study 58% of the patients had cancer (mean age 66), in a study of elderly men dying in a geriatric ward (mean age 81) only 15% had cancer.³ The holistic approach to medical care, long advocated by the hospice movement, relies on effective communication among patients, their relatives or carers, and hospital staff. This can happen only if patients have family and friends close by and if their minds are reasonably free from confusion. Difficulties in communication with elderly dying patients are commonly encountered, whether due to cerebrovascular disease, dementia, or causes of acute confusion; these patients may also be more likely to be socially isolated than younger patients.³ Their terminal care therefore demands more time from those attending them.

When death is unavoidable it should not be regarded as indicating failure. Medical and nursing care has much to offer to improve the physical quality of life of dying patients. Holistic care of dying patients outside hospice settings, encompassing physical care as well as attention to social and emotional needs, should become the rule rather than the exception in medical practice.

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1 Mills M, Davies HTO, Macrae WA. Care of dying patients in hospital. *BMJ* 1994;309:583-6. (3 September.)

2 Maguire P. Barriers to psychological care of the dying. *BMJ* 1985;291:1711-3.

3 Blackburn AM. Problems of terminal care in elderly patients. *Palliat Med* 1989;3:203-6.

Detecting bilateral isodense subdural haematomas

Patient should lie supine for 30 minutes

EDITOR,—The failure to detect the bilateral subdural haematomas shown in the figure in R J Davenport and colleagues' paper is surprising since the case is by no means subtle in its features.¹ Nevertheless, the authors are right to point out the risk of overlooking such lesions, a risk that is increased by failure to observe all the diagnostic features evident in a computed tomogram. The authors fail to mention one of these features—namely, the differentiation of subacute collections into hypodense fluid anteriorly and hyperdense fluid posteriorly. The inward displacement of the cortical mantle by a posterior hyperdense collection is evident in the authors' figure. This sedimentation

effect is enhanced by ensuring that the patient lies supine for at least 30 minutes before the study. If this is not done complete mixing of the material is possible, with resulting bilateral isodense collections, which may occasionally be elusive.

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1 Davenport RJ, Statham PFX, Warlow CP. Detection of bilateral isodense subdural haematomas. *BMJ* 1994;309:792-4. (24 September.)

Appearances in scan were obvious

EDITOR,—R J Davenport and colleagues remind us that the detection of subacute subdural haematomas on computed tomography is not invariably straightforward.¹ The figure in their paper, however, shows a rather more obvious example than I usually use for teaching junior clinicians; it should not have been misinterpreted. The computed tomographic signs of isodense subdural collections are given in textbooks, even if the publication of "lessons" such as that reported by Davenport and colleagues suggests that a number of radiologists do not detect them. (The questions of unsupervised reporting of clinically important imaging studies by trainee registrars and of computed tomography being performed by general radiologists are too big to pursue here.)

In both cases reported by the authors the computed tomograms were interpreted as showing diffuse swelling of the brain, presumably without change in radiographic density. This picture, however frequently described, is rarely seen other than in a few children with acute head injury. For reasons that are not clear, "cortical venous thrombosis," which was suggested in the second case, is currently a popular neurological diagnosis; it virtually never causes the computed tomographic picture described. Bilateral subdural haematomas are not only a much commoner cause of the picture described but have undisputed therapeutic consequences: were radiologists to stop seeking subtle signs of intracranial venous thrombosis they would probably harm few of their patients.

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1 Davenport RJ, Statham PFX, Warlow CP. Detection of bilateral isodense subdural haematomas. *BMJ* 1994;309:792-4. (24 September.)

Authors' reply

EDITOR,—We broadly agree with the diagnostic points made by Ivan Moseley and T Powell. Both correspondents believe that the illustrated case was straightforward and are surprised that there was any delay in the diagnosis. To our mind, however, the purpose of the Lesson of the Week is to show how cases are actually managed rather than how they might ideally be managed, in the hope that readers from a wide range of disciplines may benefit from the mistakes made.

Many patients presenting with headache are managed in non-neurological units, where staff may be less familiar with appearances on computed tomography, be they subtle or unsubtle. Such was the case with our first patient. The initial incorrect interpretation of the computed tomogram, by a registrar in radiology with four months' neuro-radiological experience, was not challenged until a neurological opinion was requested. Although the computed tomogram in this case was more obvious than that in the second case (not published in our paper because of lack of space), we chose to use it

because the difference between the two images is dramatic (in particular, highlighting the obliteration of the sulcal spaces); we thought that even those who do not review computed tomograms of the brain regularly (that is, the bulk of the *BMJ*'s readers) would appreciate this.

Lest the neurological community believe that such a mistake could never occur in a neuroscience unit we included the second patient; this time the diagnosis was initially missed by a consultant neurologist and neuroradiologist, both with many years' experience. It was this episode that prompted us to write the paper.

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New resource allocation formula

Agism by stealth

EDITOR,—In estimating the resource consequences of use of inpatient services by age bands Peter Smith and colleagues classify geriatrics as a non-acute specialty and assign reduced weight to expenditure on the care of elderly people.¹ This ignores the usual practice in Britain, where most geriatric departments provide acute care. Such care is more expensive than acute care for younger people because the length of stay is longer (14 days in my department); this is due to the patients having multiple diseases, the aging body recovering from illness more slowly, and discharge planning processes.

The adoption of Smith and colleagues' formula, reported by John Warden,² will greatly disadvantage those areas with high proportions of elderly people and may effectively reduce acute care for this group. Such a policy runs contrary to the document from the Royal College of Physicians³ commended by the NHS Executive as part of its priorities and planning guidance for the NHS.⁴ There was a public outcry when individual hospitals were thought to be rationing treatment on the grounds of age—practising overt agism. The application of this formula will lead to funds being moved away from areas with a high proportion of elderly people—agism by stealth.

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1 Smith P, Sheldon TA, Carr-Hill RA, Martin S, Peacock S, Hardman G. Allocating resources to health authorities: results and policy implications of small area analysis of use of inpatient services. *BMJ* 1994;309:1050-4. (20 October.)

2 Warden J. New funding formula for NHS. *BMJ* 1994;309:1109. (29 October.)

3 Royal College of Physicians. *Ensuring equity and quality of care for elderly people*. London: RCP, 1994.

4 NHS Executive. *Priorities and planning guidance for the NHS: 1995/6*. Leeds: NHSE, 1994.

Author's reply

EDITOR,—Kalman Kafetz makes two important points in relation to our study of resource allocation, noting, firstly, that we classified geriatrics as non-acute. We did this simply so that we could explore the determinants of need specific to that specialty. By doing this we got round the problem of needing to identify costs of patients in geriatrics relative to those in other specialties. In the event,

we were unable to develop a satisfactory model of needs in geriatrics, and Kafetz may be interested to know that we understand that the NHS Executive plans to allocate funds for geriatrics using the formula we developed for the acute sector.

The second point is that our recommendations will result in a shift of resources away from areas with high proportions of elderly people. This is also true. To understand why it should be so it is important to emphasise that our results are based on the actual use of resources by NHS patients during 1990-2. The report of the study explains in some detail that, while our work offers what we think is the best representation of national average use of NHS services in those years, it cannot capture need that was not reflected in use of NHS inpatient services.¹ We have emphatically pointed out that if a strategic shift of resources towards particular care groups is desired the NHS Executive has the freedom to increase the weighting given to those groups in the application of the formula.

We refute the claim that use of such research results in agism by stealth. Indeed, we believe that when resource allocation is based on explicit empirical research it becomes much easier to identify and quantify changes in policy. If Kafetz believes that elderly people are systematically being denied their fair share of resources he should direct his attention at NHS policymakers.

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1 Carr-Hill R, Hardman G, Martin S, Peacock S, Sheldon T, Smith P. *A formula for distributing NHS revenues based on small area use of hospital beds*. York: University of York, 1994. (Centre for Health Economics occasional paper.)

Socioeconomic status does not always reflect health

EDITOR,—The first briefing document from the BMA's Health Policy and Economic Research Unit "flags up" some issues for a revised resource allocation formula, recommending that it should include "a component for the impact of deprivation on health" and that "a deprivation measure must be added to ensure that inner city areas . . . do not lose out against more affluent retirement areas" (unpublished paper). I had not expected to read such old fashioned socialist dogma, presented without evidence or justification, in a publication of the BMA.

Resource allocation formulas were originally based on standardised mortality ratios with adjustments. If social deprivation causes (or is associated with) morbidity the excess mortality will be picked up by the standardised mortality ratio. Many deprivation indices have been developed. Sheldon *et al* commented, "There is an evolving industry where indices are developed" and "those health authorities which express most interest in refining formulas by varying the factors included tend to be those which have lost out with the current formula."¹

Williams *et al* criticised the Department of Health's review of weighted capitation in 1993, saying that it favoured retirement districts, most of which were coastal, at the expense of inner cities and large business development areas.² The *Health of the Nation*, however, comments that coronary heart disease is the single largest cause of both death and premature death. A survey of heart disease in England and Wales by the Faculty of Public Health Medicine in 1986 listed three north west coastal locations—Liverpool, Southport, and Blackpool—in its 10 worst areas. By contrast the 10 areas with the lowest incidence of coronary heart disease included four inner city areas in London—Tower Hamlets, Lewisham, Greenwich, and Waltham Forest. Clearly one cannot