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