

Decision making in the critically ill neonate

SIR

Senior members of a teaching hospital have presented the results of a study¹ that, I would like to suggest, should not have been performed for a number of reasons:

1. Women in the 2nd and 3rd trimester of pregnancy are in need of reassurance that all is well, and that they may expect a normal baby. Even if randomized, it must be unsettling for an expecting mother to be induced to visualize the scenario of a hypothetical severe malformation, more so since 13.5% of the participants came from the infertility clinic, where they had been exposed to some of the darker aspects of reproduction. The women did participate voluntarily, but they were recruited during their routine medical visits, that is, their medical care was not sufficiently separated from their commitment to the research project.

2. Multiple choice and "one to two-word factual answers" are absolutely disanalogous to real life tragic decisions which are preceded by intense consultation, deliberation and advice. It seems frivolous to equate a test answer with the highly dramatic situation which the authors acknowledge to be characteristic of "critically ill neonates".

3. What kind of knowledge has been gained with regard to "times of overwhelming stress"? It needed no large survey to confirm that cultural and religious attitudes weigh heavily in dramatic life/death decisions. Statistics will not help in any way to short-cut the ethical deliberation that needs to be exhaustive enough to probe all values involved in actual neonatal decision making.

4. The methodology is flawed, the conclusions are trivial, with hardly any predictive power. And yet, the paper acknowledges the support of "generous" material and personnel resources. Does this not show a deficient allocation policy?

What did the local research ethics committee have to say? The paper does not mention submitting to any ethical review by the institution's Institutional Review Board (IRB) or Local Research Ethics Committee (LREC). Shouldn't the editors accept-ing such a paper offer some clarity on

the research ethics involved? This is non-therapeutic research that illustrates how (potentially) harmful investigative methods will not yield ethically acceptable conclusions.

References

- 1 Hammerman C *et al.* Decision making in the critically neonate: cultural background v individual life experiences. *Journal of Medical Ethics* 1997;23:164-9.

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Response to Kottow

SIR

We would like to thank Profesor Kottow for sharing his concerns regarding our article,¹ and we appreciate this opportunity to respond. Firstly, we do not believe that there was any - even subtle - pressure upon our subjects to participate in the research by virtue of the fact that they were recruited during clinic visits. They were recruited by volunteers who made it clear that they were unassociated with the medical and/or nursing staff of the clinic. Their doctors were completely unaware of the patients' participation or lack thereof in responding to the questionnaire. Several women preferred not to respond and were quite free to do so.

Furthermore, while it is certainly true that pregnant women in the 2nd and 3rd trimester are anxious about their pregnancy, our questionnaire was preceded by a carefully worded disclaimer reassuring them that the questions were hypothetical, stressing that the overwhelming majority of pregnancies remain uncomplicated and that the following questions were **TOTALLY UNRELATED** to her pregnancy. The questions themselves were formulated by a team consisting of a neonatologist, an obstetrician and a medical social worker, with careful consideration given to these delicate issues. Both the disclaimer and the questions were reviewed by a psychologist before the study was begun. The volunteer, who approached each potential subject, further reassured her of the hypothetical nature of the questions and the fact that they were totally unrelated to her pregnancy.

The issue of one to two word factual answers being able to represent real life tragic decisions is one over which we too agonized. Unfortunately, or rather fortunately, such research cannot be done in real time. We are well

aware of, and have related to, the limitations of this approach in our discussion. Nevertheless, questionnaires such as we used, albeit flawed, are a well accepted technique in this area of research.²⁻⁴

We clearly agree that ethical decision making must probe all involved values. We had absolutely no intention to "short-cut ethical deliberation" but intended, rather, to help staff involved in these deliberations to understand better the decision-making process and to sensitize them during their "exhaustive probing" with the parents during stress.

As to the alleged triviality of our conclusions, again we must disagree. We are not merely confirming that cultural and religious values are important. Statistics enable us to grade the relative importance of various parameters. It was not inherently obvious to any of us that cultural background would supersede subsequent, possibly poignant, life experiences in importance in the decision-making process.

Professor Kottow's implied criticism of resource allocation is equally inappropriate, in our opinion. The "generous support" which was acknowledged, was a private donation from my cousin (note same last name) which was used to fund the translations of the questionnaire into the Arabic and Russian languages - not large sums by any criteria.

We did, of course, seek permission from our local institutional review board (Helsinki Committee), which was granted.

In conclusion, we feel that our methodology was well thought out, carried out with ethical propriety and in no way trivial. On the contrary, we remain convinced that these data can improve staff sensitivity and awareness in dealing with parents during times of stress.

References

- 1 Hammerman C, Kornbluth E, Lae O, Zadzka P, Aboulafia A, Eidelman M. Decision making in the critically ill neonate: cultural background v individual life experiences. *Journal of Medical Ethics* 1997;23:164-9.
- 2 Todres ID, Guillemin J, Grodin M, Batten D. Life saving therapy for newborns: a questionnaire survey in the state of Massachusetts. *Pediatrics* 1988;81:643-9.
- 3 Segal S. Ethical issues presented by children with congenital anomalies. *Seminars in Perinatology* 1992;16:39-72.
- 4 Byrne P, Tyebkhan J, Laing LM. Ethical decision-making and neonatal resuscitation. *Seminars in Perinatology* 1994;18:36-41.

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Editor's note

As well as criticising the authors of the paper in the *Journal of Medical Ethics*, Professor Kottow also implicitly criticises "the editors" for failing to "offer some clarity on the research ethics involved". When a paper submitted to the *Journal of Medical Ethics* has been accepted by its reviewers, and is found acceptable by the editor, and (where appropriate) has had approval by a relevant research ethics committee, then this editor would only consider offering "some clarity on the research ethics involved" if he perceived some major ethical problem concerning the conduct of the research. While understanding the dilemma referred to by Professor Kottow, the editor did not consider it necessary or appropriate to add his comments. However, papers addressing this area (ethical aspects of potentially intrusive enquiry) would be welcomed, subject to the journal's usual policy of peer review.

Causing death or allowing to die? A rejoinder to Randall's comments

SIR

Dr Randall has written a thought-provoking response to my paper,¹ but I fear that she has overextended and overgeneralised my arguments.

Causation

I argued that the withdrawal of feeding from a persistent vegetative state (PVS) patient could be regarded as the cause of that patient's death.² Dr Randall claims that if this is accepted, "then it must follow that *in all cases* where doctors have withheld or withdrawn life-prolonging treatment for *any reason* they have caused the patient's death" (my emphases). This does not follow. A distinction has to be drawn between starving someone who is unable to feed himself, or herself (such as a baby or bed-ridden patient) and ending attempts at emergency resuscitation. Surely one could not withdraw or withhold nutrition and hydration from terminally ill cancer patients, and then argue that their deaths were caused by the underlying disease? In many cases in which treat-

ment is withdrawn from a patient, who dies shortly thereafter, it is clear that the treatment had merely been prolonging the dying process. The difference in the PVS cases is that such patients are not generally regarded as being terminally ill.

Intention

Dr Randall argues that the doctors in the PVS cases do not themselves believe that they intend to cause their patient's death, hence cannot be said to "intend to kill". This flies in the face of the legal position, as described by the judges in the House of Lords in the Bland case, and the quotations I included from Lords Mustill and Browne-Wilkinson make clear that, in law, the doctors did intend to bring about Mr Bland's death. So far as the law is concerned, if a person has foreseen something as a virtually certain consequence of his or her actions, then that person can be said to "intend" that consequence, even if he or she does not "desire" that particular result. No one would claim that doctors ever "desire" their patients' deaths, but for legal purposes their intentions are quite another thing. Hence a terrorist who deliberately blows up a plane to attract publicity to his cause could be held by the law to have intentionally killed the plane's passengers (and hence could be charged with their murder) even if the terrorist did not actually desire their deaths, and indeed, even if the terrorist genuinely hoped that no one would be killed. It is enough that the deaths were foreseen by him as a virtually certain consequence of his act.³

Indistinguishable cases?

Dr Randall asserts that my major premise is that "morally indistinguishable cases should not be treated differently by the law". I made no such claim. Indeed, I conceded in my conclusion that even if certain omissions are morally equivalent to positive acts, "there may be good reasons of public policy for the strong stance which the law takes against positive acts [as opposed to omissions] which are intended to take life". According to Dr Randall, my arguments lead to the conclusion that "...if allowing to die is permitted in the PVS cases ... then so must non-voluntary euthanasia be permitted". I am at a loss to understand where this conclusion comes from - part of the point of my paper was to point out the irony, as I saw it, of the fact that the patient *did* consent to her own death in

the Cox case, while the PVS patients did not so consent (since they were obviously incapable of so doing) yet Dr Cox was prosecuted while the doctors in the PVS cases were not. The aim of my paper was simply to describe the legal reasoning in the Cox case, and contrast this with the legal response to the PVS cases, and to question whether these legal approaches were consistent. I certainly did not suggest that "compulsory non-voluntary and indeed involuntary euthanasia" be legalised. In particular, at no point in my paper did I advocate that the law ignore the need for patient consent - indeed I specifically state that my arguments relate to the desire of patients for a quick death where this "is requested by the patients themselves".

This is linked to Dr Randall's final contention, that my reasoning would make it legally obligatory to administer lethal injections to patients. She describes relatives as having a similar obligation, and paints a horrific picture of the potential consequences. I fear that she has once again overstated my case, and confuses the difference between the law making something permissible, and making it mandatory. My argument was rather that, if one accepts that in certain circumstances it is more humane to administer a lethal injection than to prolong a patient's dying by withdrawing feeding, then the law ought to give some credence to this. The "moral obligation" referred to by Beloff is to support the argument in favour of positive acts of euthanasia, in certain circumstances. "Legal recognition" of this would mean that the law would support the doctor who took steps, similar to those of Dr Cox, to end a terminally ill (and consenting) patient's life by lethal injection. This would mean that such doctors would not face prosecution. It does not mean that it would become mandatory for doctors to kill their patients, nor that doctors (or relatives) should be prosecuted for not doing so.

References

- 1 Ferguson PR. Causing death or allowing to die? Developments in the law. *Journal of Medical Ethics* 1997;23:368-72; Randall F. Why causing death is not necessarily morally equivalent to allowing to die - a response to Ferguson. *Journal of Medical Ethics* 1997;23:373-6.
- 2 There is concern amongst some doctors that a patient in a PVS may suffer when hydration and nutrition is withdrawn. Bissett-Johnson A, Ferguson PR. Striving to keep alive? Care and treatment decisions affecting severely handicapped patients in Britain. *European Journal of Health Care Law* 1997; 4(4):321-45.