

Letters

Autonomy and identity

SIR

Akabayashi *et al* presented us with an account of the difficulties when attempting to respect the patient's autonomy while we do not know the patient's own understanding regarding the autonomy we are attempting to respect. Most times we, as doctors, face difficult decisions, we do not have previous, reliable knowledge of the patients' views on the issue which we are finding difficult to resolve. Even previous discussions which happened far from the turmoil of cancer disclosure or similar events, can only be relied upon to a limited extent. We have all seen patients changing their minds in the face of catastrophe, in ways not only unpredictable to their doctor, but also to themselves. Transcultural study of the meanings and practice of individual autonomy provides a very useful way of extending our understanding of these issues, enlarging our horizons, as it does, beyond the anglo-saxon view.

The main point, however, is to construe a definition of autonomy which will encompass the cultural and individual variations of whatever autonomy stands for. Here I can only offer my view that autonomy stands for whatever enables the preservation of our identity. This view allows for the common conflict between individual and society: while we feel autonomous standing for what we feel ourselves to be, society can only understand our autonomy as the preservation of our social identity. If we act to change the view society has of ourselves, we will probably be criticised for being unduly influenced by someone, for not facing our responsibilities, or through some other form of discourse which just means "keep on being as we see you, so that we may keep on recognising you". The extent to which social identity is important in defining the individual's view of his or her own identity is

variable between cultures and between individuals. The result is the paradox reported by Akabayashi, of surveys showing that the majority of individuals in Japan would want to be told if they had cancer, but would not wish their relative to be told if the relative had cancer.

Autonomy is just a tool to carve and preserve our identity, and the relevant question is not: "How do you want to exercise your autonomy", but: "How do you define yourself".

This takes us to the main issue of the Akabayashi paper: the second-guessing process which enabled doctor and patient to study each other without committing themselves to a specific line of action. The purpose of the phrase used by the doctor was not to convey information, but to allow the patient to define herself. Even for a lay person, the phrase used did not convey any useful information. To be useful, the issues raised had to be explored, and the initiative rested with the patient. The use she made of that offer - "The ball is in your court now" - defined more than any answer could do.

This was an extremely elaborate way of exploring a patient's attitudes without intruding on those same attitudes, and, provided the patient is equipped to follow the events, an admirable example of respect for autonomy and patient identity. Our "duty" to convey information to the patient does not respect autonomy if it imposes information on the patient, as it were by default, whether the patient wants it or not. It is, however, a sign of our culture that elaborate mechanisms of communication are abandoned in favour of immediacy and clarity. It is likely that most Western patients are not equipped to follow this kind of communication, and it is not difficult to imagine Western patients asking questions when they do not wish to know the answer, if confronted with such an enigmatic phrase. Anyhow, I would contend that the principle that guided the doctor in this case is appli-

cable to any cultural setting: to offer the patient the opportunity to face the decision he or she has to take, without feeling committed to a preset pattern of behaviour, and in such a way that the doctor will have feedback from the patient without having to convey the message the patient may well wish to avoid. Regarding the family, there are several issues to be considered. For instance, they may well want to protect the patient from news they feel he or she would be unable to deal with. Also they may well want to protect themselves from a situation they would not know how to deal with (like having a cancerous patient in the family) and which could threaten the stability of the family. It is also possible that the family might follow a cultural pattern, which they understand as the proper way to deal with these issues, with little regard for the needs of those involved, aiming for social approval.

Except in particular circumstances, doctors tend to know their patients much better than they know the relatives. Where conflict exists, this is probably another serious issue and the patient's attitude will have to be re-explored.

At the end of the day, the doctor is that patient's doctor, aiming at preserving that patient's physical health, but also that patient's wellbeing amongst his or her relatives. The stronger the family ties, the stronger the influence of "familial identity" in the patient's view of his own identity.

What we want to avoid is forcing things on the patient without knowing the patient's attitude towards what we are forcing on him.

Reference

- 1 Akabayashi A, Fetters MD, Elwyn TS. Family consent, communication, and advance directives for cancer disclosure: a Japanese case and discussion. *Journal of Medical Ethics* 1999;25:296-301.
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Japanese physicians and the care of adult patients in persistent vegetative state

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The finding that Japanese physicians are reluctant to withdraw artificial nutrition from patients in persistent vegetative state (PVS) is of note because, as the authors of a recent paper in the journal point out, Japanese physicians cannot be described as being strongly subject to the Judaeo-Christian influence.¹ Despite this, the Japanese physicians show the same reluctance as many Western doctors to withdraw nutrition and hydration from their patients.^{2,3} However, the authors do not explore the reasons behind this unexpected finding as fully as they could. They do not question the view that artificial nutrition and hydration (ANH) is medical treatment. Although in the UK evidence presented to the House of Lords in the Bland case⁴ suggested that ANH is medical treatment, those who use gastrostomy tubes tell me that using a tube is easy and does not have the characteristics of medical treatment. Rather the insertion and removing of tubes are decisions and procedures that are subject to the rules of medical consent and benefit for the patient.

All doctors know that removing nutrition and hydration from a patient in PVS will cause death. The authors'

ethical analysis that maintaining ANH is an act of life prolongation is, therefore incorrect. Rather continuing to feed a patient with a tube in situ is a continuation of care. Removing the tube, or preventing its use, is an act of intentional killing.⁵ What Japanese physicians appear to be reluctant to do is deliberately to end life. The blurring of the distinction between inserting a gastrostomy tube and feeding via a tube does not seem to be helpful either in understanding the attitudes of doctors or in helping them to reach an ethical conclusion with which they appear comfortable.

References

- 1 Asai A, *et al.* Survey of Japanese physicians' attitudes towards the care of adult patients in persistent vegetative state. *Journal of Medical Ethics* 1999;25:302-308.
- 2 Schostak RZ. Jewish ethical guidelines for resuscitation and artificial nutrition and hydration of the dying elderly. *Journal of Medical Ethics* 1994;20:93-100.
- 3 Soloman MZ, O'Donnell L, Jennings B, *et al.* Decisions near the end of life: professional views on life sustaining treatments. *American Journal of Public Health* 1993;14:83.
- 4 Airedale NHS Trust v Bland [1993] AC 789.
- 5 Treloar A, Howard P. Tube feeding: medical treatment or basic care? *Catholic Medical Quarterly* 1998;49:5-8.

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Ethical ethics committees?

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At a recent health authority meeting Professor Stacey, the NHSE Head of Research Ethics, was quoted as stating that for multicentre trials rapid responses were required from Local Research Ethics Committees "and so the decisions on the majority of these studies cannot be made at full monthly meetings of the committee".¹ Professor Stacey has stated that each decision could be made by two members of the committee with delegated powers who could discuss it over the telephone.

This seems to have a substantial impact upon the democratic process and one wonders about the ethical validity of the decisions coming out of a process in which the majority are required to be made by two members, following telephone discussions. Perhaps your readers might wish to comment - particularly if they share my concern.

Reference

- 1 North and East Devon Health Authority Meeting, Sept 1999. Support paper: *Research Ethical committees*:1.

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