Abstracts of Note: The Bioethics Literature

This section is meant to be a mutual effort. If you find an article you think should be abstracted in this section, do not be bashful—submit it for consideration to feature editor Kenneth V. Iserson care of *CQ*. If you do not like the editorial comments, this will give you an opportunity to respond in the letters section. Your input is desired and anticipated.

Spike J, Greenlaw J. Ethics consultation: Persistent brain death and religion: Must a person believe in death to die? *Journal of Law, Medicine & Ethics* 1995;23:291–4.

When is a person dead? When a physician declares him or her dead. When is a brain-dead person taken off a ventilator? When the family or surrogate agrees.

These can be two very different events as this case and the accompanying discussion point out. Nearly every bioethics consultation service has been faced with patients declared dead by brain criteria ('brain dead') whose relatives demand that medical treatment be continued so that a miracle can occur. These cases normally resolve themselves in a few days when the patient becomes unstable and the heart ceases functioning. Yet according to the authors, there have been at least a half dozen cases in the United States over the past few years where these patients, mainly children, have existed on ventilators from 4 months to 3 years. What should the physicians, institutions, and ethics committees do in these cases—or in those that are of shorter duration?

The first step is to ensure that the diagnosis is correct, as it was in this case. The authors then suggest that a time-limited period be established after which the ventilator (they suggest 24 to 48 hours) will be discontinued. This allows the family time to accept the death. They suggest that aside from questions of potential insurance fraud for billing for medical services to a corpse, continuing medical support only demonstrates our emotional and legal queasiness with the concept of brain death and our fear of adverse publicity. While unilateral discontinuance of medical support in these patients may be characterized as medical arrogance, no chance exists for a medical miracle. Relatives should be sympathetically counseled that medical interventions are not required for religious miracles. A family's discussion of religious miracles may itself demonstrate a mode of petitionary prayer and open avenues of communication for the clinician to give them realistic guidance.

Hermann R, Méhes K. Physicians' attitudes regarding Down Syndrome. *Journal of Child Neurology* 1996;11:66–70.

How do the attitudes of Eastern European physicians compare with those in the West concerning the treatment of Down Syndrome newborns? Children with Down Syndrome, the most frequent chromosomal disorder, often present not only with mental retardation, but also with musculoskeletal and visceral anomalies. Those with duodenal atresia or congenital heart disease were, until about 30 years ago, allowed to die without intervention. Western physicians have changed their attitudes toward treating these children over the

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past decades. This paper reports on a survey of the attitudes and behavior of Hungarian pediatricians, child neurologists, and pediatric surgeons toward Down Syndrome children.

The most striking difference between the Hungarian physicians' responses and previous studies of Australian and Canadian physicians was that only 42% of the Hungarians would consult with parents about treatment decisions, as opposed to 80% of Western physicians. Similar to their colleagues, 80% of Hungarian physicians would consult with other physicians (but fewer than 10% would ask nurses), as would 90% of Australians and 95% of Canadians. Most Hungarian doctors in all three specialties preferred that a hospital-based ethics committee make the final decisions. Only 10% of Hungarian physicians would demand a court order for recommended surgery on these children if the parents refused. While this is lower than in the United States or Canada, it may reflect an absence of legal guidance. Overall, the attitudes of Hungarian pediatric specialists suggest that their treatment of Down Syndrome children parallels that of Western countries.

Pennings G. Partner consent for sperm donation. *Human Reproduction* 1996; 11:1132–37.

Sperm banks often demand consent for donation from the donor's procreative partner. In many countries, this practice occurs informally, while in some, such as France, the law requires written consent. This common practice runs counter to the widespread and generally accepted principle that a competent adult has autonomy to do with his body what he wishes.

Proponents of required partner consent give several reasons for this. They include sexual exclusivity, family composition, and procreational exclusivity. They equate artificial insemination by donor (AID) with adultery. While the authors discount it, the question revolves around whether insemination or intercourse is the 'adulterous' act. (This may be more a question for historical sociologists than for ethicists.) The issue of family arises with any concern and suffering family members may have about unknown family members (the issue of donated sperm) who live unknown outside of the family. Procreational exclusivity represents ceding reproductive powers to another person (such as the spouse). Many psychological issues surround this surrender and the requirement for permission to donate sperm.

The authors generally discount the reasons given to require partner consent for sperm donation. Individual autonomy is a major factor in their reasoning. Another is that it may often be unclear just whose consent is required: spouse, close genetic relations, or other partners? The data show that many donors do not inform their partners of sperm donations, although the data are conflicting. From a moral point of view, the authors feel that the relationship between partners determines whether there is an obligation to reveal sperm donation. It is not, however, part of the hospital's or the state's duties to make donors get prior consent.

Nightingale SL. Exception from informed consent research requirements for emergency research. *JAMA* 1996; 276:1632.

This short report from the U.S. Food and Drug Administration describes the basic elements of the method institutional review boards (IRBs) can now use to approve the study of experimental drugs and medical devices in persons with life-threatening illnesses who are unable to give consent (and who have no identifiable surrogate imme-

diately available). Federal government rules on this are now uniform, since the National Institutes of Health (NIH) simultaneously published its "Emergency Research Consent Waiver," which contains the same rules. These rules became effective 1 November 1996.

The elements for IRB approval are: (1) the subject has a life-threatening illness; (2) available treatments are unproven or unsatisfactory; (3) no other practicable research method is available; (4) the subject cannot give consent (or no surrogate is available); (5) the risks and benefits are reasonable compared with currently available interventions; (6) prior consultation with the local community; (7) public disclosure of the study design prior to beginning; and (8) an independent data monitoring committee.

These rules are meant to protect potential subjects from abuses by those researching emergency and critical care interventions. Those familiar with the fields, however, wonder who is protecting all of those patients who suffer and die because current techniques are insufficient? Sometimes trying to attain philosophical perfection interferes with the good, the right, the compassionate, and the beneficial. It is, however, at least a slight opening in the barrier that has prevented emergency and critical care from significantly advancing in many areas for the past decade.

The full 56-page text of this rule can be downloaded from the Internet (http://www.fda.gov//opacom/morechoices/fed996.html).

Peters TG, Kittur DS, McGaw LJ, First MR, Nelson EW. Organ donors and nondonors: an American dilemma. *Archives of Internal Medicine* 1996;156: 2419–24.

Why don't Americans donate cadaveric organs in greater numbers despite a growing number of patients in life-threatening need and the marked success of organ transplantation? Organ donation has increased marginally, but primarily through broadening the organ donation criteria. In 1994, for example, while 6,710 patients received life-saving heart, liver, or lung transplants, 3,097 patients died waiting for an organ. Yet 76% to 94% of liver, heart, pancreas, and kidney recipients are alive one year after the transplant. Nearly half of potential donor families approached to give consent for organ recovery refuse to permit this lifesaving measure. To find out the difference in attitudes between these two groups, the authors surveyed demographically matched focus groups of self-described potential organ donors and nondonors in five U.S. cities.

They found that neither group had much specific information regarding organ donation and transplantation, both groups distrusted government involvement, and both were highly influenced by the mass media. Donors seemed highly motivated and were a bit more medically sophisticated. They were more knowledgeable about brain death.

In general, nondonors were suspicious and distrustful of medicine and their communities. In particular, they believed that few organs would go to minorities or the poor and that physicians would prematurely declare dead those patients with signed organ donor cards. They also focused on transplantation failures (despite personal contacts who had successful transplants), recipient pain and suffering, and the need to go to their graves 'whole.' They either were unaware of their own religion's teachings on organ donation (nearly all Western religions permit organ donation to save a life) or felt this way despite their religion's formal position.

These findings suggest that, rather than it being a purely educational issue,

being an organ donor in the United States reflects an individual's sense of bonding with his or her community. Since one other finding was that both groups believed a reasonable 'incentive' to donate was for organ donors' families to have a preferred status as organ recipients (similar in many ways to what pushed organ donation forward in Singapore), we may need to consider this if we are to increase organ donations.

The Ethics Committee of the American Academy of Otolaryngology—Head and Neck Surgery: Ethics Position Papers. *Otolaryngology—Head and Neck Surgery* 1996;115:179–249.

A useful group of teaching materials for those teaching ethics to otolaryngologists, this group of papers in a single journal volume provides what is, essentially, their ethics manual. The topics covered are informed consent; patient rights and surrogacy; delegation of authority; research; collegiality; commercial relationships; compensation; advertising; obligations to patient, profession, society, family, and self; and teaching methodologies. Each topic begins with a short introduction, and most then have one or more case studies for the topic with an extended discussion. Based on the well-regarded American Academy of Ophthalmology Ethics Committee's manual, *The Ethical Ophthalmologist: A Primer*, this provides substantive teaching material on which to base ethical instruction in residencies and continuing education.