

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.

McEwen JE, McCarty K, Reilly PR. A survey of medical directors of life insurance companies concerning use of genetic information. *American Journal of Human Genetics* 1993;53:33–45.

In the minds of ethicists, clinicians, and the public, the great bogey man of genetic testing continues to be insurance companies. Will these companies unscrupulously use genetic information to deny coverage to high-risk individuals? This article represents a limited survey of answers to this question by life insurance company medical directors. (The ability to purchase life insurance policies is most likely to be adversely affected by genetic information, unlike employer-purchased group health insurance policies.) Significantly, many of the insurance company medical directors declined to respond to the survey, although many replied to the investigators, telling them that they could not or would not answer the questions. By itself, this raises the possibility that those who are worried about the insurance industry's use of genetic information are not paranoid. Of the medical directors who answered, most said that they would want access to any genetic information that existed about an individual but would not require genetic testing. Some, however, would recommend that their company use genetic testing for conditions that were untreatable, that had high fatality rates, and that caused premature deaths. The determining factor for using a test would be its sensitivity and specificity. Most of these companies, however, already use genetic information derived from patients' medical histories, such as the frequency of specific types of cancer, heart disease, or diabetes in an applicant's family. Two peripheral findings also raise some concern. The medical directors who responded seemed to be deficient in their knowledge and understanding of human genetics. Also, it appears that the actuarial

ratings for many genetic-based conditions are based on subjective decisions rather than objective data. Is there cause for concern? Yes.

Riis P. Medical ethics in the European Community. *Journal of Medical Ethics* 1993;19:7–12.

With the European Community struggling to come together on economic and political issues, this author suggests that they also need to find common ground in the area of medical ethics. He acknowledges that although the Community now has a common cultural core based on fundamental human rights and democratic systems, significant differences exist in the existential/religious realm. This area, based on differing religious (or nonreligious) belief systems, has scarcely been affected by the political changes within the community. Therefore, he believes that although political bodies, such as parliaments, can deal with medical ethical problems, they may not want to address these issues because little consensus may be easily reached. If they do deal with these issues, they will do so poorly because these issues are beyond their normal scope. The author believes that the Community should work "to change pluralism so that, instead of being a supermarket of incoherent options, it becomes a number of coherent ethical options, chosen according to an individual citizens' own overall preference." He believes four main areas will be the focus of European bioethical debate in the next decade: 1) The composition, structure, and role of research ethics committees (IRBs); he suggests eventually forming national and then Community-wide committee networks; 2) equitable access to healthcare amidst scarcity; he also suggests that patient rights, including autonomy, be advanced, as well as eventually promoting patient duties towards the healthcare system; 3) the human genome

project; the clinical benefits and detriments of using this knowledge will need to be explored; and 4) futility and euthanasia; although he does not use the former term, he suggests that research on knowing when and how to stop medical treatment and thoroughly investigating euthanasia are vital to a humane healthcare system. As described, the European Community has a full plate of ethical concerns to address; the world community will eagerly await any progress they make.

Sonnenblick M, Friedlander Y, Steinberg

A. Dissociation between the wishes of terminally ill patients and decisions by their offspring. *Journal of the American Geriatric Society* 1993;41:599-604.

When elderly parents are terminally ill, what medical treatment do their children want for them? These Israeli researchers interviewed the adult offspring of terminally ill patients to find out how aggressive they wanted to be with their parents' care, whether the decisions correlated with what the parent actually wanted, and who was to be the decision maker for different therapeutic options. Most offspring wanted continuation of nonnarcotic medication (73%), intravenous feeding (78%), narcotics (69%), and feeding tubes (66%). Many opposed resuscitating (42%) or beginning dialysis on (39%) their parent, although more than 20% would leave these decisions up to the physician. Euthanasia was desired by 7% of the children. Factors that significantly influenced the offsprings' decisions about resuscitation included age (over 45 years old more likely to request a do-not-resuscitate order), religious observance (Ultraorthodox and Orthodox requesting resuscitation more frequently), visiting frequency (those visiting less than once per week not wanting resuscitation), and place of birth (Europeans wanting a do-not-resuscitate order much less frequently than any other group). Of most importance in this study, however, was that an individual offspring's request for treatment often disagreed with both their sibling's desires and their parent's prior expressed wishes. How these findings factor into the concept of surrogate decision making remains an interesting question.

Jakobi P, Weissman A, Paldi E. The extremely low birthweight infant: the twenty-first century dilemma. *American Journal of Perinatology* 1993;10:155-9.

Bioethics committees are increasingly being asked about the ethics of continuing life-support measures on extremely low birthweight (ELBW) babies (less than 750-800 grams). Because good ethics begins with good facts, this article can supply the currently known facts about this group of babies. Although the subject of very low birthweight babies (less than 1,500 grams) has been well discussed, ELBW babies are a newer medical entity—a group that not all societies even recognize as persons. Before the advent of modern technology, ELBW babies were simply classed as miscarriages or stillborns; this situation still exists in many countries and produces misleading international statistics on neonatal mortality. These authors point out the ELBW babies (often described as being delivered at less than 26 weeks gestation) have an extremely poor prognosis, and the greatest effect of resuscitative efforts is to prolong their very expensive deaths (averaging \$1,000 per day across Western countries). They also report that up to one-third of the children who do survive are profoundly neurologically or physically disabled. The major abnormalities are cerebral palsy, blindness, deafness, severe hypotonia, and serious developmental delays. The authors suggest that physician discretion on initiating resuscitation in the delivery room coupled with more informed parental involvement will provide at least part of the solution. As they say, however, we still do not know the answer to the question, "When does appropriate care end and abuse of very small infants begin?"

Kinsella TD, Verhoef MJ. Alberta euthanasia survey: 1. Physicians' opinions about the morality and legalization of active euthanasia. *Canadian Medical Association Journal* 1993; 148:1921-6.

What are physicians' attitudes toward legalized active euthanasia? Although much debate has occurred, few unbiased facts are available. This large study of Canadian physicians represents an important addition to the information we have on the topic. Although most (51%) of the respondents in this cross-sectional sample believed that active euthanasia should be legalized, only 28% said they definitely would practice active euthanasia if it were legal; 51% said they would not and 20% were uncertain. Whether the physician believed active euthanasia was morally acceptable significantly related to their type of practice (specialists not most likely to encounter patients re-

questing active euthanasia were most likely to say that it was morally acceptable), their religious activity (those not religiously active most commonly believed that it was morally acceptable), and their religion (those with no specified religion and non-Orthodox Jews believed it to be moral). The physicians' religion and religious activity (paralleling their belief in the morality of active euthanasia), sex (male), and where they graduated medical school (United Kingdom) significantly related to whether they would be willing to put active euthanasia into practice. Nearly 20% of the respondents reported that at least one patient had requested their active assistance in dying. Despite relatively high physician acceptance of the practice, however, active euthanasia remains illegal throughout Canada.

Iserson KV, Stocking C. Prevalence of ethics, socioeconomic and legal education requirements for postgraduate medical programs. *Journal of Clinical Ethics* 1993;4:225-9.

Ethics, socioeconomic, and law are the milieu in which medicine is practiced. This study assesses the presence of current and pending postgraduate educational requirements in these areas and their evaluation during residency site surveys and Board examinations. The 1991 Accreditation Council for Graduate Medical Education (ACGME) General and Special Requirements were reviewed to assess the published requirements for bioethics, socioeconomic, and legal education. The executive director of each of the 22 primary or conjoint medical specialty boards recognized by the ACGME and the chairperson of the 25 Residency Review Committees (RRCs) were then surveyed by mail to determine 1) whether the respondents considered each topic important in their specialty, 2) whether bioethics, economics, and legal education was present in their specialty's curriculum, and 3) if not present now, whether there were plans to add these topics in the future. Although the general requirements require ethics and socioeconomic education for all specialties, only four specialties (16.7%) (Family Practice; Pediatrics; Preventive Medicine; Psychiatry) list special requirements in any of

these areas. Twenty-one of the 22 U.S. specialty boards (96%) and 24 of the 25 RRCs (96%) responded to the mailed survey. Seven specialties (Internal Medicine, Obstetrics and Gynecology, Orthopedic Surgery, Plastic Surgery, Otolaryngology, Physical Medicine & Rehabilitation, and Ophthalmology) have plans to add special requirements for bioethics education. Internal Medicine is the only specialty that plans to develop special requirements in law; none reported plans to add requirements in socioeconomic. Only the Psychiatry and Ophthalmology RRCs cited their residency programs for deficiencies in ethics education (Ophthalmology based citations on the general requirements); only Psychiatry cited deficiencies in legal education; and only Ophthalmology and Preventive Medicine cited deficiencies for education in socioeconomic. No statistically significant difference existed between cognitive and procedural specialties in inclusion of bioethics ($P > .1$) or legal ($P > .5$) questions on their Board Examination. Cognitive specialties, however, were more likely to have socioeconomic questions on their Board examination ($P < .06$). Although the total number of written Board examination questions ranged from 150 to 655 (mean = 350.5), no more than three questions on bioethics (Physical Medicine & Rehabilitation, Preventive Medicine), four on socioeconomic (Family Practice, Pediatrics), and eight on law (Emergency Medicine) were reported. It is unclear whether residency education can by itself make physicians more ethical, more culturally sensitive, or more legally astute. However, these goals can be established as desirable, closely associated with professional competence and considered to be factors in assessing that competence. Little effort apparently is being made to emphasize the current educational requirements in these areas. If the requirements for ethics, socioeconomic, and legal education in residencies continue to be ignored by specialty boards in their certifying examinations and by RRCs surveying education programs, then the requirements are meaningless and are merely window dressing to appease a public concerned about the humaneness of medical practitioners.