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.

Waisel DB, Truog RD. The cardiopulmonary resuscitation-not-indicated order: futility revisited. *Annals of Internal Medicine* 1995;122: 304–8.

Common practice dictates that do-not-resuscitate (more properly, of course, do-not-*attempt*-resuscitation) orders stem from agreements between the healthcare team and the patient or surrogate. In some cases, patients autonomously decide to forego life-saving interventions. This paper explores the other end of the spectrum—physician-initiated unilateral do-not-resuscitate (DNR) orders based on futility. While the futility debate swirls in the bioethics literature, some institutions have taken the step of incorporating futility-based decisions into their policies. This paper reviews four such policies and summarizes three general proposals for incorporating futility into clinical decisions. Allegheny General Hospital's (Pittsburgh) policy states that "When the attending physician believes that life-sustaining treatment may be potentially 'futile,' that is *physiologically unable to work*, then it is not necessary to initiate this treatment. The physician does not need permission to forego such treatment." The Veterans Affairs Medical Center (Seattle, Washington) allows the physician to make a unilateral decision based on either quantitative futility: "a very low or rare probability of achieving the return of vital organ function and survival beyond a short period of time," or qualitative futility: where the quality of life falls well below the threshold considered minimal by general professional judgment. Beth Israel Hospital (Boston) uses the criteria that either there is no chance of patient recovery or no reasonable likelihood that CPR efforts would restore cardiac and pulmonary function. Johns Hopkins Hospital (Baltimore) says that physicians may refuse requests for a life-sustaining intervention if it is "highly unlikely to have a beneficial outcome, or if it is highly likely merely to preserve permanent unconsciousness or persistent vegetative states or require permanent hospitalization in an intensive care unit." After reviewing the futility concepts based on physiologic, quantitative-qualitative, and cost-benefit parameters, they conclude that any current unilateral policy should be based only on physiological futility. In their view, the dangers are imposed value judgments, imprecise definitions of quantitative and qualitative futility, inexact data, lack of certitude of economic benefits, and the role of patient and physician autonomy. They believe that Allegheny General Hospital's policy may be a good model to follow, but as professional and societal consensus emerges on some of the sticky issues, we may progress to allow more physician-autonomous decisions.

American Society of Human Genetics, Ad Hoc Committee on Genetic Testing/Insurance Issues. Background statement: genetic testing and insurance. *American Journal of Human Genetics* 1995;56:327–31.

As genetic technology charges forward at incredible speed, this paper attempts to answer some of the complex questions about the relationship among practitioners, patients, and insurers. It discusses the basic premise of insurance—that it provides protection against unanticipated loss. The authors then discuss the problem of defining "genetic conditions" and "genetic tests." They briefly show that although some disorders have a purely genetic basis, most diseases cannot be as clearly categorized. These include such seemingly pure genetic disorders as sickle-cell disease and cystic fibrosis, because of their gene's variable penetrance. Trying to define a genetic condition beyond single-gene defect diseases becomes even murkier. They believe that genetic testing will have major impact on life and disability

Cambridge Quarterly of Healthcare Ethics (1995), 4, 556–558. Printed in the USA.

insurance, rather than health insurance. They base this belief on the assumption that most health insurance is employer based and does not discriminate against isolated at-risk individuals. As they point out in a brief section on "legal issues," however, recent court cases (e.g., *McGann v. H & H Music Co.*) may invalidate this assumption. At present, insurance companies do not require genetic tests, although they collect genetic information from family histories and prior diagnostic tests in patient medical records. They can also get this information from a *very large* insurance industry database, such as MIB, formed to cross check information about potential insurance applicants. (Who knew that this existed? What does this say about our privacy? Our society was concerned about the credit bureaus. This database *goes way beyond* credit histories! It has your medical history, albeit in abstracted form.) They also suggest that the individual may cause the insurance companies to "adversely select" them for coverage if they conceal knowledge of a genetic or other disease, and as a result get lower insurance rates. In the end, though, this committee comes up with questions, rather than answers. They meekly seek shelter in suggesting that universal healthcare will solve the problem of genetic information-based health insurance discrimination. In fact, this might make the problem worse. Unfortunately, as genetic testing becomes cheaper and more accessible, the problem of insurance availability based on genetic information will only increase. Perhaps this committee should go back to the table, try working out some real guidelines, and suggest some workable answers.

Spital A. Mandated choice: a plan to increase commitment to organ donation. *JAMA* 1995;273:504–6.

Who should decide whether a person donates his organs (or tissues) after death? Should it be the individual or his family? Spital's concept of mandated choice would require competent adults to make their decisions known at a specific time, such as when getting drivers licenses. This decision would then constitute legal permission to take organs or tissues after death, rather than requesting this permission from family members. At present, of course, surgeons take virtually no organs or tissues without family permission, even if the deceased signed an organ/tissue donor card. (Presumed consent to take eyes exists in at least 13 states. Presumed consent for organ donation exists in much of Europe.) In this study, the Gallup Organization randomly surveyed US adults with telephones to determine their attitude toward organ and tissue donation. While 74% had thought about it, only 30% planned to denote after death. Sadly, of all respondents, only 38% had told their families about their wishes. This suggests that the people now being asked for permission, usually family members, generally do not have the information they need to make an informed decision. People seem to understand this. They overwhelmingly (82%) felt that it was more appropriate for the individual to decide about organ donation for himself than for his friends or family to make the decision after his death. Also, more than twice as many respondents (63%) said that they would be likely to sign up to donate if mandated choice became law. Not discussed here, and a worry of many in the organ/tissue field, is that if mandated choice were to become law, people might be asked to make this binding decision without adequate information and under adverse circumstances, such as when applying for drivers licenses. While pairing mandated choice with drivers licenses seems logical because most competent adults have and carry their licenses, at least two difficulties have emerged. First, many minors apply for licenses, and their decisions may not be legally valid. Second, because many licenses are now valid for 25 years or more, any decision made at that time may be seemingly irrevocable. Spital has a good idea here—let adults make decisions about what they want done with their corpses. Modified versions of mandated choice are now wending their ways through many state legislatures. Perhaps in the meantime, we should suggest that people talk to their families.

Holm S. Moral reasoning in biomedical research protocols. *Scandinavian Journal of Social Medicine* 1994;22:81–5.

The Helsinki-II declaration and the Danish Research Ethical Committee's (REC) guidelines require an "ethics section" in all biomedical research protocols. This author reviewed the ethics sections in 134 research protocols submitted to a Danish REC. Despite the requirements, 20% of the protocols lacked ethics sections. Of the balance, the sections averaged only six lines of text (1.1% of the entire protocol) and contained three ethically relevant statements. One-third of these statements were purely formal, such as stating that the protocol accorded with the

Helsinki-II declaration or had been submitted to an ethical review committee. Another one-third dealt with the processes of informed consent and the subject's voluntary participation and ability to withdraw from the project. The balance contained more elaborate ethics sections. Pediatric protocols seemed to have the most elaborate ethics sections and ethical arguments. The author concluded that the paucity of any ethical deliberation in the research protocol ethics sections was due to researchers' perception that the review itself was only a procedural hurdle to overcome. Perhaps it is also due to researchers' lack of knowledge about what constitutes ethical issues or the framework in which to contemplate and express such issues about their research.

Orentlicher D. The limits of legislation. *Maryland Law Review* 1994;53:1255–1305.

Bioethicists often quote the law. In this article, Dr. Orentlicher, an M.D.-J.D. who staffs the American Medical Association's Council on Ethical and Judicial Affairs, outlines the statutes concerning end of life. He concentrates on laws dealing with living wills, durable powers of attorney for healthcare, do-not-resuscitate orders, and healthcare surrogacy. He then discusses these laws' problems, starting at a place most of us have not considered—that the statutes themselves mislead the public about their rights regarding end-of-life decisions. As he points out, the absence of an explicit statute does not mean the individual does not have the right to execute an advance directive under common law. As Justice O'Connor said in *Cruzan*, states may have a constitutional duty to respect an incompetent patient's appointment of a surrogate decision maker. The presence of an end-of-life statute also suggest that such laws describe the full extent of a person's rights. Not so. Again, many common law rights may exist that are not written into laws. Some states also have provisions that are probably unconstitutional, such as prohibitions against withdrawing artificial fluids and nutrition. Ambiguity also plays a nefarious role in confusing end-of-life statutes. What, for example, does "terminal" mean? (Arizona, when drafting its current law, decided to omit the term, because no other state had an acceptable definition in its laws. No dire consequences have resulted.) He also discusses the problem of healthcare providers not understanding the patient's wishes. This may be due to unclear directives, socioeconomic differences between the patient and the healthcare provider, or spending too little time discussing these issues with the provider. The article then discusses the predominance of physicians' values in end-of-life decisions, usually because of a lag between theory and practice, a fear of malpractice, futility, patients not wanting to exercise their autonomy or being ignored, or paternalism. As a solution to all of the problems with end-of-life laws, the author suggests several solutions, including a reform of the current laws, probably in line with the *Uniform Health Care Decisions Act* (see Sabatino CP. The new uniform health care decisions act: paving a health decisions superhighway? *Maryland Law Review* 1994;53:1238). This would, among other things, eliminate the discrepancies among state end-of-life laws. He also suggests physician payment reform, encouraging physicians to spend more time with their patients discussing end-of-life issues. He also suggests strengthening the informed consent doctrine. Finally, however, he believes that recognizing the strong influence physicians have over end-of-life decisions under our current laws will go a long way toward improving the current situation.