



1-1-2012

## Bioethics

Carol Ann Mooney

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### Recommended Citation

Carol A. Mooney, *Bioethics*, 2 NOTRE DAME J.L. ETHICS & PUB. POL'Y 581 (1987).

Available at: <http://scholarship.law.nd.edu/ndjlepp/vol2/iss3/7>

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## FOREWORD

### BIOETHICS

CAROL ANN MOONEY\*

The bioethical debates of the past decade have brought into focus a fundamental issue—whether the proper role of law is to protect the welfare of persons governed or to preserve their right to self-determination. The appropriateness of a given medical procedure is at base an ethical and religious determination. The pluralism of American society and respect for the moral integrity of the individual have led to the general conclusion that medical care decisions should be made by the patient.

In order to implement the right to autonomous decision-making, the law has concentrated its efforts upon structuring a procedure which affords the patient freedom to make a substantive decision. This emphasis upon procedure rather than substance is misleading. It gives the illusion that the law has cleverly avoided making any normative decisions and has conveniently left that burden with the individual. In reality, however, the law evidences a fundamental moral decision, a determination that autonomy is the first good.

Elizabeth Bouvia's dealings with the California courts during the past several years have exposed the substantive issues which are inevitably intertwined with the process of protecting autonomy. Elizabeth Bouvia is now 28 years old. She is a quadriplegic, cerebral palsy victim who is bedridden. Because she is unable to orally ingest sufficient nutrients, Ms. Bouvia is nourished through a naso-gastric feeding tube. In 1983 she sought the right to be cared for in a public hospital while she intentionally starved herself to death. Her request forced the court to consider whether there are any inherent moral limitations upon a person's right to self-determination, limitations which should be legally enforced. Ms. Bouvia was denied the judicial assistance needed to accomplish her goal. In April 1986, however, a California Appeals Court upheld her right to refuse the feeding tube. The Court found that

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\* Associate Professor of Law, Notre Dame Law School.

the right to refuse treatment is basic and fundamental and "its exercise requires no one's approval."

In contrast, the right to demand treatment may not be so far reaching. A number of reasons may support the difference in breadth, chief among which is that responding to the demands of one patient may result in neglect of another, while refusal of treatment never creates such conflicts. The laetrile controversy of the late seventies, however, indicates that even if the rights of others are not directly affected, the law is still willing to impose some protective limitations upon the right to control one's destiny. The Supreme Court refused the pleas of terminally ill cancer patients and their spouses to enjoin the federal government from interfering with the interstate shipment and sale of laetrile, a drug not approved under the Federal Food, Drug and Cosmetic Act.

In this issue of the *Journal*, Dr. C. Everett Koop, Surgeon General of the United States, and Mr. Edward Grant, a lawyer with Americans United for Life, examine living will legislation and judicial decisions regarding withdrawal of life-prolonging treatment. They conclude that in the name of autonomy, the legal and ethical prohibitions against euthanasia have been weakened. The article emphasizes that decisional processes created for incompetent patients should be evaluated not only in the narrow context of whether a particular patient's right to self-determination is preserved, but the process should also be judged in light of its impact on society as a whole. Current procedures presume that the only problem is the over-treated terminally ill patient. As a result, these procedures encourage a philosophy which views death as a desired outcome. Koop and Grant believe this perspective creates a danger that, in the guise of protecting the integrity of personal decision-making, the fundamental interest of all citizens in the protection of their lives will be compromised.

Professor George Smith's article discusses the question of self-determination in the context of the new procreational technology. He advocates legislation limiting the use of artificial insemination and *in vitro* fertilization to married women. Professor Smith concludes that the Supreme Court has recognized a fundamental right to remain fertile as well as a right to avoid conception, but that the Court has not recognized a fundamental right to conceive. Therefore, laws limiting access to procreational technology only need a rational basis. Smith believes the state's interest in promoting the institution of marriage and the raising of children in a traditional family setting provide such a rational basis.

The articles in this symposium deal with diverse issues. At the core of each discussion, however, is a recognition that it is impossible to respond in a value-free way to the issues arising with the rapid expansion of medical technology. A task force of the Child Neurology Society recently determined that adult brain death criteria may not be adequate for some children and the task force circulated a draft of brain death criteria for children. In a discussion of that draft, Mr. Ellis, a member of the Hunton & Williams law firm, points out that even brain death criteria, which identify a scientific event, are not universally seen as morally neutral. The definition of the event and the selection of the scientific criteria are based on moral criteria.

Two articles written by Notre Dame law students appear in this issue. David Kessler's article concerns the rights of children to refuse life-saving treatment on religious grounds. While the courts have been unanimous in denying a child's parents the right to forego, on religious grounds, life-sustaining treatment for their child, the criteria for allowing the child himself to refuse treatment are unclear. Kessler distinguishes unemancipated minors from those minors who are as responsible for themselves as any adult, and he argues for the right of emancipated minors to make decisions concerning their own medical treatment.

Karen McCartan has surveyed the legal, ethical and public policy issues attending the practice of *in vitro* fertilization. Like Professor Smith, she argues that some limits be placed on the availability of procreational technology. Both England and Australia have imposed regulations on the practice of *in vitro* fertilization in those countries, yet curiously, the United States lags behind in regulatory action. McCartan proposes criteria, based in part on the Australian regulations, which should govern the future practice of *in vitro* fertilization in this country.

The way our legislatures and courts respond to the emerging bioethical issues will have a profound impact upon the development of our society. This *Journal* issue hopes to contribute to the ongoing debate by emphasizing the social and moral dimensions of issues which are often examined only in light of their impact upon the individual.

