An Ethicist Urges Offering All Options In Disability Cases

By Leslie Steven Rothenberg

The ethical issues associated with children born with congenital anomalies that produce both physical and developmental disabilities elicit strong emotional reactions from everyone involved. Questions raised include the autonomy of patients, the degree to which public and private resources to the babies and families involved, the wisdom of governmental intervention to monitor medical treatment of such patients, the degree to which public and private resources should be used to support such patients, and the appropriateness of assessments by observers as to the quality or value of life with disabilities.

Ethics consultants, members of hospital ethics committees, clergy and others may be asked to consult in response to such dilemmas and to offer advice. Are those of us who have the responsibility (and temerity) to raise ethical issues for the consideration of others sufficiently conscious of our own ethical obligations in doing so? Of particular interest is the degree to which we are willing to subordinate our own values in order to expand the range of options available to patients and their families. A recent experience illustrates the problem.

Several months ago I received a telephone call from a lawyer who was seeking to assist the parents of a seven-week-old baby born with several congenital anomalies. I was told the parents were facing a number of decisions about the child’s care and needed help in understanding their options. Would I be willing to advise them over the telephone? I agreed and within an hour I received a call from the child’s mother, who described herself as in her mid-30s, upper middle-class, married to a successful businessman and with another child, a boy four years old.

She said the baby, a boy, had been delivered five weeks prematurely and the first word that there might be a problem came about 36 hours after the delivery. Difficulty inserting a feeding tube indicated there might be an obstruction. It turned out that there was a tracheoesophageal fistula, which the parents agreed to have corrected surgically.

Because she developed an infection, the mother did not see the baby until three days after his birth. She laughed as she told me that since she and her husband have large ears, she was surprised to see what small ears the baby had. She also noticed that his eyes kept rolling back into his head. She said she remembers the doctors telling her, “Give the baby a chance; he’s premature.” But a new problem seemed to emerge almost every day. The child’s genitalia looked strange. His hearing seemed impaired. Then the doctors diagnosed a congenital heart defect and a regurgitation problem, both of which would require surgery. And an ophthalmologist reported that the baby had no optic nerve in one eye and only half an optic nerve in the other.

The pediatrician said that all but the vision problems could be corrected surgically, but the parents insisted on a second and more complete work-up by a neurologist and a geneticist. This disclosed that the baby had a midline injury in the base of his brain and that he had perhaps five or seven conditions associated with a congenital syndrome. The child would be retarded, but the physicians could not predict the degree of retardation. He would need continuing multidisciplinary care.

If the parents took the child home they would need a lot of medical equipment (including a suctioning machine, a continuous intravenous drip, and a heart and respiratory monitor) and would need to learn CPR.

Meanwhile, their four-year-old was having trouble coping with all these events. Beginning with the mother’s enforced rest and then continuing with their daily preoccupation with the baby’s mounting list of problems, the older child became increasingly angry and frustrated. He announced to his parents one evening: “I don’t want to live with you anymore. I want to live with grandma and grandpa.”

The hospital began pressuring the parents to take the baby home saying that their insurance company would not pay for his continued stay, but they were frightened that if they did so and the baby died because they failed to respond to alarms, they would be jailed. They also felt incapable of caring for the infant. Their pediatrician referred them to a state center at which a physician said that her highest hope for the baby was that by age 10 he would be able to dress without help and be toilet-trained.

The parents felt they were “on a roller-coaster and wanted off.” The physicians apparently had not been helpful to them in discussing their parental options hinting that any needed medical interventions for which they refused authorization would be done by court order. The hospital social worker erroneously told them they could legally “abandon” their child and let him become a ward of the state. The state center,

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which had unsuccessfully explored the possibility of adoption, offered a foster home placement for the baby, but that would make the parents legally responsible for his care, which has powerful emotional implications, as well.

When I asked the parents about the possibility of arranging adoption for their child, they said, "No one would ever want to adopt a child like this." But when I told them I might be able to put them in touch with someone who knew a family interested in adopting their child, they said I should try.

After making inquiries I was able to give them the name and telephone number of Mrs. Janet Marchese (56 Midchester Ave., White Plains, N.Y. 10606, 914 428-1236). Mrs. Marchese, a waitress by day, volunteers her time in the evening to run the Down Syndrome Adoption Exchange, which depends entirely on contributions (The Joseph and Rose Kennedy Foundation pays her telephone expenses). Another such agency, focusing on adoptions of children with spina bifida, is run by Mrs. Judy Grafstrom in Xenia, Ohio (513 372-2040). Mrs. Marchese found a family in California that is eager to adopt the child and by the time this article appears the adoption should have been completed.

This case illustrates the benefit to both child and parents of exploring all the options. Ethicists and all health professionals should be aware of such options and regardless of what their own choice might be if they were the birth parents, they should offer them to the families involved.

(Dr. Rothenberg is director of the Program in Medical Ethics, UCLA Medical Center.)

Books

Recent Acquisitions

(New additions to the collection of the National Reference Center for Bioethics Literature)

Lynn, Joanne, ed. BY NO EXTRAORDINARY MEANS: THE CHOICE TO FORGO LIFE-SUSTAINING FOOD AND WATER. Bloomington, In.: Indiana University Press, 1986. 272 p. The authors of these essays are major writers in bioethics. They offer moral and legal perspectives on withholding or withdrawing treatment from the terminally ill.

Shelp, Earl E. BORN TO DIE? DECIDING THE FATE OF CRITICALLY ILL NEWBORNS. New York: Free Press, 1986. 250 p. The view is taken that the parents have the right and responsibility to decide the treatment for their handicapped infant.


Feinberg, Joel. HARM TO SELF. New York: Oxford University Press, 1986. 420 p. (Vol. 3 of THE MORAL LIMITS OF THE CRIMINAL LAW.) Paternalism, autonomy and informed consent are examined. The author considers how far a person can involve himself voluntarily in dangerous behavior.
Limited Attention Paid by Ethicists To Genetic Testing

By LeRoy Walters

Ethical issues in human gene therapy have been widely debated, and a set of guidelines for gene therapy proposals has been published by the National Institutes of Health. In contrast, recent advances in the diagnosis and prediction of genetic disease have received relatively little ethical analysis. There have been no books or symposia dedicated to the ethical aspects of the new diagnostic techniques. To its credit, the Congressional Office of Technology Assessment is currently conducting a study of public-policy questions that may arise in the wake of new approaches to genetic testing. Dr. Neil Holtzman, on leave from the Johns Hopkins University School of Medicine, is coordinating this study.

Huntington's disease is perhaps the condition that best typifies the emergence of a new era in genetic testing and screening. This disease, to which Woody Guthrie fell victim, typically begins at the age of 35 to 40 and leads to progressive neurological deterioration and premature death, usually by the age of 55. Researchers have identified a genetic marker that is very closely linked with the dominant gene that causes Huntington’s disease. Thus, presymptomatic testing for the presence of the gene that causes the illness is now a technical possibility; current estimates are that this test will be accurate in 96-97 per cent of cases.

A second condition for which presymptomatic genetic tests may shortly be available is the tendency to develop early atherosclerosis (hardening of the arteries) and consequently, premature heart disease. Several academic laboratories and biotechnology firms are actively engaged in the search for genetic markers that correlate with this tendency. In the future, similar genetic markers may be discovered for Alzheimer's disease, certain types of cancers (for example, malignant melanoma), and even for conditions that are usually called mental illness, such as manic-depressive disorders.

These new diagnostic possibilities will obviously complicate the current debate about the ethics of prenatal diagnosis, but I would like to focus on ethical dilemmas involving already born individuals. One can, I think, divide the ethical questions raised by postnatal genetic diagnosis into two general categories—questions that involve the (nuclear and extended) family and questions that involve larger social institutions. Obviously there is some overlap between these two categories.

At the family level, persons considering marriage, spouses considering child-bearing, and parents, will, in some cases, face the questions, Who should be tested, and When should the testing be performed? The questions are now being faced by individuals and couples at risk for Huntington’s disease. In three locations—Boston, New York and Baltimore—pilot programs of presymptomatic testing for at-risk individuals have already been initiated. All three of these testing programs are following detailed clinical protocols that have been carefully reviewed by the local institutional review boards. Ruth Faden, of the Kennedy Institute and the Johns Hopkins University School of Hygiene and Public Health, has been involved in the planning and implementation of the Baltimore program.

Would a reasonable adult who is at risk for Huntington’s disease consent to be tested? Answers to this question vary. The negative aspect of being tested is that, under present conditions, nothing can be done to delay or prevent the development of disease in a true positive. Thus, a true positive who consents to be tested simply finds out that he or she is doomed to develop a terrible disease and to die prematurely. On the plus side, testing could assist a couple or individual in decisions about marriage or child-bearing. Further, members of the extended family could be alerted, and already born children could be informed of their risks at the appropriate time. Finally, one could set one’s priorities and plan one’s life accordingly.

The risk-benefit ratio for presymptomatic testing may look considerably different to individuals and families in cases where preventive medical intervention is possible. Imagine, for a moment, that you are offered a well-validated genetic test for a tendency to develop premature atherosclerosis or a manic-depressive disorder later in life. If dietary changes or medication could prevent or ameliorate the manifestations of disease, the reasonable person might be more inclined to accept testing than in the case of presymptomatic testing for an inexorable condition like Huntington’s disease.

At the level of larger social institutions the primary question about the new generation of genetic tests is: Who should have access to the results of an individual’s genetic tests, and

Think Tank Planned On Black Bioethics

The Kennedy Institute and the Howard University College of Allied Health Sciences are co-sponsoring a workshop called the Black Perspectives in Medical Ethics Think Tank. This event, the first in a four-phase project, will be held at the Omni Shoreham Hotel in Washington from Feb. 11-13. Its goal is to identify problems and strategies and to plan a conference of national or perhaps even international scope for late 1987 or early 1988.

The second phase of the project will be to convene the conference, which will be attended by key black scholars and educators in the field. Phase three will be the publication of a Proceedings on Black Perspectives on Medical Ethics. And the fourth phase, the ultimate goal of the project, is to develop a significant number of black scholars in bioethics who can conduct research, teach and provide an informed voice on biomedical issues that affect black Americans.
Genetic Testing
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why? Insurance companies and employers are two social institutions that may argue that they have "a need to know" such information. At least one commercial firm plans to market a battery of tests for various genetic markers; insurance companies and employers are likely to be among their first customers.

From one standpoint, the potential interest of insurance companies and employers in such information is perfectly understandable. No longer would an insurance company have to base its underwriting of individual health and life insurance policies on the answers to questions like "When did your grandparents die and what were the causes of their deaths?" Genetic markers would provide much more precise risk-related information about individual applicants for insurance. Similarly, employers might reasonably be reluctant to invest in expensive executive training for an employee who is likely to die by the age of 40. More controversially, employers might refuse to hire someone who is destined to die prematurely or who could adversely affect the firm's experience rating for future health insurance premiums.

On the other hand, individuals may view the requirement of genetic testing as a prerequisite for gaining employment or getting insurance as an unwarranted intrusion into their privacy. Further, questioning by potential employers or insurers about people's histories of genetic testing could have the adverse affect of deterring people from being tested for tendencies to develop preventable health problems. The parallels between this issue and current debates about the ethics of testing for antibody to the human immunodeficiency virus (HIV) are plainly evident.

In sum, researchers are making progress toward better techniques for genetic diagnosis and for gene therapy. If, as seems likely in the foreseeable future, technologies for genetic diagnosis outstrip those for therapy, we shall be confronted with an awkward interim in which we can diagnose and predict what we cannot, or cannot completely, prevent or cure. For that possibly extended interim we need to develop an "interim ethic"—one that allows large social institutions to avoid unreasonable harms, while at the same time protecting the liberty and welfare rights of individuals and families.

(Dr. Walters is director of the bioethics program at the Kennedy Institute.)

Roundup

- Concern for Dying is holding a seminar titled "Death, Dying and Decisionmaking: Psychological Care of Patients and Families," at the Seabrook Island Conference Center, Charleston, S.C., from March 6-9. The seminar is designed to provide a forum for a small group of physicians, nurses, social workers and lawyers in which they can explore and develop the psychological understanding and counseling skills needed to provide care for patients/clients and their families facing life-threatening illness and/or trauma. Participants are encouraged to bring their own case material for discussion during the seminar. For further information contact Concern for Dying, 250 W. 57th Street, N.Y. N.Y. 10107, (212) 246-6962.

- Call for Papers: The 27th Transdisciplinary Symposium on Philosophy and Medicine will be devoted to the topic, "Historical and Philosophical Problems in Medical Genetics." Papers are invited that explore the concepts of genetic health and disease, the nature of explanation in medical genetics, the ethics and the ethos of medical genetic research and practice, from the perspectives of the history of medicine, the philosophy of science, medical anthropology and sociology, and ethics. The symposium is planned for Dec. 11-12 in San Francisco. Final papers are due no later than July 1 and they will be competitively reviewed. For a more detailed description of the conference write to Eric T. Juengst, Ph.D., Division of Medical Ethics, UCSF School of Medicine, 1362 Third Ave., San Francisco, CA. 94134.