Ethical Conflicts in Health Care Technology

by David J. Harris

Any discussion of ethical issues regarding the application of medical technology requires a point of departure. Advances in medical science are publicized rapidly by the news media. Public appeals are made for funds to help defray unusual medical expenses for families. Government officials intervene so that the costs of solid organ or bone marrow transplantation can be covered by Medicaid, a program that pays the medical expenses of the non-elderly indigent. The Oregon legislature voted not to include transplantation in its Medicaid program because more individuals in the state would benefit from improved basic services for women (particularly pregnant women) and children. In the United States, expenditure for health care as a proportion of the gross national product is one of the highest in the world, yet we are not at the top in terms of health statistics.

There are several points of conflict. Research in biological science has produced new medical knowledge and technical skill at a dizzying rate. In my own career in medical genetics, the information base has multiplied by a factor greater than five. The potential for dramatic intervention in people's lives seems almost limitless.

David J. Harris, M.D., is chief of the Section of Genetics at The Children's Mercy Hospital, and professor of pediatrics and biological science at the School of Medicine, University of Missouri-Kansas City.

Beginning in the 19th century, anesthesia and antisepsis rapidly expanded the scope of surgery. Immunization and antibiotics reduced mortality from infectious disease. The development of mechanical ventilators, better administration of intravenous fluids and the use of potent drugs now allow the postponement of death for many people.

The World Health Organization includes a definition of health in its constitution: "A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." Measurements of the health status of a nation or smaller governmental unit are in the form of vital statistics. The most obvious facts recorded are births and deaths. Deaths may be further classified by the cause of death, as well as the individual's age at the time of death. Births can be classified by the mother's age. Demographers use statistics like these to construct arrays known as life tables. Mathematical techniques are used to project the age distribution of the population, as well as life expectancy.

The age structure in the United States now is quite different from that of the turn of the century, and also different from that of the Third World. In those societies there were many infants, with fewer surviving into each successive age category. A graph of such a population looks like a pyramid with a broad base and a narrow top. Yet even under those conditions, if a baby made it through childhood he would live as long as an adult in the United States of the 1980s. Our age structure looks more like a rectangle, with fewer deaths until middle age.

There is also a shift in causes of death. Severe infections complicating malnutrition are the leading causes of death in the undeveloped world. The tombstones of children in colonial Massachusetts often listed smallpox and diphtheria as the reason for their demise. (Quite a number of epidemics were well described at the time.) The most frequent causes of infant deaths today are prematurity and birth defects. Later in childhood, accidents and cancer become more prevalent. During adolescence and young adulthood, accidents, suicide and homicide are the most frequent causes of death.

The key determinant of a long life expectancy is a low infant and child mortality. People surviving into their 80s is more a function of not dying of diarrhea as a baby than drugs given when they are 70. We need to examine mortality rates for specific diseases to determine whether medicine or some other social phenomenon is responsible for improving our life expectancy.

Thomas McKeown, in *The Role of Medicine: Dream, Mirage or Nemesis?*, presents a relevant illustration. In the British Isles, death rates for a number of conditions have been calculated since 1850. A number of disorders such as respiratory tuberculosis increased with industrialization, and then began to fall well before the

introduction of efficient chemotherapy in 1947. Using various data, McKeown concludes that the significant reduction in mortality resulted from better nutrition, hygiene and contraception.

Because our current health care system places a premium on acute care, McKeown challenges us to understand disease in a more comprehensive way. This is not to denigrate the importance of clinical medicine and its real achievements, but to insure that the proportionately greater needs of the mentally ill, the retarded and the elderly are truly met. His paradigm emphasizes understanding the causes of disease with the following classification scheme:

I. Relatively intractable

A. Genetic diseases
B. Other diseases determined at fertilization
C. Diseases in which the environmental influences are prenatal

II. Preventable: associated with poverty

III. Preventable: associated with affluence

IV. Potentially preventable: not known to be related to poverty or affluence

The history of disease control suggests that prevention is paramount, and is largely the result of non-personal services such as social manipulations or governmental responsibilities. Included are the provision of clean water and adequate sewage disposal. Education in both the general sense, and in the narrower health sphere, can minimize the impact of illness.

This paradigm should be reflected in medical education and research. Medicine needs to include preventive, curative and care functions. McKeown particularly thinks that medical practice should have several clearly defined goals: "To assist us to come safely into the world and comfortably out of it, and during life to protect the well and care for the sick and disabled." He believes that prenatal diagnosis of genetic defects, with the availability of safe termination of pregnancy, is crucial. In the area of care, diagnosis and therapy of acute illness are not sufficient; long term care and rehabilitation need improvement. The end of life should be comfortable, if not cheerful.

We need to distinguish and characterize levels of technology in providing medical care. Therapeutic effectiveness may occasionally have no obvious connection to science or technology. The personal interaction between physician and patient has long been known to relieve symptoms. This role was originally played by the shaman or priest. The principal act is communication. Rituals that include words and actions are invoked to provide healing. The skills are intuitive; some teaching is possible by the observation of effective examples. We evaluate this in a contemporary physician by commenting on his or her "bedside manner." There are many times that an individual only needs the application of these human skills to recover. In McKeown's scheme these are essential services, no matter what else is available.

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Lewis Thomas has written an analysis of technology in medicine. In his view, high technology is based on an understanding of the disease mechanism, whereas most people today regard high technology as the use of complicated machines. The method of therapy or prevention directly affects the cause, and the materials are produced easily and economically. Once these methods are generally available they seem mundane and may be taken for granted. Examples include treatment of bacterial infections with antibiotics or immunizations for poliomyelitis, and other disorders that are part of routine child health today. An older product, smallpox vaccine, has now been applied so extensively around the world that this disease does not exist in the natural state.

Using techniques that relieve symptoms or postpone death without altering the underlying problem is prevalent in medical care today. These require a large number of highly trained personnel, as well as increasingly complicated devices and drugs. Included in this category are cardiac bypass surgery, organ transplantation, and most modes of cancer therapy. Early in the life cycle, the neonatal intensive care unit for treating the complications of premature birth is

an outstanding example.

It is possible that a more thorough understanding of our health problems would result in more economical health care. The costs of prevention have in general been far less than treatment. Polio is a good example. Artificial ventilation allowed survival of severely paralyzed persons. There was intense debate about how paralyzed limbs should be handled. After recovery from the illness, rehabilitation involved braces and possibly orthopaedic surgery. Vaccination is clearly cheaper.

Disease prevention and significant reduction in mortality and are largely the result of better nutrition, education, hygiene, contraception, clean water and adequate sewage disposal.

Part of the debate regarding the use of current technology centers on questions of equitable access and personal autonomy. Individuals need the right to decide whether or not they will be treated. They need to understand the risks and benefits of the treatment plan. There is no certainty that a treatment will work, only probability. (Most physicians and patients are very uncomfortable speaking in such relative terms.) The costs include where the person feels he is in the life cycle, the monetary expense, as well as the discomfort of side effects. For instance, a pediatric oncologist described a drug as, "it makes ipecac (used to induce vomiting) look like an antiemetic (a drug used to stop or prevent vomiting)." That same drug also produces kidney damage and hearing loss, particularly after cranial irradiation. These issues make deciding to proceed very difficult.

Some large expense items were mentioned in the introductory comments. An infant born at about one pound will generate a hospital bill of $250,000. Examining the statistics of any large metropolitan area in the United States will show that the burden of prematurity, low birth weight, and infant death rests largely on the shoulders of the poor. More people are finding that their insurance policies will not pay for particular kinds of care. In our society a number of livelihoods depend on the current system. In addition to physicians and nurses, who are the most visible in the health care system, there are many ancillary workers and administrative personnel in health care institutions. There are also manufacturers and suppliers of equipment and pharmaceuticals. We tend to forget about the employees of insurance companies and government that pay for the services. The health care-industrial complex is indeed formidable. Simplification could produce a major economic dislocation.

It is clear that McKeown's principles need to be applied in the primary care setting. We need to make progress in our understanding of disease. And because most of the frequently tried approaches are really "half-technologies," they are ineffective in the long run. In the scientific community there is hope that immunology and genetics will ultimately give better solutions. In the short term, however, there will be new half-technologies which must be controlled if we are to avoid problems.

We now come to the threshold of new problems. These are being generated by advances in genetics that use methods to study DNA directly. Until now, geneticists have made inferences from observations of events several steps removed from the genetic material itself. The conclusions were often elegant, and predictions were made about what would actually be observed at the molecular level. The possibilities for direct observation are now at hand.

The first "big science" project in biology and medicine has been started, the Human Genome Project. Its purpose is to make a detailed map of the human genetic code, to determine the sequence of DNA by which we are formed.

One hopes that the genome project will develop more sensitive tools for diagnosing hereditary disorders. This could be done at the onset of symptoms, pre-symptomatically, or even prenatally. In the latter instance one would be predicting illness, possibly a long time before it appears. This is being done now on a limited basis with Huntington's disease, a degenerative disorder of the nervous system. Together with improved carrier tests, couples would have various reproductive options.

In the United States, the burden of prematurity, low birth weight and infant death rests largely on poor people.

Another avenue being explored (and some products are already available) is the treatment of disease with human hormones produced by bacteria. Attempts are also being made to place functioning genes in tissues of experimental animals to correct genetic defects. Experimental attempts are directed at both mature tissue and reproductive cells, so that an organism carrying a genetic variant will not

transmit it to his offspring. These experiments have many technical problems, so that actual performance of this therapy is not in the immediate future (although a human experiment with artificially introduced genes has been done).

As stated, all of this sounds helpful and benign. However, there are a number of issues that must be confronted, and these may be posed in a series of questions. Who decides if genetic tests are to be performed on an individual: the person, his doctor, his employer, the health insurance company, the state? Who on the list receives the information, and who decides what is done with it? It is conceivable, because it has been done in the past, that genetic tests could be used to exclude "high risk" individuals from certain occupations, whether or not the risk is real.

A major current problem is equitable access to available care. Will those who need or can benefit from technology be able to use it, or will the earnings of stockholders be the decisive factor?

Other forms of health benefits discrimination are possible, such as a couple at risk for having a child with a particular illness would be required to undergo prenatal diagnosis and selective abortion or not receive any coverage for that child's care. The state might decide which parents are biologically acceptable. One difficulty with the last proposal is that a mutant gene may seem deleterious, but could actually provide benefits under different environmental circumstances. We do not have the wisdom to determine what our genetic make-up should be. We are certain that it should be highly variable in order for our species to survive.

A major problem currently is access to available care, since there are so many people who have no medical insurance. Many of the services provided in the past by academic medical institutions were subsidized by grants used to develop clinical techniques. Since the relative availability of such funding has decreased, charges are levied in both the "private" and "public" sectors. The field of molecular genetics has appealed to venture capital sources, so providing services is expected to be highly commercialized. Once again, will those who need or who can benefit from the technology be able to use it, or will the earnings of stockholders be the most important factor?

The implementation of new techniques, as well as the retention of old ones, should be based upon benefits for both individuals and society. Part of the equation is that the procedure should work and relieve pain and disability. If these ends are not accomplished the effort is futile and therefore pointless. At such times human interaction is far more important. One need not do something just because one knows how.

In health care, human interaction is often more beneficial than implementing techniques. One need not do something just because one knows how.

A powerful influence at present is economics. As medical technology has developed, both complexity and costs have increased. This has blocked its availability to significant portions of society. With the shrinking of preventive services, people become more seriously ill and require far more expensive secondary measures. A major example of this is the relative inability of poor women to receive prenatal care; their babies are born needing expensive neonatal intensive care provided by most states through public funding. Although much has been said in the political arena about health care costs, in the end all of us will need to decide what is the appropriate amount to spend, given what is spent for other aspects of life.

We need to make choices so that abuses or undesirable applications of technology will not occur. Since achieving this goal requires planning, we must be well informed and prepared to discuss the problems honestly and openly. By avoiding this debate we risk more than our health, we jeopardize our individual and social freedoms. ♦

References

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