



PRENATAL GENETIC TESTING

The completion of the first survey of the human genome by the Human Genome Project has rightly been celebrated as a milestone in the fields of both genetics and clinical medicine. After decades of time, large sums of money, and much effort, the mapping project is essentially completed. Now the project shifts to the more difficult task of identifying the function of the thousands of genes in the human body. The map tells us where the genes are, but not what they do. That remains the question to be solved over the next decades. Thus, in many ways, the truly difficult work is only now beginning.

In the meantime, one routine diagnostic intervention of the last several decades will become even more common and will continue to raise more complex personal and institutional ethical questions: prenatal diagnosis for the purpose of screening the chromosomal status of either a 12- to 14-week-old fetus or a pre-implantation embryo, in conjunction with in-vitro fertilization (known as preimplantation diagnosis). I believe this diagnostic technology will become more common because the search for gene function will most likely first focus on effects caused by single genes. Single genes are easier to identify, and therapies for single-gene diseases may be easier to develop. Thus, I argue that the first significant locus for the application of information from the Human Genome

*The Potential
Loss of
Human
Dignity Will
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Consistent
Ethical
Response
from
Catholic
Health Care*

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Project will be prenatal diagnosis, primarily the technology of amniocentesis.

TECHNOLOGICAL PROBLEMS

Amniocentesis, as a procedure, is encumbered by two types of problems: informational and therapeutic.

Informational Issues The informational problem with amniocentesis is that we have the capacity to diagnose more anomalies than we understand; our diagnostic capacity outstrips our interpretative capacity. Given the sophistication of the technology, we will be able to identify more and more abnormalities, but we will have no idea of their significance or implications, if any. The immediate consequence of this handicap is more confusion for already distraught parents who have committed themselves to this pregnancy but now learn that on chromosome 10, for example, something unusual appears—but its significance is unknown.

What does one do with such information? Worry is clearly one answer, although a highly unsatisfactory one. One possible solution is for the physician not to inform the parents of information that appears to be insignificant. However, this choice raises two more problems: what defines "insignificant" information, and are parents entitled to *all* information that is learned from this test? Given the current climate that emphasizes patient autonomy, withholding information is clearly problematic.

Another solution may be for the physician to specify with the parents exactly what information they want: information relevant to the specific reason for the test, for example, or all information from the test. With this approach, the physician could explain in advance that not all the information from the test would be clinically relevant.



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Another dimension of the informational problem has to do with the diagnosis of genetic diseases that are so-called "late-onset" diseases—such as breast cancer and Huntington's disease. These diseases do not present until later in adulthood, and until then the individual will be symptom-free and have a good quality of life. Yet the parents, at the time of diagnosis, know that there will be problems ahead, regardless of future therapeutic developments. This burden is new, and one without a frame of reference for how to handle it—resulting in a problem with no satisfactory answer.

Therapeutic Issues The therapeutic problem is that regardless of the importance of the information received, clinical treatment will be limited. Our diagnostic capacities are currently more advanced than our therapeutic capacities. The major downside of the Human Genome Project is that interventions for genetic disease are a long way off. Trials for gene therapy are in the very beginning stages, and therapies even for single-gene diseases are not yet a reality. In addition, if the disease is multigenetic, as the majority of diseases are, the wait will be even longer—primarily because of the difficulties associated with identifying the interaction of various genes. The options for couples who receive a positive diagnosis for a fetal disease are poor: Abort the fetus, avoid future pregnancies, use donor gametes to avoid the disease in the future, or proceed with childbirth and let the disease run its natural course. If the last option is chosen, the family may face several barriers, including social disapproval for not having "solved the problem" through an abortion; strains in terms of time, money, and interpersonal relations; and finally the reality that funds and social services for treating diseases are in increasingly short supply. Because the disease was diagnosed prenatally, it may, moreover, qualify as a preexisting condition and therefore disqualify the child from insurance.

WHAT IS AT STAKE: HUMAN DIGNITY

The key value challenged by these technological problems is that of human dignity, or the *sanctity of the life of the individual*—particularly when this value is seen from the broader perspective of the consistent ethic of life most clearly articulated by the late Cardinal Joseph Bernardin.

The issue of abortion, for example, can be presented as a quick and inexpensive solution to a

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difficult problem. Abortion can also be presented as a solution to the so-called quality of life problem: No one should be forced to live under the circumstances presented by this disease. Such responses, although deeply imbedded in American culture, stand in sharp contradiction to the sanctity of life.

The sanctity of life is also violated by social policies and insurance plans that provide less care and fewer resources for those with certain diseases. Those who commit themselves to the care of a child born with a particular disease or set of handicaps find themselves financially isolated and often socially alone.

Catholic health care institutions and social service agencies face the same financial difficulties that other public institutions do but, I would argue, have a particular obligation to step forward in such situations and to be as responsive as possible. The charge has been made that some groups think the right to life begins at conception and ends at birth. Although this is a characterization of the right-to-life movement, it contains an element of truth in that more resources seem to go to the prevention of abortion than to the long-term support of a child. The problem of long-term support is a critical one because of the genuine shortage of resources and the growing realization that market interventions themselves will not resolve the current health care crisis. Catholic institutions can make a critical difference in health care, and particularly in genetic counseling, by making it known that they will make every effort to provide medical resources for a child and, perhaps more importantly, that they will engage the larger community in providing both financial and social services. The clear message of the consistent ethic of life should be that this family will not be alone in their time of need. This ethic will be difficult to practice, but it is the appropriate ethic for a Catholic facility.

SPECIFIC PROBLEMS FOR CATHOLIC HEALTH CARE

Although the problems emerging from the technology of prenatal diagnosis and the provision of long-term care are difficult and complex, they almost pale in comparison to the institutional problems that present themselves when such procedures are proposed in a Catholic health care facility.

The bad news is that requests for prenatal diagnostic procedures will only increase. First,



as more information from the Human Genome Project works its way into both the medical and popular literature, more people will want access to this information. Second, as the malpractice climate increases, more physicians will recommend any and all tests that might make them less liable for a lawsuit. Third, insurance companies may see prenatal diagnosis as a cost-effective way to eliminate future care costs. The cost of a prenatal diagnosis and abortion is nothing compared with the costs associated with treating various diseases. Thus, pressure from a variety of places may fuel a demand for prenatal testing, regardless of whether any medical indication to do so exists.

Related to these three concerns is what I would call the "public relations" problem of prenatal diagnosis. This problem is simply and directly the association with abortion. Many refer to these procedures as "search and destroy" missions. Also, in this country as well as internationally, use of this technology for sex selection is growing. This use is not a medical indication, to say the least. Although one can argue that fewer than 5 percent of prenatal testing procedures result in abortions, for some even that number is too high because any abortion for any reason is morally unacceptable. Although no institution can ultimately determine what individuals will do with information that is provided to them, its staff members can certainly influence how individuals perceive a situation and understand what options they might have.

Some might argue that because of the possibility of an abortion after amniocentesis, Catholic facilities should not offer this service. But Catholic facilities have the opportunity to provide such services in a much different atmosphere than public facilities. They also have the opportunity to demonstrate their commitment to the consistent ethic of life by bringing the family into a wider community of care and support. Providing a sympathetic and supporting community in a Catholic hospital may make the critical difference in the decision individuals make.

Yet another aspect of the problem reveals itself in the current climate of mergers, already a touchy subject in Catholic health care. What should be done if the partner facility routinely provides such testing services? What should be done when a women's clinic wants to lease space within an inner-city Catholic hospital?

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Recent discussions in Catholic circles suggest a very strict interpretation of the principle of cooperation and concern with scandal if a Catholic facility is associated with a facility that provides sterilization or abortions. Seeking any kind of compromise here seems to be close to impossible.

I argue that prohibiting certain mergers, even though problems are associated with them, may commit a greater evil by not providing health care for the poor. The genuine scandal may be no Catholic presence in an inner city. My judgment is that a strong, committed Catholic presence, grounded in the consistent ethic of life, can do more good than the maintenance of institutional purity. Clearly Catholics do not want to support (or be perceived as supporting) abortion clinics, but neither should they abandon those who need care the most—whether from poverty or from distress over an infant with a severe disease. The line may be difficult to draw and maintain, but I would argue that commitment to those in need should be the primary commitment.

Problems such as the ones I have identified will only grow in intensity and complexity as technology progresses and more people demand such technological interventions be performed. Some demands may seriously challenge the Catholic ethic, but we must also think of the good of children and families and constantly try to implement high-quality health care in the larger context of the consistent ethic of life. Such an ethic will reassure people that they are not alone and that they will not be isolated because of decisions they make on behalf of their child. Implementing this ethic will make all the difference. □

SUGGESTED READING

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