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Project Vampire, the apt nickname of the Human Genome Project, preys on indigenous peoples.

bioethics and biotechnology

Marking the Boundaries in a Brave New World

by Adriana Gomez and Deborah Meacham

Square tomatoes, grandmothers who give birth to their own grandchildren, the patented replication of human insulin—these new technologies aren't simply absurd or outrageous, they are very real. New possibilities, new discoveries, emerge at a dizzying speed that is awe-inspiring and sometimes frightening.

Clearly, the progress of science and technology is impossible to ignore. The recent cloning of an adult sheep in Scotland and similar feats with a monkey in the U.S. immediately led to concern about human cloning. An endless debate has been reopened: What are the exact limits of biotechnology? How far can science progress without violating established ethical principles, especially when these principles are also subject to constant reevaluation? How do we mark the boundaries of this brave new world?

A chronological list of the most relevant scientific discoveries of the past few years would indeed be an interminable task and would probably only confuse those of us who do not speak this scientific language. However, it is useful to examine some of these milestones for the points of reference they offer, as well as for the vivid examples of the issues and the concerns they raise.

A Problematic Progress

The Human Genome Project is among the most impressive biotechnological activities. Organized in 1988, this project is dedicated to deciphering the human genetic code, determining the characteristics and purposes of nearly 100,000) genes. Today, the Human Genome Project is in the initial stage of analyzing and describing the lineal structure of the genome, and almost a third of all the genes have already been deciphered. The complete list is expected by the year 2005.

One of the most important benefits of this enormous task is the understanding of which genes transmit the hereditary characteristics within the human species and how this transmission is carried out. When we know how and where to locate specific genes, it will be possible to directly intervene, manipulating the genetic material to correct the genetic flaws. Diabetes; schizophrenia; hereditary hypercholesterimia; certain types of hypertension; Alzheimer's; severe immuno-deficiency disorders; breast, skin, prostate and colon cancer; obesity; osteoporosis; all these ills are linked to genetic information that today can be detected by genetic screening. The ability to diagnose genes whose basic information is incorrect or has been altered by external factors leads directly to genetic therapy in which the anomalous gene is replaced by a healthy one through surgical intervention at a cellular level.

But here the controversy starts: requests for patents on the detection of certain, specific genes (such as BRCA 1, which is linked to breast cancer) have been widely rejected.

Patenting implies the ownership of a gene: a specific economic interest would be granted the monopoly of this genetic material and could commercialize genetic tests for this gene at exorbitant prices.

Discrimination based on genetic codes is another problematic issue raised by genetic diagnosis. Some businesses and insurance companies already discriminate against individuals whose genetic screening has revealed "defective" genes. Not only has the individuals' confidentiality been violated, but these genes may never actually be "expressed" or become active.

The ability to clone living beings is another astonishing, but controversial, achievement of biotechnology. This technology proposes the development of superior animal specimens and improvements in the diagnosis and treatment of diseases. Cloning could also produce tissues and organs based on human genes in animals (such as sheep), for transplant into humans. But human cloning is viewed as an extreme violation of the natural order and is particularly troubling when we consider the total absence of regulation.

Advocating Natural Order

These and other projects place information of the human genome in the hands of a few. Will it be possible for these scientists to resist "playing with the building blocks of life?" This understandable temptation has led many individuals and institutions to vigorously protest the nonregulated progress of biotechnology. They maintain that the real value and potential for using this knowledge for positive change is wildly overestimated. On the contrary, they insist, many of the illnesses and genetic alterations that we witness today are actually caused by toxins and environmental conditions resulting from the improper use of modern technology.

Concerns about the consequences of the indiscriminate use of biotechnology began in the 1970s, with the invention of genetic engineering. Over the past 25 years, genetic engineering has focused principally on the discovery and manipulation of microorganism, plant and animal genes. This work has achieved some significant benefits for medicine, agriculture and industrial production, but with many potentials and risks.

Historically among the first movements to defend genetic rights, the Foundation on Economic Trends, in Washington, D.C., began a campaign in 1996 against the patenting of the BRCA 1 gene and other genetic information. Another U.S. organization, the Council for Responsible Genetics, opposes patents on any form of human life, which should not be bought, sold, or commercialized in any form. The Declaration of the Indigenous Peoples of the Western Hemi-

sphere (1995) condemned the Human Genome Project, which gathered blood and tissue samples from some 700 indigenous communities around the world (giving rise to the nickname: Project Vampire). The indigenous activists maintain that genetic technology is an absolute violation of the natural order and harmony that define a healthy genetic diversity. Attacking another angle of biotechnology, the ecological organization Greenpeace began actions against the use of foods created using transgenic components, the so-called genetically modified organisms, which are considered potentially dangerous to our health, as well as the environment.

Biotechnology, a Gender Perspective

Scientific progress, particularly in the area of reproductive health has, without a doubt, brought enormous benefits for women, beginning with improved access to contraceptive technology and the differentiation of female sexuality from obligatory reproduction. The widespread commercialization of the Pill in the 1960s radically changed the lives of an amazing number of women. However, this progress was paid for by thousands of Puerto Rican women who were unwittingly used as research subjects for the development of this technology, an experiment directly linked to demographic control.

Other somber events in the history of reproductive technology include the development and promotion of the Dalkon Shield and DES. Widely used in several countries, these technologies left a trail of death and disease. Today, the Norplant implant, Depo-Provera (an injectible contraceptive), quinacrine sterilization and studies on antifertility vaccines have been the target of the international women's health movement. This concern is due not only to the secondary effects of these methods, but to their enormous potential for abuse on the part of governments and international agencies distributing these questionable methods to women of a lower educational and economic background whose decision-making ability is limited.

Besides method of fertility regulation, several highly complex and expensive technologies are used today in the area of reproduction. They include: prenatal diagnosis; electronic fetal monitoring; fetal imaging devices; caesarean deliveries; artificial insemination (using donor sperm); *in vitro* fertilization of the biological or surrogate mother; cryopreservation of eggs and embryos; embryo transplant; and many others.

Even though these techniques have assisted the reproductive experiences of many women, it is increasingly necessary to supervise these medical practices and their impact on the patients' lives, especially since they are exercised within the framework of socialized gender roles and expectations. We must question the degree to which women seek recourse to reproductive technology because of their own personal desires or because of the social obligation to become a mother.

Pregnant women become consumers, the clients who purchase a variety of examinations, clinical tests, and sophisticated diagnoses which supposedly guarantee a "happy ending" for pregnancy and birth. If the women doesn't take advantage of these multiple interventions, then she "risks" her chance for a safe birth and a healthy child, and she will be considered "responsible" if she rejects the excessive medicalization of her pregnancy.

Beatrice Stemerdingkaren of the Women's Global Network for Reproductive Rights terms this situation "the fallacy of choice." In her presentation at the 8th International Women and Health Meeting, she explained that these new technologies, such as the test for detecting fetal anomalies, place a number of choices before the pregnant woman: whether or not to take the test, to continue the pregnancy or to abort. However, these choices are already "decided" by society: "If she doesn't take the test, she is considered irresponsible. If the child is born with some defect, again, she is responsible." Under the weight of reproductive technology, "choices become obligations."

Abortion, an inalienable right of women, has always been the object of passionate debate. This issue is taken up by bioethics, and much of the discussion centers around the question: When does life begin? Fairly independent of this precise and perhaps unfathomable instant, these are two basic arguments in favor of abortion: one prioritizes the rights of the woman (all people have the right to do as they please with their own body), and the other stresses that every child has the right to be wanted.

In infertile couples, the absence of pregnancy, the inability to be parents, is especially difficult for the woman: even in the most "developed" societies woman's destiny is still reduced to her biology. If they cannot achieve motherhood "naturally," women are offered a

variety of costly, complex technologies. The string of "miracles" is endless: substitute mothers; women who give birth after menopause; mothers who bear their grandchildren for their daughters; women who become pregnant with the frozen sperm of their dead husbands; women who freeze their eggs to become pregnant later in life, etc. The ethical concerns raised by these possibilities are clearly quite complex.

Surrogate motherhood, perhaps one of the most controversial reproductive innovations in a strictly legal plane, is actually a profitable business in the United States, asserts Argentine writer Luis Sabini.

He adds that North American law has established that, in a dispute between the biological and surrogate mother for the child, the decision will be made by whoever provided the sperm, the father, a biotechnological re-invention of *patria potestas*. Sabini also indicates that the industry of surrogate mothers points, in the near future, to the search for mothers in the Third World. "This will be a real trade in uteruses."

Obviously this range of possibilities is really only available to a limited number of potential parents: heterosexual couples with a good deal of money. In many countries, artificial insemination is denied to lesbians on the basis of moral and legal considerations.

Bioethics: Balancing Progress and Principles

Since technology is developing at such a rapid pace, it must be accompanied by considerations of the ethical implications. Bioethics, a concept born in the U.S., deals with all the complex issues mentioned above. A multidisciplinary field, bioethics is the study of ideal conduct by scientists, researchers and medical professionals who work in genetic engineering, assisted reproduction, clinical drug trials and similar areas. In this effort, bioethics incorporates elements from a number of fields, including medicine, philosophy, law, theology, genetics, anthropology and ethics. The original and innovative discipline analyzes the concerns that arise in animal experimentation and advocates the protection of species and of future generations. Bioethics also reflects on unborn human life in the case of abortion, prenatal diagnosis, artificial fertilization and fetal tissue research.

Most recently, bioethics that takes women's perspective into consideration has been proposed by a number of women and even some men. Now many speak of feminist bioethics.

In her article "Ethics and Human Reproduction: International Perspectives" North American academic Ruth Macklin, underlines three moral principles that provide the framework for an analysis of the ethical aspects of human reproduction. The first of these is the principle of individual liberty, which implies that the best social policy is that which is less restrictive of individual liberty. Thus, informed consent and respect for the individual are two conditions necessary for the exercise of freedom of choice. Second is the utilitarian principle that defines rectitude in society as the greatest good for the greatest number of people. This principle should be applied by establishing policies that guarantee safe abortions, as well as access to information and contraceptive methods. The third principle is the principle of justice which maintains that all individuals in any given society deserve equal access to the benefits and services that meet basic human needs. In general, Macklin asserts, all the great ethical principles can be approached from a feminist perspective.

Rebecca Cook, Canadian professor and feminist, emphasizes that a feminist perspective in ethics or bioethics must begin by accepting that women have been and continue to be oppressed, and that this repression is morally and politically unacceptable. Cook approaches bioethical principles through their potential to promote women's interests.

Finally, Mexican anthropologist and journalist Marta Lamas indicates that "bioethics' liberating proposal is... the defense of the citizen's freedom of choice and respect of her/his will. This position demands that we accept the existence of plurality and difference as a fundamental human condition..." The decision to have a organ transplant, use medically-assisted reproduction, seek euthanasia, or choose abortion is based on the values of the individual who makes these decisions. "In this sense, it is the violation of the individual's covenant with her/his conscience that is immoral or unethical and not the supposedly objective circumstances."

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