Human Experiments:
Redrawing the Ethical Boundaries

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Late 1993 was marked by revelations that hundreds of nonconsenting Americans had been used in radiation tests that began in the 1940s and continued much longer. The full facts of these experiments are not yet known. Earlier in the year, the National Academy of Sciences blew the lid off World War II chemical weapons experiments involving 60,000 American GIs, including at least 4,000 used in gas-chamber experiments that left many permanently disabled. For nearly 50 years, the victims kept their secret, having been told that if they revealed the military experiments, they could be charged with treason.

These examples and others like them—the Pentagon's hallucinogen experiments (1950-1975) and the Tuskegee syphilis experiments (1932-1972)—suggest that researchers can all too easily find themselves on the wrong side of ethical boundaries. It may be, however, that as scientific capabilities change, the boundaries themselves need to be redrawn. Consider some current cases.

Questionable Experiments Involving Children

At the National Institutes of Health (NIH), healthy short children are injected with a genetically engineered growth hormone. The 40 or so children already involved are not deficient in the hormone. They are simply short. Their parents consent to the experiment, and the children themselves affirm their assent. And 156 times every year until they reach their adult height, they get injections that are not medically necessary.

No one argues with the use of human growth hormone (hGH) for hormone-deficient children, who would otherwise be dwarfs. Until the early 1980s, they were the only ones eligible to receive it. Because it was harvested from human cadavers, supplies were extremely limited. But genetic engineering, beginning in the early 1980s, has changed that. The hormone can now be manufactured in massive quantities, leading pharmaceutical houses to eye a huge potential market.

Short stature, of course, is not a disease. The problems short children face relate only to how others react to their shortness and their own feelings about it. The hGH injections, on the other hand, may pose some risks, both physically and psychologically.

Consequences of Human Growth Hormone

The injections speed the growth rate in 50 to 80 percent of nondeficient children over the short term.[1-9] It is not clear, however, that final adult height is increased. There are indications that, for many children at least, the growth spurt simply occurs earlier. For those children who get no effect at all from the injections, the net result may be to aggravate feelings of shame and failure.[10,11]

Growth hormone also causes the liver to manufacture more insulin-like growth factor, or IGF-I, which is thought to play a role in breast cell growth and lactation. It is not yet known whether children with more IGF-I circulating in their blood have a greater risk of cancer or a poorer prognosis should cancer develop.[12,13] However, several lines of investigation suggest this possibility. Test-tube studies show that IGF-I encourages breast cancer cells to multiply, and it is even more potent in this regard than estrogens. Growth hormone may be one reason why women over 5'6" have double the risk of developing breast cancer than women below 5'3", particularly for premenopausal cancers.[14-16] Tamoxifen, a drug used in the treatment of breast cancer, reduces IGF-I,[13] an effect which may be partly responsible for its anticancer effect.

Growth hormone can also cause abnormal leanness,[17] aggravate preexisting kidney disease,[18] and stimulate the production of growth hormone antibodies.[19]

The ethical questions raised by the experiment would not have to be asked, had technology not grown to the point of allowing the wholesale use of the hormone.

Control Groups Receive Inferior Treatment

Children are the subjects of other controversial NIH experiments. An $11.5 million pertussis vaccine trial in Italy included a placebo group—1,550 infants who received

no protection against pertussis at all. The investigators expect that 5 percent of this group will develop the disease. An earlier NIH trial administered placebo vaccines to 2,600 Swedish infants. Such experiments would never be permitted in the United States, given the availability of an effective vaccine, and it was only after continued arm-twisting and money changing hands that the Europeans agreed to the NIH contract.[20]

It should be noted that, in both the growth-hormone experiment and the vaccine trials, parents gave informed consent. However, parental consent does not remove ethical responsibilities in experiments on children. It is doubtful, for example, that a clinician prescribing anabolic steroids to children would be relieved of ethical problems simply because a parent consented to such treatments.

New ethical problems are also emerging in nutrition research. In the past, it was ethical for prevention trials to include a control group, which received very weak nutritional guidelines or no dietary intervention at all. However, that was before diet and lifestyle interventions, particularly those using very low fat, vegetarian diets, were shown to be able to reverse existing heart disease, push adult-onset diabetes into remission, lower blood pressure significantly, and reduce the risk of some forms of cancer. The Women's Health Initiative, finally under way after much political wrangling, includes a control group receiving much weaker nutritional guidelines. It may be that in the not-too-distant future, such comparison groups will no longer be permissible.

Unknown Dangers in New Drugs

A more widespread ethical problem, although one that has not yet received much attention, is raised by new pharmaceuticals. All new drugs are tested on human volunteers. There is, of course, no way that subjects can be fully apprised of the risks in advance, because that is what the tests are conducted to find out. Monetary compensation makes up for repeated blood tests and the other inconveniences that are routine for test subjects. But, should any serious health problem actually result, monetary compensation cannot begin to make up for the potential results. Manufacturers, of course, hope that animal tests will give a good indication of the potential risks. However, neither animal tests, nor the human premarket tests themselves, reveal the full range of drug risks. A U.S. General Accounting Office study found that of 198 new drugs entering the market between 1976 and 1985, 102 (52 percent) caused adverse reactions that premarket tests had failed to predict.[21] And no less disconcerting, many of the drugs in question were unnecessary by any reasonable clinical standard. No fewer than eight were sedatives, such as Valium and Librium. Two were antidepressants similar to others already on the market. Several others were variations of cephalosporin antibiotics, antihypertensives, and fertility drugs. Certainly, some new drugs are necessary. But a great many new drugs are simply patentable variations of other successful drugs, sold to gain a share of a profitable market. The risks taken in this type of trial by subjects, and to a certain extent by consumers, are not in the name of science, but in the name of market share.

Human beings, of course, are not the only potential victims of unethical research practices. Given the emerging history of abuses and secrecy in human experimentation, the idea that animals—the 20 million chimpanzees, cats, dogs, and rabbits used every year in laboratories—will somehow be better treated is unconvincing, to say the least. Whether the subjects are humans or animals, any assumption that experiments are always necessary, always carefully monitored, and always ethical is a fiction.

Constant Vigilance Is Necessary

Ethical problems are not always, and probably not usually, the result of new technologies that have yet to be harnessed. There are always tremendous temptations for scientific investigations to go too far. Curiosity is a powerful human motivation which can lead well-meaning people to actions that are harmful, and even fatal, as a look at the most extreme cases clearly shows. When psychiatrist Robert Jay Lifton studied the experimenters responsible for the most hideous Nazi crimes, he found that, while some were clearly sadists, most were ordinary people in circumstances that permitted the full unfolding of human curiosity, propelling human aggression into the machinery of death.[22]

The growth of technology only makes vigilance more necessary. Like growing human beings, growing science has strength that exceeds its control. And, like everyone else, scientists have to learn inhibition and restraint and can occasionally fail to inhibit an impulse of curiosity.

As governmental bodies review evidence of past abuses, the airing of buried secrets may improve vigilance against future abuses. But abuses will continue as long as there are experiments on subjects who are not in a position to give full informed consent and as long as technology provides novel ways of affecting their lives.

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