

/s/ T/86 Hastings Center for Bioethics.
Moral Imperatives in Research.
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When I was a very young child, and first motivated to enter a scientific career, I had certain misconceptions about science. I thought it was among the imperatives of human existence to achieve understanding of ourselves, and of the world in which we found ourselves -- indeed I saw that as the flowering of the religious impulse, to illuminate ignorance, to use that as a route to understanding whatever purpose there might be to our existence.

In addition, medical and agricultural science offered great promise of human benefit: more efficient crops and vaccines and drugs that could help feed the hungry and provide against pain, sickness and death.

All of these seemed to confer on science something of a sacred calling, fraught also with great responsibility to conduct its affairs in as humane a way as possible, to minimize pain and risk within the necessities of getting answers to humanly important questions.

With some astonishment, I have grown up in a world in which most of those premises are challenged by the political and public majority. Science is suspect, to where apart from any other activity it is presumed guilty until declared otherwise, e.g. by the bureaucracies of ethical review and the IRB's -- so that even to do an experiment without prior approval is already an infraction. Some presumptions of guilt are categorical, for example in the disqualification of prisoners from ever volunteering in an experiment, regardless of their express intention. At least the forms of informed consent are an available recourse for legally competent adults -- but better not ask too closely what that ritual has actually achieved. And what contortions we face in testing drugs that might be extended from adults to children.

So above all, there is a new god, of individual autonomy -- the enshrinement of the right to absolute selfishness in disregard of any alleged interests of the community, for example in the validation of new drugs and vaccines, indeed even of the old ones that may be used indefinitely without clear evidence. Not just selfishness, even orneryness: the individual has the right to refuse treatment even when every commonsense judgment would insist on that in his self-interest. The only domains that occur to me where individuals can be coerced on behalf of the community are military service, taxation and jury duty; and the first two of these are exposed to perennial democratic debate. If one stretches that a bit, one might add compulsory education.

This calculus imposes no obligation of self-sacrifice, say for medical testing on behalf of the multitude -- and however noble a purpose that might seem, it is all too easy to see how abuses might creep in, in its name. The same, I suppose, accounts for endless preoccupation on the property rights of ownership of a single embryo, to the relative neglect of the ethical issues raised by the millions of deaths that might be averted by more broadly shared responsibility for the health of children exposed to vaccine-preventable disease. I will confess that I do feel some obligation to devote my talents and energies to those macroscopic burdens. Experience has taught me to stress self-interest rather than ethical obligation when I speak to others on this matter.

These new principles, of the transcendent inviolability of the individual are unshakeable; and together with many other scientists I do not dare challenge them. Like Descartes, after Bruno's immolation, we have accepted that science could only continue in submission to these rules of ethical authority, and that we had better not interfere. Mere nonchalance, not to mention hostility, on the part of the ecclesiastical, no I mean political, authority is enough to undermine our funding at a critical time.

So if there is no obligation to submit to research, how can there be an obligation to conduct it? Simpler to pretend that we do it out of whim and curiosity, perhaps livelihood, profit and prestige; and if some public good can come out of it despite all the harassments, so much the better. Should we make any larger claims for ethical obligation to sustain the enterprise, and therefore its ethical priority, we will be shaking the temples at our peril.

In fact, how could I argue otherwise? Perhaps some scientists are saints, but enough are not (a possibly blessed truth) that they can hardly be trusted merely because they profess a vocation. The enterprise has grown large and dollar-laden, and subject to fierce competitive pressures. Many others do experiments that I would deem to be premature, risky, or most often just plain sloppy. Since you will not delegate the authority for decision to me, it must go to some broader public interest, hopefully reasonably informed by scientific expertise. But do not be disappointed or surprised if that bureaucratically laden process is rather slow and inconclusive in bringing about all the succor that science could more rapidly muster in principle. I hope you will be able to conclude that, in exchange, ethical regulation has won its merits by the remediation of abuses in significant scale, and that these could not be dealt with in any better way. My modest proposal is to put a mite more stress on methodological rigor, so that whatever experiments are done at least have substantial scientific value.

--- At another time, I gathered and taxonomized the motives I could locate for fear and suspicion of science. Let me pass out those tables, and see if you can help me elaborate that "technopathy".

Hand out will be:

196. Lederberg, J., 1972.

The freedom and the control of science - notes from the ivory tower.
Southern California Law Review 45:596-614.

275 Biomedical Science, Infectious Disease, and the unity of humankind.

"Nobel" colloquium, Paris, Jan 1988. Mitterand-Wiesel
JAMA 260 (5): 684-685 (1988) 8/5