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A shocking American report with lessons for all

A remarkable and chilling report from a subcommittee of the United States House of Representatives detailed many experiments in which people were exposed to potentially toxic doses of radioactivity simply to satisfy scientific curiosity.[1] The people had no hope of benefiting themselves. In some cases they had given "informed consent," although it is doubtful that they had been well informed about the dangers of radiation. Those who were not asked to consent were prisoners or hospital patients including the mentally and terminally ill. The experiments took place between 1945 and 1971; the early experiments might be excused by the ignorance of the long term effects of radiation, or explained by the atomic hubris that followed the bombing of Hiroshima, but some of the later experiments took place when the dangers were only too well known.

Some examples will give the flavour of the report. Between 1961 and 1965 at the Massachusetts Institute of Technology 20 elderly volunteers from the nearby New England Age Center were injected with radium or thorium to examine the metabolism of these substances. The subjects had volunteered to take part in experiments studying the aging process but not a study such as that done. There was no benefit to the volunteers and no long term follow up.

From 1945 to 1947, 18 hospital patients with a short expectation of life were injected with plutonium to measure the quantity retained in the body. The subjects received between 1·6 and 98 times the permissible occupational dose at that time. One of the subjects was 5 years old. There was no informed consent, and many of the original diagnoses were inaccurate; seven of the patients lived for more than 10 years, four for more than 25 years, and one was alive 36 years after the experiment. The injections were represented as experimental treatments for the patients' illnesses—a statement that was palpably dishonest.

Between 1963 and 1971 over 100 inmates of Washington and Oregon state prisons were subjected to testicular irradiation to determine a dose that would sterilise them. The projects were funded by the Atomic Energy Commission to the tune of $1·5m. There was no long term follow up to guard against the risk of testicular tumours.

During 1946 and 1947 six patients with good renal function were injected with increasing doses of uranium-234 and uranium-235 to determine the dose necessary to produce renal injury. The patients were mainly chronic alcoholics, homeless, and emotionally disturbed—and one was having hallucinations. The carrot for taking part was a warm bed in hospital.

It is unnecessary to go on. Undoubtedly in these experiments ethical standards were flouted in a manner that is almost beyond belief. The one redeeming feature is that the United States is an open society and therefore this information has become available. In many other countries it would remain an official secret.

Doctors everywhere will condemn this disregard of human rights, but these experiments are an extreme extension of the phase 1 trial in which potential drugs are given in man for the first time. Any agent intended for human use should be fully evaluated in the test tube and in laboratory animals before being used in man, but interspecies variation ensures that not all possible hazards will be predicted. Trials in healthy subjects must always be ethically dubious and are a breach of human rights if participants are not fully informed or are coerced into taking part. Thus prisoners, inmates of mental institutions, and employees of the firm or institution doing the experiments are not suitable subjects. The Helsinki Declaration of the World Medical Association states that the physician may justify experimentation on humans only if it has a therapeutic value in terms of the subject.[2] Some people might willingly forgo their rights as an altruistic act, but studies in which the person runs a risk but will not benefit need to be governed by the strictest ethical criteria.[3]

Experiments within medical establishments are already covered by comprehensive guidelines.[4] What this congressional report achieves is to shock us into regulating human experimentation in non-medical, academic, industrial, and military environments.

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AIDS: a faltering step

Last week the annual representative meeting of the BMA passed by 183 to 140 votes a motion saying that doctors should be allowed to test a patient for antibodies to the human immunodeficiency virus (HIV) without first gaining consent (p 148). The debate was largely concerned with what the proposer called "occasional circumstances," but the motion did not contain that phrase and nor did most of the reports in the media. The BMA thus appears to have departed from the advice given by both the World Health Organisation and the Department of Health and Social Security, and, in our view, the decision might do serious damage to Britain's attempt to contain the epidemic of the acquired immune deficiency syndrome (AIDS).

So far Britain has done reasonably well in its struggle to contain the disease. In particular we have resisted the tendency seen in some countries to victimise those in risk groups and to use draconian measures in what will certainly

be vain attempts to contain the disease. Doctors are naturally expected to take the lead in countering any epidemic, and it is a pity that the debate in Bristol was so confused. Doctors must now be seen by their patients as putting themselves before those they should be caring for. This is a poor example for other groups within the health and social services.

The clinical, ethical, and possibly legal reasons why last week's decision is wrong are worth repeating. Firstly, the risk of health workers becoming infected is very small and can be countered by adopting careful techniques with all patients. Around the world hundreds of thousands of health workers have treated patients infected with HIV and only five have become infected as a result of broken skin or mucous membranes being exposed to infected blood. In addition, hundreds of health workers have suffered inoculation injuries while treating patients infected with HIV, and only four are known to have become infected. The risk is thus extremely small. Doctors have always been expected to take risks in caring for their patients, and the risks taken, for example, by a doctor caring for patients with tuberculosis before there was effective treatment were much greater than the risks taken by doctors caring for patients infected with HIV.

The second clinical argument against the decision is that testing without consent will do little if anything to reduce the chances of becoming infected. Most patients suspected of being infected will give consent for a test when properly counselled. Those who do not can be treated as if they were infected. In an emergency, when an unconscious or desperately ill patient cannot give consent, a test will not help much because it takes hours to get a result. In three recent well publicised American cases where health workers became infected through broken skin or mucous membranes a test would not have helped because the results would not have been available. HIV infection was not suspected in two of the patients, and in one of these exposure occurred during attempts at resuscitation in an emergency room. Furthermore, needlestick and splash injuries are always accidents and will not necessarily become less common because health workers know that a patient is infected with HIV.

The clinical arguments for testing without consent are thus marginal, but those against are considerable. Patients who are told that they are infected when they never even knew that they were being tested may experience substantial psychological and social consequences. And who will tell the patient? Certainly anybody who considers testing a patient should be prepared to counsel the patient fully when a result proves positive. A recommendation to see an AIDS counsellor as quickly as possible is not enough on its own. The doctor who has done the test without consent is also likely to have destroyed his relationship with that patient.

Although it did not come through in the reports in the media (and nor, to be fair to the media, did it come through much in the debate itself), the debate was supposed to be about cases where the patient was not in a high risk category for infection with HIV and the test was necessary to help in differential diagnosis. Such a patient might have a perplexing presentation, and infection with HIV might be the longest of shots. The proposer of the motion thought that in such circumstances more distress would be caused to the patient by getting his consent than by simply doing the test. The assumption was thus that the test result would be negative, but sometimes it will not be negative, which will increasingly be the case as the epidemic progresses. What then will the doctor say to the patient? We can see only the most exceptional circumstances when such testing would be justified; usually consent can be gained and counselling given, and in the process the patient can be educated about HIV infection and told that the doctor's opinion is that the chance of his being infected is very small. The argument that in testing in such circumstances without consent doctors would simply be doing what they have always done is not a good one: firstly, something is not right simply because it has always been done—and if there is a positive side to AIDS it is in the way that it has tested our traditional thinking and our courage; and, secondly, the diagnosis of HIV infection in our society at the moment carries consequences that are probably more dramatic than a diagnosis of syphilis in an age before syphilis could be treated.

Most important of all—and here we enter the ethical arguments—when doctors say that it is acceptable to test patients without consent they are likely to destroy the trust that those at risk of HIV infection, which is most of the population, have in doctors. We have no chance of defeating the AIDS epidemic if we do not have that trust. It would be a disaster if people stopped coming to doctors for advice and treatment because of the fear of possible indiscriminate testing without consent. Any move that drives risk groups underground must be resisted. This is now a real danger. It is a basic tenet of medical ethics that we do not treat patients without their consent, and we have to have very good reasons for breaking that doctrine, as the BMA's *Handbook of Medical Ethics* emphasises. In this case we do not have such reasons, although we might have some justification in rare circumstances. For instance, if a patient is unconscious it may be right to test for antibodies to HIV as part of assessing intracranial disease. Even then, however, the next of kin should be consulted.

We were thus pleased that the chairman of the meeting in Bristol confirmed after the debate that any testing without consent should be at the discretion of a caring doctor, ruled by existing ethical standards. We were also pleased that the Bristol meeting agreed with the conference of local medical committees that the information that a patient was infected with HIV would not be passed on to other doctors without the patient's consent. (This illustrates the prevailing confusion last week: if the aim of testing without consent is to protect health workers and their families then presumably the information that a patient is infected should be passed to all of those staff.)

The legal reasons against testing without consent we leave to others as they are far from clear, but the chairman of the BMA's council was quoted as saying that patients who had been tested without giving consent should consider consulting a lawyer or referring the doctor to the General Medical Council.

We hope very much that a way can be found to ameliorate the possible effects of the decision to test without consent—in particular, to overcome any feeling by doctors not at the meeting that the decision is carte blanche to test whom they like. It may be acceptable in extreme circumstances to test without consent to aid differential diagnosis. But such testing should not be done simply to protect doctors from the very small chance of becoming infected themselves.

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