Review: Paid to participate in "mild torture"
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REVIEW OF THE WEEK

Paid to participate in “mild torture”

Why do people participate as paid so-called volunteers in clinical trials?
Boleslav Lichterman reviews a book that considers participants’ motivations and the potential problems

In his recent interview for a Russian medical periodical (Meditsinskaya Gazeta 18 March 2011:19) Evgeny Chazov, a director of a Moscow research centre for cardiology and a former health minister of the Soviet Union, praised the healthy volunteers who regularly participate in testing new drugs, risking their health for token payments. “We are ready to award them merit certificates,” he said.

The Professional Guinea Pig provides a view on those who volunteer for cash that suggests less altruism. The book is adapted from the doctoral thesis of US anthropologist Roberto Abadie, who presents the results of ethnographical research into paid participation in clinical trials conducted in Philadelphia in the early 2000s. This is a study “of how bodies became commodified and integrated into a market economy.” It is based on a semi-structured survey of 18 healthy volunteers, aged from 18 to 65, who earn their living by enrolment in phase I clinical trials. Usually such trials are aimed at studying the toxicity of new drugs and involve 30 to 100 participants.

Most of the participants in Abadie’s research were unemployed or partially employed anarchists, with flexible schedules and no family. Their main motivation was “easy, quick money.” The income from so-called guinea pigging can reach $15,000 (£9000; €10,200) to $20,000 a year, similar to the salary of a McDonald’s employee. The pharmaceutical industry refers to trial participants as paid volunteers who receive “financial compensation for time and travel expenses.” Abadie comments, “It is hard not to note the oxymoron. How can someone simultaneously be paid to do something and to do it voluntarily?” He quotes one experienced “guinea pig” from West Philadelphia who referred to the activity as a “mild torture economy”: “You are not asked to produce or to do something anymore, you are being asked to endure something … And I am letting people pay me in exchange for the control they have over me.” Some human guinea pigs compare themselves with sex workers; desired and rewarded for their compliant bodies.

Abadie writes, “Financial compensation plays a central role in recruiting and retaining volunteers,” who are “almost using their bodies as ATMs [cash machines] to fund their lifestyles.” Anarchist volunteers were also cynical about the studies, and sabotaged the food and drug regimens whenever possible.

Risk management among professional guinea pigs is discussed at length. The author explains his study was inspired by the death of Ellen Roche, who had volunteered to participate in an asthma study at Johns Hopkins Bayview Medical Center in Baltimore, Maryland (BMJ 2001;322:1565). The trial run by Paraxel in Northwick Park Hospital, London, when six participants became severely ill, is another well known example of serious adverse drug reactions among trial volunteers (BMJ 2006;332:683). However, such events are rare. In Abadie’s study, paid participants did not care much about the risks, though they tended to avoid psychiatric drug trials because in these they were leasing their minds as well as their bodies. These professional guinea pigs consumed herbs, and drank large amounts of water and unsweetened cranberry juice afterwards—their preferred methods to cleanse the body. They were less concerned about longer term risks.

The book also considers a similar number of people with HIV in the community in Philadelphia. Compensation for participation in phase II, III, and IV trials is much lower than for phase I. Patients are supposed to enter such trials for altruistic reasons. However, because drugs are provided through their insurance plans, volunteers may hesitate to enter a trial, “unless their lives are at stake or the trial is for a very promising drug.” The author narrates the stories of three people with HIV who joined the trials, “to empower themselves in their fight against the disease.”

A special chapter provides a brief history of the clinical trial enterprise. An estimated 90% of drugs licensed before 1970 were first tested on prisoners. The situation changed after the Belmont Report was issued by the US Department of Health, Education, and Welfare in 1979. According to the report, participation of human subjects in clinical trials should be overseen by independent ethics committees (institutional review boards or IRBs). Abadie argues that the professional guinea pig (paid for endurance of pain, discomfort, and the boredom related to a clinical trial) is a new occupational category in deindustrialised Philadelphia.

In the last chapter there are interesting insights into the attitude to informed consent forms by volunteers. Paid volunteers do not trust scientists and the pharmaceutical industry, but patients with HIV are reliant on their doctors and researchers. The author interviewed the principal investigator of HIV trials and the chair of the local institutional review board, and concludes that, “while the consent form is a necessary safeguard, IRB oversight of the informed-consent process may not be sufficient: it assumes a ‘free, uncoerced’ subject that does not exist, and it focuses on informing subjects of the goals, risks, and benefits of a trial and not on policing the way the trial is carried out.”

What is Abadie calling for? Firstly, he recommends creating a centralised register of paid trial participants, which would prevent them from simultaneous participation in multiple trials, and enable follow-up studies. Secondly, he recommends restrictions on numbers of trials, because most are conducted on so-called “me too drugs”—drugs structurally similar to pre-existing drugs already on the market. The author suggests taxing “me too” trials, and providing tax incentives for trials of completely new drugs.

The main limitation of Abadie’s study is the small number of research subjects. There were more than 80000 clinical trials being conducted in the United States in 2002. Does a group of 18 Philadelphian anarchists represent the whole trial population? The Constant Gardener, a novel by John Le Carré, focuses on unethical clinical research in third world countries. Can the results of a US study be extrapolated to the rest of the world? Let us hope that the “mild torture economy” of clinical trials will be the subject of future international studies.

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