Book reviews

Acres of Skin

Acres of Skin presents an angry, distressing and provoking description of human experimentation within the American prison system. Specifically, it focuses upon experiments conducted by investigators from the University of Pennsylvania at the nearby Holmesburg Prison, from 1951 until 1974. The research was halted following congressional hearings in 1973 which revealed incidents of misuse or potential misuse of vulnerable populations (pages 194-197).

Hornblum documents disturbing transgressions of appropriate context and care in performing human experiments. If his recounting of the use of mind-altering drugs under defense department or CIA contracts is the most disturbing, he is equally upset about the testing of Retin-A which has proven useful in acne treatment. His treatment seems biased. Nevertheless, as a clinical researcher and former faculty member at the University of Pennsylvania I felt compelled to do a little background reading and pose a few questions for myself:

1. Is Hornblum’s comparison with Nazi abuses justifiable?
2. Should the Nuremberg Code be the reference code?
3. Is he correct in isolating prison experimentation as particularly egregious?
4. Does he fairly assess risk and injury?
5. Did America make a correct decision in subsequently excluding prisoners from the pool for necessary human experimentation?

I have grown weary of the often hysterical tone now dominating American public debate and this book jangled those raw nerve ends. The Nazi reference is convenient but slipshod. At the centre of Nazi transgression was a public policy—enforced by a ruthless dictator—which declared whole subgroups within human society to have “lives not worth living”. The willing complicity of many Germans and German physicians with these policies remains a huge warning to all of us. Nevertheless, it was in the context of the totalitarian governments that the great transgressions against human dignity occurred in the twentieth century. In Nazi Germany experiments designed to involve severe suffering, often to end in the death of the subject, were part of a racist pseudoscientific insanity and were approved at the highest level. No such pattern supported the Holmesburg experiment nor is it fair to suggest equivalent amoral behaviour by Dr Kligman or his collaborators.

Like Annas and Grodin, Hornblum uses the Nuremberg Code, developed to justify prosecution of war criminals, as his reference. However, the earlier, 1931 Reich’s Health Council Circular: Regulations on New Therapy and Human Experimentation, and the subsequent Helsinki Declarations (I - IV) seem superior. These codes do not hang so much on the essential principle of consent—which occupies some one-third of the verbiage in the Nuremberg Code—and better address critical medical requirements necessary for safe and appropriate human experimentation. In addition, these codes do not suggest a “guilt by association” conclusion. None of the codes seem to address the importance of external scientific and ethical review, both for determining the legitimacy of a proposed experiment and the need to terminate an experiment.

Hornblum states that consent procedures were inadequate. None the less, our perspectives have changed dramatically and analysis of civilian practice in the early 1950s and 60s for obtaining consent for therapeutic or experimental interventions would also be judged inadequate. In general the prisoners were so attracted by the compensation that, after twenty years of experimentation the participants were angry when two of their colleagues testified against the experiments before congress (page 198).

However imperfect the consent might have been, we must conclude that consent was obtained for these experiments.

Hornblum suggests that many prisoners were injured by their participation, but does not objectively document the extent and seriousness of such injuries. This is important. Years ago Comroe pointed out that five patients died before the first successful mitral valve replacement. He did so critically, asking whether it was the surgeon or the patients who were the heroes and also questioning whether these desperate patients were afforded the opportunity to make a truly informed consent. In a closing chapter Hornblum rails on about Retin-A (a potent and useful acid medicine), its irritating properties and the role of Holmesburg “guinea pigs” in its development. I am troubled by an author who links irritated skin to Nazi transgressions. Clearly some prisoners were scarred by dermatological experiments, but they continued to volunteer and after twenty years it seems a majority of prisoners involved would have chosen to continue their involvement.

Hornblum does an excellent job of portraying the coercive aspects of prison life and the restrictions upon prisoners which made participation attractive. He even presents moderately convincing information which suggests that prisoners are not particularly good experimental subjects.

Yet, the drug to protect infants from fatal blood cell destruction if they are born to mothers with incompatible blood types was developed with the cooperation of convicts at Sing Sing. It would appear that both prisoners and society benefited from these activities.
Moreover, it is clear that prisoners were free to refuse participation with no adverse consequences and still sought to participate. Consent was deficient, methods were deficient. But the modern era of controlled trials began only a few years before the Holmesburg experience and the steps necessary to minimise abuse were developing in parallel in the civilian society. (The Economist noted in October 1998 that publication of the first randomised controlled trial occurred in 1948 - streptomycin usage in tuberculosis.)

In summary, this is a useful and provocative study. It would have been better if the author had been less overtly biased and had better studied the concurrent evolution in human experimental studies outside of prison. Two more issues warrant attention. First, I find human experimentation necessary, despite its hazards while Hornblum asserts that “progress is optional” (page 244). Secondly, in his passionate distaste for the Holmesburg Prison experiments, Hornblum diminishes the horrors suffered in the camps of the Axis powers and I find that offensive.

References

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Welfare in America: How Social science Fails the Poor

William M Epstein, Madison, Wisconsin Press, 267 pages, £35.95 (hb) £15.95 (sc).

The title of William Epstein’s book suggests that the author’s primary purpose is a moral one; to call social scientists to account for failing the poor. Yet, it is hard to detect any coherent moral framework or even political philosophy from which he has derived a duty to the poor as a necessary part of the professional ethic of social scientists. He simply takes it for granted. Furthermore, readers concerned with medical ethics will find the book a double disappointment. Despite the promise on the back cover that the analysis of welfare policy will include “effective health care”, health issues are only tangentially touched on. Even the one passing reference to Medicaid, as absorbing half of all welfare expenditure, is made in the course of establishing Epstein’s opening argument that the rhetoric of the welfare debate focuses disproportionately on one narrow area - poverty - which accounts for a mere ten per cent of the total welfare budget. The curious intensity of popular and political concern with what is a minor slice of public spending forms the backdrop to the argument of the book.

The main body of the volume is a detailed and damning critique of the research of recent decades on poverty and certain associated problems (specified in consecutive chapters as family structures and intergenerational dependency; work and worklessness; training programmes for welfare recipients, and the role of personal social services in policies to combat poverty). There then follows a final chapter advocating an as yet untried policy of “generosity” which starts from the premise that the author has demonstrated the total failure of the research process to establish a rational basis for choosing between existing policy strategies. At this point it becomes clear that the foregoing critique of welfare research is simply an oversized legitimating prologue to a polemical climax in which the need for a radical and expensive programme of social and cultural engineering is proposed in passionately vague terms.

Epstein places his critique of welfare research within an analysis of the ideological nexus out of which both research and policy emerge. He distinguishes two main theoretical positions, the conservative and the liberal. The former tends to locate the cause of poverty in the moral or “characterological” deficiencies of individuals and broadly favours market solutions. The latter is inclined to see the causes of poverty as lying in institutional defects and to advocate state intervention. So far, so unremarkable. He goes on, however, to claim that research in the social sciences has signally failed to provide scientific verification of either set of assumptions but has acted as the legitimating vehicle of “mythic beliefs” which then masquerade as factual propositions.

The research and policy process both fail for related reasons. Social scientists themselves exist within the “constituency” of one or the other schools of theoretical assumptions. Their research typically seeks to verify the preferred presumptions or to falsify those of their opponents, but it fails to employ sufficient scientific rigour because the researchers have acquired status in a series of constraints which undermine the adequacy and rationality of their procedures. Prominent among these unchallenged axioms is the need for fiscal restraint.

In the first place this sets arbitrary limits on the cost of research and thus tempts researchers to take methodsological short cuts - for example, the failure to use genuine randomised controlled trials which is often condoned by researcher bias and practices embodying “limited rationality” of all of which result in an inability to develop adequate tests of causation. The imperative of fiscal prudence also drives the policy process to seek out low cost welfare solutions.

Epstein believes that these conditions have produced an increasing consensus between conservatives and liberals that the core objective of welfare policy should be “social efficiency” and that any policy must be shown to have an immediate, positive impact on social cohesion and economic productivity without even short term disruptive consequences.

In the detailed critique of specific research and its relation to policy development Epstein’s anatomisation of ideological processes largely gives way to a perspective composed of equal parts of a positivistic research methodology of impossible purity and a functionalist model of society which is not only curiously at odds with the framing argument about ideological conflict but which has at its heart an oddly old-fashioned and un-nuanced concept of socialisation as a learning process pure and simple. The sociology of the book is thus mildly schizophrenic and detached from the author’s apparently sui generis ethical stance - after all, functionalism, notoriety, has been...