reviews

BOOKS • CD ROMS • ART • WEBSITES • MEDIA • PERSONAL VIEWS • SOUNDINGS

The Abuse of Man: An Illustrated History of Dubious Medical Experimentation

Wolfgang Weyers

Ardor Scribendi, \$35, pp 756
ISBN 1 893357 21 X

Rating: ★★

After the Nuremberg trials Nazi experiments on humans were brushed aside as pseudoscience and as having nothing to do with mainstream medical research. Abuses in other countries could not be so dismissed, but here the culprit was generally held to be the state. If only, so the argument runs, the doctor would be free from the corrupting pressures of the state and ideology, the ethos of the doctor's duty of care would ensure that patients could never be exploited as human guinea pigs.

But what if we accept that experimental abuses had plausible rationales? Some experiments might have more valid scientific reasons than others, but what if even the most gruesome research had some basis in medical science? Wolfgang Weyers offers an

overview of human experiments from their origins in ancient medicine to modern times, written very much in terms of scientific motives and the relative strengths and weaknesses of what he coyly dubs "dubious experiments."

Weyers recognises that one difficulty of a medical view is that medical critics have also been experimenters. The physiologist Andrew Ivy, who had a hand in drawing up the Nuremberg Code, and W K Beecher at Harvard were themselves involved in conducting or condoning dubious experiments. Indeed, the author opens the book with a confession and apology that he conducted investigations that went beyond what was clinically necessary.

The book is very much a doctor's view of human experiments, and this has certain advantages. Weyers is a dermatologist, with an interest in dermatological abuses in experiments. What was historically a marginal medical specialty sought through experimentation to establish its credentials. As we move from European medicine in the 19th and early 20th century to US medicine after the second world war, we see how dermatologists took advantages of access to human material.

But the insider's approach has disadvantages, for the history of human experimentation is far more than just an internal medical discourse. Where the author strays into general history he loses critical faculties, and the book lacks crucial context.

Above all, what is lacking is a proper sense of the victims of experiments. Bringing the victims into the story is not

sentimentality. Without giving the subjects a historical voice and agency, the author can't explore critically the scientific conduct of the experiments. He does not explain that experiments were sabotaged. Protests were articulate and formed the cornerstone of what became informed consent. The victim's voice and the victim as active rather than passive are fundamental, but—and this is what makes the book so flawed—this does not come through in the book.

We see the strengths and weaknesses of Weyers' approach when he deals with the Ravensbrück sulphonamide experiments. He makes some excellent points regarding the dermatologist Herta Oberheuser, who cultivated links to academic pharmacology and dermatology at the Medical Academy of Düsseldorf while in Ravensbrück. He mentions how the orthopaedic surgeon in overall charge and his assistants communicated the experiments to a supine audience of leading German medical researchers. He doesn't give the victims a voice or any identity as individuals (we still have no clear idea of how many people were victims of the Nazis' experiments and who they were). He never mentions that these people protested bravely and eloquently during the war to the camp commandant and that they managed to communicate their ordeal and even to take photographs of their wounds.

Weyers recognises that his is an unfinished history. He admits that "the days of medical paternalism are over" and that it is necessary for the doctor to put aside any sense of superiority. This is well and good, but it is only half the story, because it does not pursue issues of experiments as accountable to their participants and to society.

In the United Kingdom abuses in experiments continued after the second world war, notably with the testing of radiation doses and nerve gases. We need to give greater attention to the victims of the experiments and to regard them as more than complaining nuisances.

This book is a breakthrough in its examination of the medical rationales for the atrocities. But it is so flawed in its conception and execution that it fails as an authoritative overview.

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The Ravensbrück "guinea pigs"—upon whom Nazi doctors carried out experiments—at a function to honour the man who led their rehabilitation

Items reviewed are rated on a 4 star scale
(4=excellent)

Die Krankheitserfinder: Wie wir zu Patienten gemacht werden [Disease Mongers: How we all become Patients]

Jörg Blech

S Fischer, €17.90, pp 256
ISBN 3 10 004410 X
www.s-fischer.de

Rating: ★★★★★

When the German journalist Jörg Blech read a press release claiming that a university professor had confirmed a new psychiatric diagnosis for stressed fathers—"caged tiger syndrome"—he felt enough was enough. Blech, medical correspondent on the weekly news magazine *Der Spiegel*, decided it was time to write a book about invented diseases.

Die Krankheitserfinder: Wie wir zu Patienten gemacht werden [Disease Mongers. How we all become Patients] is a worthy and well written successor to Anglo-American publications from the 1990s, such as Lynn Payer's *Disease-Mongers* (see *BMJ* 2002;324:923).

Blech's book, launched by a cover story in *Der Spiegel* (11 August 2003), is a bestseller in Germany, where it seems to have touched a nerve, judging from the approval of the majority of several hundred letters to *Der*

Spiegel and to Blech personally, mainly written by doctors. This positive response might spring from the fact that Blech does not condemn modern medicine and drug therapy altogether, but just the exaggerations and perversities of pharmaceutical marketing. Ideally Blech would like patients to read the book before their next visit to the doctor and to use his 12 point checklist on how to recognise an invented disease before taking their medicines.

The author has studied the international literature thoroughly—including the recent *BMJ* theme issue on medicalisation (13 April 2002)—and has enhanced the picture with specific German experiences, confirming two trends identified in earlier publications. Firstly, Blech discovered that the pharmaceutical industry was redefining the diagnostic limits for natural changes in the body—mostly brought on by ageing—in order to treat "patients" even without symptoms. Secondly, he discovered that new diseases were constantly being invented, especially in psychiatry—for example, hyperactivity in children and certain forms of depression.

One condition particular to Germany and Austria that Blech cites is the "Sisi syndrome," said to affect 3 million Germans. The syndrome was invented by a public relations firm and launched in 1998 with a book by a medical journalist, scientifically approved by medical experts. The name derives from the Austrian Empress Sisi, who hid her depression behind restless activity and physical exertion. (Blech told me that the PR firm had suggested to drug company SmithKlineBeecham (SKB) that this "new" form of depression should be called "Princess Di syndrome," which would have made it more global. SmithKlineBeecham

"I see you have wellbeing syndrome ... that's highly dangerous": how *Der Spiegel* launched the book

apparently decided against this.) German psychiatrists have distanced themselves from the "Sisi syndrome," publishing a study proving its non-existence.

The German pharmaceutical industry said that it was not taken aback by the book. It has also said that Blech's criticism does not change the fact that treatments are available for only a third of known diseases and that most drugs in development deal with major fatal or disabling diseases, such as infections, cancer, and heart disease.

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Pox: Genius, Madness, and the Mysteries of Syphilis

Deborah Hayden

Basic Books, £20.99, pp 379
ISBN 0 465 02881 0

Rating: ★★★★★

At the end of the 19th century the syphilis expert Alfred Fournier estimated that 15% of the population of Paris was infected with syphilis. There was probably a similar prevalence in big cities across Europe and the United States. And yet, as Deborah Hayden notes in her introduction to *Pox*, there are almost no memoirs or biographies by or about people who had syphilis during this era. Syphilis, she writes, "was life's dark secret."

Pox is Hayden's ambitious attempt to shine some light on this darkness. She

argues that although syphilis is rarely explicitly mentioned in the memoirs, biographies, or even the medical records of famous 19th and 20th century figures, if you are alert to the right clues, you can make a convincing case for a diagnosis.

Hayden's detective work leads her to some pretty explosive conclusions. Oscar Wilde's *Portrait of Dorian Gray* was a secret parable for Wilde's struggle with syphilis. Vincent Van Gogh started painting images of death in 1886 after contracting syphilis. James Joyce had the pox. And Hitler's life story and behaviour only really make sense in the context of his syphilis, which he may have contracted from a Jewish prostitute.

It is almost impossible, of course, for any syphilis detective like Hayden to prove that a historical figure had the disease, since a posthumous tissue sample is rarely available for testing. Hayden admits that retrospective diagnosis is a fragile art. All she is able to do is to gather a body of circumstantial evidence to support the diagnosis from the records of her subjects' lives.

Because of the stigma attached to the illness, and out of a desire to protect the subject's reputation, these records rarely, if ever, mention the word syphilis. What Hayden manages to do so wonderfully is to

find recurrent patterns of symptoms and behaviours in her subjects' lives that are best explained by syphilis.

The typical pattern that she finds begins with high risk sexual behaviour. There is fever and malaise, then some form of medical treatment, such as mercury, arsenic, or potassium iodide, followed by a long list of progressive pains and ailments. Later in the subject's life, there are unusual emotional and behavioural disturbances that can include mania, euphoria, depression, and hallucinations. There may also be physical signs, like changes in handwriting, tremors, eye signs, and heart murmurs. Death may be preceded by a period of dementia or psychosis.

Again and again Hayden finds this pattern. Like all great whodunnit stories, she builds clue upon clue until the reader is convinced that it was syphilis that done it. Fortunately, she goes beyond simply explaining away her subjects' lives as being merely a byproduct of their secret infection. Instead, she uses syphilis as another lens through which we should view the complicated genius, madness, and creativity of some of the most influential figures of the past 200 years.

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Disseminating science

The Royal Society has convened a working group to look at how research reaches the lay media. Alex Williamson offers an insider view

Imagine this scenario. A group of university researchers gets funding to study the causes of a well known human genetic disease (disease X). Disease X is fatal in a small percentage of cases, but there is a range of effective, but expensive, treatments for its symptoms.

After six months of the four year study many of the patients who have been tested seem to have the same rare combination of changes in a particular gene. The researchers also discover that some of the patients with this rare combination of genetic changes also had the same rare childhood illness (illness Y). Illness Y is fatal in about a half of cases, and it is not known how to cure or prevent it. Illness Y produces very painful symptoms, for which there is no effective treatment. It was not previously known that disease X and illness Y might be linked.

The researchers' initial conclusion is that the rare combination of genetic changes may be responsible for both disease X and illness Y. Any treatments for disease X, they think, may be effective against illness Y.

By coincidence, the research study is partially funded by the drug company that makes some of the treatments for disease X. The rest of the funding comes from a medical charity.

The researchers need to decide whether they should go public with their initial conclusion at this early stage of the study. They believe that if they make their preliminary conclusion public, some people will want the expensive treatments for disease X to be tested on children with illness Y.

The researchers consider these options:

- Hold a press conference and announce their initial conclusion to journalists within a few days

- Present their initial conclusion at a scientific conference within the next three months to gain the views of other researchers in the field and simultaneously to announce their initial conclusion to journalists

- Prepare a scientific paper describing their initial conclusion and submit it to a journal to be assessed by other researchers in the same field and, if approved, published within 12 months and simultaneously announced to journalists.

Does this sound familiar? If you were one of these researchers, what would you do?

A Royal Society working party is using the above hypothetical scenario to assist in its consultation on best practice in communicating the results of scientific research to the public. Patrick Bateson, vice president of the Royal Society, chairs the working party, which also includes scientists, journal editors, publishers, journalists, and experts in consumer affairs. I agreed to join the working party because, as a medical publisher, I have first hand experience of the flaws in the peer review process. I have also seen the distress caused to patients when a new piece of

THE ROYAL SOCIETY

Bateson: research has profound effects on public opinion

research is misrepresented or exaggerated by the authors or by the lay media.

At a recent press conference Bateson said that the results of scientific research have profound effects on public opinion and policy, so it is important that scientists practise the highest standards of professionalism and integrity when communicating their results. At present, scientists rely almost exclusively on the practice of peer review, in which other experts check the quality of their results, analysis, and interpretation before they are made public. However, we know that peer review is not perfect, and some papers published in leading peer reviewed journals are afterwards found to be based on false or poorly interpreted results.

Two recent and well publicised retractions have fuelled anxieties about the credibility and quality of peer review. In September *Science* retracted a paper describing severe effects in monkeys that were given ecstasy. Two of the 10 animals died. The results shocked many and were seized on by the lay press in their campaigns against recreational drugs. It was then discovered that the monkeys had been mistakenly given methamphetamine, not ecstasy. In another case *Nature Medicine* retracted a paper that had reported favourable outcomes of the first human applications of a hybrid cell vaccine. The report had received much hype and raised the hopes of cancer patients. After publication, however, doubts were raised about the scientific rigour of the study.

Researchers themselves may raise the public's awareness of science and their anxieties by publicising questionable results that may or may not have been subjected to peer review. We are all only too familiar with the debate over the measles, mumps, and rubella vaccine stimulated by Andrew Wakefield's research and the claims about the birth of human clones.

The working party expects to report its findings to the council of the Royal Society early in the New Year. We hope that this will provide advice to researchers, journalists, and the wider public.

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WEBSITE OF THE WEEK

Medical errors It wasn't that long ago that many people regarded doctors' opinions and actions as near miracles. Nowadays, however, the doctor-patient interaction is more of a deal, where terms must be respected. If a provider does not offer the best quality products, the clients know full well how to safeguard their rights. Hammurabi's rules are back, and if doctors make mistakes in treating their patients they must pay—and the price might be their liberty, as an editorial in this week's *BMJ* discusses (p 1118).

Perhaps reflecting society's changing attitudes to medical mistakes, there are several websites available that seek to support patients who have been on the receiving end. These include Medical Accidents (www.medical-accident.co.uk), a patient-led group, applying "business-accepted processes, standards and solutions to medical concerns." Visitors can fill in a complaint form, or learn how to go about engaging specialist solicitors.

Action for Victims of Medical Accidents (www.avma.org.uk) defines "a medical accident" as "when avoidable injury has been caused as a result of medical treatment or failure to diagnose." As well as offering advice and support, the website contains news and a section on finding a local solicitor.

Health professionals, of course, also need help. One place to get it is at the webpage of the NHS Litigation Authority (www.nhs.uk), which is part of the NHS and is supposed to manage clinical negligence claims. Useful guides on risk management and litigation are available to download.

Another useful site for healthcare professionals is that of the Institute for Safe Medication Practices (www.ismp.org), which focuses on reports about medication errors. Medication errors can be reported here so that they can be published and avoided in the future.

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PERSONAL VIEW

Caring for the elderly: a cautionary tale

That a society should be judged by the degree of protection it offers its most vulnerable members is a truism scarcely worth repeating. Despite government efforts, special inquiries, a Royal Commission, and rafts of good intentions, the problem of long term care for elderly people remains. Elderly people deserve more: any of us may have to face personally the problems we collectively fail to solve. Frail elderly people could be excused for imagining that our society offers them little beyond goodwill, sympathy, and the hope that they will stay out of sight.

Nearly 10 years ago several elderly patients were discharged from Park Prewett Hospital in Basingstoke to a private nursing home, as part of a phased running down in the pursuit of "care in the community," brought forward hastily because the home was expanding.

Three weeks later three of them were dead. One was 95 years old, extremely frail, with end stage organic brain disease, several physical problems, and severe behavioural difficulties. Confusion over responsibilities led to his having no GP cover until the day before his death. Confusion, in fact, surrounded both the decision to move the patients—taken at a private health authority meeting—and its implementation. The harm that ensued was unintended but avoidable.

As the patients' psychogeriatrician I assessed their fitness for discharge. Departmental guidance was quite explicit: no patient may be discharged without the authority of the doctor holding responsibility, and that responsibility may be delegated only by the doctor; patients should not be discharged until the doctors have agreed and management is satisfied that everything reasonably practicable has been done to organise the patient's care in the community.

At Park Prewett I found myself an unwilling observer—certain that discharge was wholly inappropriate but finessed by authorities seeking a quick solution. Knowing my clinical decision, they obtained an opinion from another consultant who shared my reservations but felt that discharge was inevitable. And they gave undue weight to the views of a ward sister who had known the patients for only six months.

Sir William Reid, the then parliamentary and health service ombudsman, said that the health authority's decision "should serve as a grim warning to any ... authority ... planning the discharge of patients from hospital to long term care." A parliamentary committee punctuated its report with striking phrases: "improper haste," "willingness to cut corners," "blatant disregard for

departmental guidance," "brazen attempt to ignore expert advice."

The secretary of state for health said that there had been critical breakdowns in the delivery of care. The health authority's chairman resigned, and there was much extravagant language. Any future proposal to handle frightened and vulnerable patients in this way would surely be condemned.

A decade later: progress or backsliding? It is now more widely accepted that long term care for the elderly is a social good. Scotland has shown the way. But the questionable decisions continue.

The media regularly highlight individual cases—harrowing examples of avoidable failure. In just four months earlier this year the ombudsman identified

- A patient with Alzheimer's disease who, after a fall that broke her hip, became incontinent, immobile, and unable to feed herself and lost all

means of communication—her consultant recommended full continuing care funded by the NHS, but the health authority's team elsewhere in the county decided she was ineligible, and the family had to pay

- Another patient with Alzheimer's disease who, though needing specialist care and full assistance with all personal tasks, was refused NHS funding on superseded criteria (the eligibility assessment forms had not been updated)
- A person who had had a stroke and was totally dependent on carers for personal care and safety who was inappropriately assessed with forms that were based on outdated criteria.

Isolated cases? Possibly—and perhaps diminishing in number as new criteria are applied. But every case of this kind is a personal tragedy. Eligibility criteria must be clear, up to date, consistent, and compassionate; and they must address the realities of life faced by elderly ill people.

The NHS ideals demand a mindset that asks how best to meet a patient's needs, how to make available the necessary resources, and how to implement decisions sensitively. It should never ask what the minimum is that can be got away with or how responsibility can be shuffled off on to someone else.

The quality of life of vulnerable elderly people need not be as poor as we have allowed it to become. Lack of resources, poor staffing, and the inconvenient demands of performance measures that are based on numbers are ritual excuses. I don't need reminding how expensive the necessary care is. Is it price we are interested in, or value?

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SOUNDINGS

Evidence based vets

This time last week, I was at the Royal Veterinary College running a workshop on evidence based medicine. I came with some credibility, since whoever prepared the chairman's brief had gleaned a story from this column of how I had once managed an obstetric emergency in a ewe.

There's a bit of a crisis on. Most jobbing vets, I am told, make decisions on the basis of what worked on the last animal. Their journals and grand rounds are full of fascinomas such as patent ductus arteriosus in the badger or firework injury in a goldfish. Owners of companion animals (pets to you and me) increasingly download guff from the internet and demand jabs, magnetic resonance imaging, or antibiotics. The academics have begun to write guidelines, but the service clinicians don't follow them. Nobody does audit, and postgraduates on short courses want a quick update but turn off like a light when offered critical appraisal.

My group of elite academics didn't miss a trick. Shown a paper on the treatment of osteoarthritis in dogs, they immediately raised questions about the provenance of the study (sponsored by a drug company with previous form for direct to consumer advertising), the sampling frame (overrepresentation of quirky breeds), compliance with medication (people might say they give their dogs the medicine, but what's the objective evidence that the tablets stayed down?), and the validity of the outcome measure (a high-tech trotting machine that purportedly quantifies the degree of limp in the cantering quadruped).

A horse that had previously won a prestigious race (the name of the horse and the race were, of course, anonymised) now had a potentially career-threatening injury. A good "outcome" for the owner might not be in the best interests of the patient, which of course raised ethical problems that evidence based medicine could not solve. In any case, the paper on the performance of racehorses got short shrift. The researchers had made the elementary error of not controlling for the jockey.

We concluded that animals deserve better evidence, and that more research is needed. As I walked to my car I mused that our commonalities are greater than our differences—until I discovered that one of their prize collection of birds of prey had crapped on my windscreen.

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