

## Patients, carers and consumers: Agency and the History of Pharmaceuticals

Pharmocracy: Value, Politics, and Knowledge in Global Biomedicine, Kaushik Sunder Rajan. Duke University Press, Durham (2017). 344pp, price \$104.95 cloth, ISBN 978-0-8223-6313-2

Pharmaceutical Revolutions: Pharmaceuticals and social change in the twentieth-century, Jeremy Greene, Flurin Condrau, Elizabeth Siegel Watkins, editors. University of Chicago Press, Chicago (2016). 320pp, price \$110 cloth, ISBN 978-0226-39073-4

While sitting with an ailing relative in the Stroke Unit at Sandwell General Hospital I found myself finally making some sense of what troubled me about the books I read for this review. On the ward, anxious family members watched expectantly as their loved ones were attached to drips and feeds, while others found relief from pressing the doctors and pharmacists for information and details of the drugs and medicines to be administered. Each complex name for these substances was repeated as if a Latin prayer, all the more potentially powerful for being incomprehensible, and often unpronounceable. The only action by the medical staff that seemed to irk or provoke those around the beds was inaction, as no one seemed to believe that time was a useful healer when the hospital was well-stocked with white boxes full of pills and IV bags brimming with potent fluids that could be put to use immediately. This scene was not one that loomed large in either of the volumes reviewed here.

Instead of patients, carers, and consumers more generally, both books prefer to focus on familiar figures in the history of pharmaceuticals. For example, take the introduction to the volume of essays edited by Jeremy Greene, Flurin Condrau and Elizabeth Siegel Watkins, which was written by all three of them. It identifies 'generations of physicians' and 'the pharmaceutical industry' as key players in the rise of pharmaceuticals in the twentieth-century and also in the cultural discourses of a 'therapeutic revolution' that the authors claim were spun to add a false lustre to this phenomenon. Just once does the introduction mention 'patients', arguing that 'patients and physicians were also invested in producing and consuming stories of revolutionary change' (p. 7). But the editors seem little interested in them, and make no mention of carers or consumers, instead devoting most of their introduction to a rather muddled effort to outline what they think the collection of essays is about.

The volume draws on Charles Rosenberg's 1977 essay 'The Therapeutic Revolution: Medicine, meaning and social change in nineteenth-century America' which explains the sub-title of this collection. Rosenberg himself contributes a short chapter at the end of the volume with his most recent thoughts on 'Therapeutic Revolution', both as a concept and as a possible future. The introduction poses the question 'what is revolutionary about therapeutics?' However, the sub-title on the cover suggests that the collection is put together to tackle issues of 'pharmaceuticals and social change in the twentieth-century'. The introduction also declares that 'the aim of this volume is to open the contextual notion of therapeutic revolution to analysis and debate' (p. 2). As the introduction draws to a close, however, readers then come across the assertion that 'this volume

probes our common-sense assumptions about what makes medicine modern' (p. 13). Which is it to be? 'Therapeutics' are not necessarily 'pharmaceuticals' as the latter is a much more specific and limited term, so the insistence on using the former throughout the introduction seems odd. Neither is it clear that 'modern medicine' is the same as contemporary 'therapeutics', or 'pharmaceuticals' for that matter. The introduction of a sense of the 'modern' at the end of the introduction does not necessarily sit easily with a discussion of 'revolution'. If the volume was really concerned with 'pharmaceuticals' as the subtitle suggests, there should perhaps be some reference to the many 'novel psychoactive substances' (NPS) produced in labs around the world over the last decade or so, not for medicinal or therapeutic purposes but for pleasure or intoxication. If the intention of the introduction is to draw the reader's attention to the tangle that comes about when trying to cram all these terms together then it is a success.

In fact, the volume of essays tackles two very simple questions and the introduction might have stated this more clearly. First, was there really a therapeutic revolution caused by pharmaceutical innovations in the last century or so? Second, how has the notion of a pharmaceutical revolution been constructed and what purposes has it served? The chapters themselves address either or both questions to varying degrees and all are useful. Kehr and Condrau's chapter (p. 126-185), for example, does a great job of tackling the second question head on by exploring the reasons why tuberculosis (TB) seemed to disappear in the 1960s. It shows that the success of antibiotic combination therapies in that decade appeared to deal with the disease to the extent that it was no longer viewed as a problem. Research institutes and health bureaucracies lost interest and a general perception began to settle in that while not eradicated, the disease had all but vanished in the wake of the 'antibiotic revolution'. As TB was now dealt with it seemed 'boring' and as such no one researched it and none saw profits or careers to be made from it.

The real reason for this disappearance from scientific view was that few were infected by it in the Northern hemisphere by the 1970s. Whereas those in Asia and Africa continued to suffer with the disease no-one showed any interest, though while it lurked there unchecked it emerged in new forms which were multi-drug resistant (MDR). It was only once these forms of TB appeared that they once again became of interest to doctors, officials and pharmaceutical companies in the North as resistance to antibiotics was identified as a threat to public health there. It was identified in this way using the language of crisis and calls for radical new drugs to be generated by pharmaceutical research. The authors conclude that 'this recombination of old imaginaries and old rhetoric of revolution, paralleled by truly novel developments in the area of pharmaceutical science, makes TB a seminal case for investigating the histories and presents of therapeutic revolutions' (p. 144). Whether TB ever went away, and whether it really came back, all depends on where you are. Only in the Global North does such a story make sense, and the factors behind it include the economics of pharmaceutical markets, the changing priorities of governments in wealthy societies, and the professional interests of medical scientists and practitioners.

Two chapters in this volume—by Elizabeth Siegel Watkins and Julie Livingston—stand out as exceptions to the observation made above that patients, carers, and consumers rarely feature in this book. In her overview of the history of the contraceptive pill in the United States, Watkins provides a neat summary of her work over the last twenty years (pp. 43-64). She points out that the rapid adoption of the pill was, in many ways, the outcome of trends that predated it, such as a changing attitude towards birth control in the US during the 1950s. However, she is clear that it was

consumers that drove the market as they quickly realised the potential of the new product, or as she says 'women knew exactly what the problem was (they wanted to prevent pregnancy) and how to treat it (by taking the pill)' (p. 51). Indeed, they proved to be active agents in sourcing and securing access to the new pharmaceutical, even in the face of medical or social opposition or scientific concerns about its links with cancer; 'if you refuse to give me the pill, I'll go get it from someone else' stated one determined user in the late 1960s (p. 51). Watkins goes as far as to suggest that the pill has been an important element in the making of the contemporary pharmaceutical consumer in North America as it 'also helped to normalize daily pharmaceutical consumption' (p. 61).

Julie Livingston's sobering study of chemotherapy in Botswana similarly touches on the reasons that patients turn to pharmaceuticals. The experience there in the 1990s of AIDS and the related return of TB had produced a situation where most ordinary people there had become 'highly cynical about biomedicine' (p. 232). It seemed to offer little help to those dying of both as there were no effective treatments for the former and limited access to appropriate drugs for the latter. This changed, however, with the development of antiretrovirals (ARVs) in the 1990s and, more significantly, public access to them from 2002 onwards. These drugs can extend the lives of those infected with HIV, and in a country where almost a quarter of the adult population have the virus, this quickly changed attitudes as people could suddenly see for themselves the benefits of using pharmaceutical substances (pp. 220-221). The author explains that this accounts for the increasing engagement of those suffering with cancer with the country's oncological ward at the Princess Marina Hospital. She argues that what drives patients and their families to the unit is 'hope' that the chemotherapy available there will deal with their tumours in a similarly effective manner to ARVs and HIV. When one patient endured the gruelling treatment Livingston observed that

This is not to say that Mofosi found no pleasure in life. He listened to music. Friends and relatives came to visit him. He read the newspapers. His mother and father were there every day, and on some weekends he was even allowed to go home on a hospital furlough. He joked with his doctors, with his nurses and with the ethnographer who followed them around (p. 231).

This is precisely why Botswana are prepared to submit themselves to such 'biomedical technologies' as never before, because of the promise that they hold out of increasing life and enabling patients to enjoy many of the pleasures that come with it. The rest of the chapter, however, shows that this 'hope' often seesaws toward 'despair' (p. 233) as poor resourcing leads to a lack of equipment for accurate and early diagnosis or as incomplete treatment regimes add suffering to the patient experience. For example, although the chemotherapy might be available, the painkillers or anti-emetics to sustain the patient are not.

The final paper in the volume gives Charles Rosenberg a chance to reflect on the notion of 'therapeutic revolution' and also to let readers know if he thinks another is around the corner. It is a missed opportunity, not least of all because he does not share the enthusiasm of Watkins and Livingston for looking at patients, carers and consumers. Perhaps reflecting the muddle of the introduction, the brief essay decides that the concept is familiar, it 'obscures as well as illuminates'

(p. 302), and that 'the origins and ultimate social fate of particular technological innovations are neither inevitable nor entirely predictable' (p. 303). It is little wonder that the author ends up worrying that 'this may seem no more than a litany of truisms' while comforting himself that 'these are ideas that were not clearly discernible in the canon of medical history when I first began to study the field as a young man' (p. 303).

Rosenberg's stab at soothsaying lacks imagination. He identifies five areas in which he senses tensions and anticipates change. The first is 'the role of the physician' (p. 306) whose autonomy he sees as increasingly eroded by bureaucratic protocols that straitjacket the practitioner. This bureaucratisation of medicine is also driving a second change argues Rosenberg, away from treating patients to treating diseases, where individuals disappear in the torrents of data and algorithms designed to identify best-case therapeutic pathways and statistical likelihoods of outcomes. A third set of tensions comes from 'the fact that the world is global in a variety of ways that implicate therapeutic options' (p. 306), which makes the author think of 'the American-trained surgeons replacing hips or heart valves in India for an international constituency of patients' (p. 308) without really explaining why. The fourth is the relationship between public and private sectors in medicine and health in which he argues that the therapeutic revolutions of the past have delivered societies to a point where 'the great majority of us assume that access to at least a minimal level of health care-like some modest level of education- is a de facto human right, and the policies of most governments have in some measure reflected this special relationship' (p. 309). He seems to be saying that the private sector will not have it all its own way in the future and that states will continue to take some responsibility for maintaining the health of their populations. Finally, Rosenberg has noticed the elderly and argues that their 'vast new burden of chronic disease constitutes in itself a revolution of a sort' (p. 309). None of these areas will come as a surprise to anyone working in the field, and the only reason readers might raise an eyebrow is that coming at the end of a book that was supposed to be about pharmaceuticals in the twentieth-century there is so little mention of any of them in this final chapter.

If the book is really about pharmaceuticals and social change then Rosenberg seems to have missed major, and fairly obvious, tensions and changes. There is no mention of the internet for example, where without any medical or expert interference consumers can now access the products of the world's pharmaceutical industries, often in defiance of regulators and professional advice. If the trajectory over the last century or so has been one driven by Big Pharma, or by efforts at control by government agencies, or by associations of pharmacists or doctors seeking to guard the gateways to therapy, then clearly these face a challenge from consumers empowered to purchase pharmaceuticals online. The advent of self-service drug therapy, where diagnosis by Dr Google and same-day despatch from dark-web clinics can provide consumers with all manner of man-made substances at just the click of the mouse flies in the face of almost two centuries of efforts at control or monopoly.

Neither is there much place for these consumers in Rosenberg's assessment of current conditions and their likelihood of leading to therapeutic revolution. They—we—seem to be an unruly lot these days. If there really was ever a time when we calmly waited for our long-distant appointments, listened carefully to our doctors and acted diligently upon their advice, it seems gone. Since antibiotics first began to appear, and became increasingly effective, cheaper and side-effect free in the wake of the Second World War, it seems consumers have been ever more convinced that

magic-bullets medicines are to hand, and if not then they are soon to be discovered. To the minds of many who are ill, or related to those who are suffering, only corporate greed, government interference or the vested interests of the various scientific professions keep us from ready access to these wonder drugs. So we challenge expert opinion, government warnings and professional misgivings to find ways of accessing the drugs we want as quickly as we can get them, often with scant regard for what is actually contained in each of the packets we purchase online, or who is being exploited to provide them.

The issue of NPS mentioned above also points to another set of processes that might appear to presage one of the 'therapeutic revolutions' of the title but which have not caught Rosenberg's eye. The products of pharmacological laboratories in Asia, South America and other places where the regulations of Western countries apply patchily, they have been outflanking regulators and tempting consumers for over a decade now. The question arises of why they are being bought. The case of thallanylzirconio-methyl-tetrahydro-triazatriphenylene (NZZ) is useful in exploring this issue. The authors of a study into one user, a male called Eddie Morra, argued that NZZ was 'an experimental drug that allow[ed] him to use 100 percent of his mind' the result of which was that he 'evolve[d] into the perfect version of himself'. The evidence they presented certainly suggested that the substance enhanced his performance at work, enabled him to develop new skills in languages and statistics that meant he was able to increase his wealth, and even equipped him to patch things up with the love of his life. Of course this is not an academic or clinical study but the plot of the 2011 film *Limitless* starring the fictional substance NZZ (and Bradley Cooper), based on the book 'The Dark Fields' by Alan Glynn (above quotes taken from official synopsis by Relativity Media; <https://www.imdb.com/title/tt1219289/>).

Nevertheless the online kerfuffle about the 'real' NZZ suggests that there are plenty of people out there willing to ignore the end of the story where addiction and exploitation are the fate of the chief character. One consumer of Modafinil, 'a wake-promoting agent', decided to take to the drug as he had read enough to reach 'a general conclusion ... that you simply become a better and upgraded version of yourself' when on the substance (<https://medium.com/@joenrudefalsner/what-if-there-was-a-pill-that-would-enable-you-to-see-things-clearer-focus-better-and-thereby-107b1806efd5>). There may be some basis for this, as a 2015 survey of the literature published in *European Neuropsychopharmacology* concluded that 'when more complex assessments are used, modafinil intake appears to consistently engender enhancement of attention, executive functions, and learning' (<https://www.europeanneuropsychopharmacology.com/article/S0924-977X%2815%2900249-7/pdf>). These substances and their consumers force a rethink about the relationship between pharmacology and therapeutics. Pharmacy becomes a science and industry no longer aimed at making people 'well', but making them 'optimised'. This could be a real 'pharmaceutical revolution' where drugs leave 'therapeutics' behind, or drive a redefinition of the whole concept of 'therapy'.

Perhaps one way to think more about these issues is to return to the question of what is meant by 'health'. This is one of the core questions in Kaushik Sunder Rajan's *Pharmocracy: Value, Politics and Knowledge in Global Biomedicine* and his answer comes squarely in the language of the Marxist. He argues that in the twenty-first century 'Health is no longer just an embodied, subjective, experiential state of well-being or disease; it can be abstracted and grown, made valuable to capitalist interests' (p. 7). The 'pharmocracy' of which he speaks is 'the global regime of hegemony

of the multinational pharmaceutical industry' through which Euro-American corporations have established 'forms of governance across the world that are beneficial to [their] own interests' (p. 6). The author draws heavily on Joseph Dumit's work to argue that within this regime 'health itself becomes a potential source of value for capital' (p. 43). Of course, some historians would argue that this all happened back in the nineteenth-century when vaccines were forced on often unwilling labourers to ensure that they were well enough to turn up to work, but Sunder Rajan is uninterested in such longer term connections.

What *Pharmocracy* does provide is excellent insights into key episodes in the recent history of pharmacology in India since 2005. Two processes form the background to these episodes. The first centres on the International Conference on Harmonisation of Technical Requirements for Registration of Pharmaceuticals for Human Use (ICH). The purpose of this was to impose standard guidelines for the conduct of clinical trials around the world. In India this measure required amendments to the Drugs and Cosmetics Rules of 1945. The second was driven by The Trade-Related Aspects of Intellectual Property Rights (TRIPS) agreement organised by the World Trade Organization (WTO) and designed to 'harmonize' intellectual property rights among member states. It forced India to amend its 1970 Patent Act. The word 'harmonization' is significant for the author, who argues that it conceals the imposition of hegemony by Euro-American pharmaceutical interests through these agreements.

As a result of these agreements Indian citizens suddenly found themselves in a double bind. In the first place the ability of Indian pharmaceutical companies to retro-engineer copycat drugs from new products coming on the market was challenged. Indian consumers who had been able to afford these cheap copies suddenly found that access to medical innovations was cut off as they were unable to fork out the prices being charged for the Western originals. At the same time many found themselves targeted as guinea pigs for clinical trials and increasingly exposed to the risks of medical experiments where untested substances were tried out on their bodies. This was because they were cheaper to hire for pharmaceutical companies. In both contexts the health of Indian citizens was lost sight of by those developing medicines, or rather was monetized by those driven simply by a financial logic. A Bhopal victim dying of cancer who was herded into a trial of one of its new concoctions by a pharmaceutical corporation is among the obscenities deployed dramatically to hammer home what all of this means in human terms. The author argues that no-one seemed concerned with treating his illness or easing the suffering of a fellow man. When they looked at him the doctors and scientists involved only saw his tumours, as these had the potential to prove that the product was effective, and could make them a lot of money.

For all Sunder Rajan's insistence on the hegemony of pharmocracy, this book is largely a study of how Euro-American pharmaceutical interests have not had it all their own way. The death of seven teenage girls in 2010 who were enrolled in a clinical study of vaccines for Human papilloma virus (HPV) sparked a movement in India to challenge unethical clinical trials there. The vaccines had been developed by Merck and GlaxoSmithKline, and they were being used in demonstration studies conducted by the Seattle-based Program for Appropriate Technology in Health (PATH), a non-profit organisation funded in large part by the Bill and Melinda Gates Foundation. They were collaborating with the Indian Council of Medical Research and the purpose was to establish whether the products should be included in India's national immunization programme. While it was never proven that the vaccine directly caused the deaths, the public outcry stoked by media interest politicised the

fatalities. Despite condemnation of PATH, no one was ever prosecuted. However, regulatory reform through parliamentary action established that in the event of injury during a trial the costs of medical care for the victim were to be met by study sponsors, and should injury or death be the outcome compensation would be paid by the same. The author does a good job of narrating a complex story (pp. 62-111), but seems to miss a key conclusion. While it appears to be a positive story of legislative intervention and regulatory change coming about because of a public distaste for 'pharmocracy,' the outcomes seem rather more problematic. After all, in the new regulations the health of the trial participants was still calculated in financial terms, so that an injury or death would simply trigger a cash payment. This could be read as a demonstration of just how far the values of the Euro-American pharmaceutical companies have become embedded in government around the world.

Gleevec, a treatment for chronic myeloid leukemia, is the subject of Sunder Rajan's second story (pp. 112-156). In 2006 the Indian Patent Office denied a patent to Novartis for the drug. The company went through a series of appeals procedures until the Indian Supreme Court ruled in 2013 and the author patiently picks his way through this tale and even includes a timeline of events to help the reader (p. 115). The issue hinged on how far the Gleevec of 2006 was a separate and distinct entity from Imatinib, which had been patented in the US and Canada in 1993. When translating the 2005 TRIPS agreement into law the Indian legislation had included a clause to prevent 'evergreening' (p. 14), where companies tinker with an existing substance as it nears the end of its twenty-year patent in order to claim it is a fresh product that requires a new patent. After seven years of legal wrangling Novartis lost its case. The real significance of this for the author is that it shows that there is still 'interpretive room for maneuver' in countries like India where a robust legislature and a determined judiciary formed 'a bulwark against global capital' (p. 154). He reads the verdict as 'one that orients pharmaceutical politics toward socially just possibilities' rather than simply the production of profit. Here is 'pharmocracy' thwarted.

In looking at the implications for India and for Indians of these 'harmonization' processes Sunder Rajan has written an important book. But there is little that is new about his analysis. After all, a picture where Big Pharma are the bad guys, hell-bent on making a buck wherever they can and measuring mankind only in terms of its potential to yield a profit from suffering is a familiar one that has been around since the 1960s. It is, however, a timely reminder that many companies continue to act in this way and make every effort to manipulate political processes and agencies in pursuit of their interests.

While reading the final pages of *Pharmocracy* I noticed that, much like the 'Therapeutic Revolution' volume, it largely neglected consumers in its account of pharmaceuticals and their histories in its concern with the more familiar figures of uncaring pharmaceutical executives and of compliant or conniving bureaucrats and doctors. Sunder Rajan ended with a story about the death of a relative, which caught my eye as I found myself reading while sat on a hard hospital chair waiting to see if mine would survive. He expressed anger at the hospital's refusal to provide tests and treatment because of the costs involved. I could see something similar from my viewpoint in an NHS ward as family members and friends quizzed all they could find in a uniform about what would happen next, which procedure could be implemented or, perhaps above all, what drugs were to be administered. From what the author wrote it sounded as if his ailing relative had much in common with my own, at least in as far as they seemed to have obstinately persisted in unhealthy habits and

behaviours that could well have explained why they came to be in hospital in the first place. After a lifetime of ignoring sound public health advice about exercise, diet and smoking, our relatives were in hospital and the author and I were ourselves nagging the medics to find a magic bullet or miracle intervention that would save them from their fates.

It seems that the spivs<sup>1</sup> of Big Pharma, the self-serving medical professionals, the unseeing officials and self-important regulators that are such familiar figures in academic accounts of pharmacy would not get away with it all so readily if we did not let them, or even encourage them. I am not sure we are simply hapless dupes unable to resist their wiles or blinded by their expertise. We indulge ourselves in lazy-lifestyles, risky behaviours and eat, drink, inject, snort and smoke away happily with only an occasional twinge of regret. Yet when we make ourselves unwell it is to those pharmaceutical products that we turn, egging on our doctors to hand over the ready remedies. This is not to moralise, as I fear I enjoy too many of the activities above to point the finger at others. It is, however, to drag patients, carers and consumers to the front of the picture in looking at the history of pharmacy and society. The key research question becomes why exactly have consumers taken pharmaceutical products in the past?

This question is largely neglected in the books considered here, but the exceptions of Watkins and Livingston show just how important it is to start from such a point. Answering it raises the possibility that the evidence will show that it is us who encourage pharmaceutical companies to take liberties with our bodies, that we expect doctors to act robotically in firing off their magic bullets, and that people demand regulation only when something goes wrong. If future research into the history of pharmacy and society sets out from that question then fresher and more complex writing will be produced than what was on offer in these books. Maybe we are the bad guys too.

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<sup>1</sup> A man, typically a flashy dresser, who makes a living by disreputable dealings, *Oxford English Dictionary*, accessed 5.2.19.