reviews

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Fevered Lives: Tuberculosis in American Culture since 1870

Katherine Ott

Harvard University Press, £10.50, pp 296
ISBN 0 674 29911 6

Rating: ★★

In 1992 the *New York Post* ran the headline: "TB timebomb. Homeless contaminate public areas in city." This headline encapsulated much of the city's anxiety about the resurgence of the public health threat that is tuberculosis and the cultural forces that influenced the response. The recent epidemic in New York resulted in a reassessment of the role of public health officials, greater awareness of clinicians to drug resistant strains and nosocomial spread within homeless shelters, prisons, and hospitals, and an increased public awareness of an ancient disease that many thought had been eradicated in the West. In the late 20th century, American society, and in particular New York society, re-evaluated its relationship with tuberculosis. And many of its responses were mirrored in the past.

In *Fevered Lives*, first published in 1996, Katherine Ott traces the cultural transformation of tuberculosis in America from 1870. She describes the changing "layers of meaning" that surrounded a diagnosis of tuberculosis and how, among the middle classes, this "most flattering of all diseases" of the 1870s was, as awareness of the social associations grew in the 1880s, transformed into a disease that was the consequence of either acquired or inherited degeneracy. She also describes how the disease mirrored "ethnic and racial fears and prejudices." For example, many believed that very different disease processes occurred in black people—"The seed of negro consumption is not in the lungs, stomach, liver or any organ of the body, but in the mind." By the turn of the century, however, the enthusiasm for blaming individual weaknesses was tempered by an increasing awareness that society's strictures were in part responsible.

Ott tells a fascinating story in describing the technology associated with medical advances, how these were interwoven with changing responses to and perceptions of disease, and how physicians' authority increased as they cornered the market in interventional expertise and microbiological understanding. At this time epidemiological awareness arising from "data-gathering techniques … gave regularity and consistency to understanding of the disease," further contributing to the medical profession's authority. Despite its subtitle ("Tuberculosis in American Culture since 1870"), Ott's book largely concentrates on the period before the 1920s. Somewhat disappointingly, little is made of the advent of effective treatment and the more contemporary issues of drug resistance and the disease's associations with HIV. These issues, and the United States' response to them, have undoubtedly been influenced by past approaches.

In April 1993 increasing rates of tuberculosis led to the World Health Organization declaring a global emergency. As tuberculosis has enjoyed a resurgence, allied as it is to economic and social fractures and the HIV epidemic, so books on the disease are also enjoying something of a revival. The fact that several overlap in the period they cover, the issues they address, and their interpretation of their research findings is perhaps not surprising. Ott, however, offers much that is fresh. She argues persuasively that "the history of tuberculosis chronicles how a romantic, ambiguous affliction became first a dreaded and mighty social truncheon, and finally an entity bound up in the public health and civic order," and she uses powerful images to support her thesis.

Overall, *Fevered Lives* offers interesting insights into doctors', patients', and the public's changing understanding of, and response to, tuberculosis in the United States over a period of dramatic transition, and it describes well how different attitudes were reflected in the changing roles adopted by the different actors in the cultural tableau.

Richard J Coker *honorary senior lecturer, Imperial College School of Medicine at St Mary's Hospital, London*

Competing interest: RJC's book *From Chaos to Coercion: Detention and the Control of Tuberculosis* was published by St Martin's Press in January 2000.

Reviews are rated on a 4 star scale (4=excellent)

APRIL BESTSELLERS

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ART

The Museum of Emotions

The Bargehouse, Oxo Tower Wharf, London, until 4 June 2000

Traditional museums house valuable objects. *The Museum of Emotions*, an art installation on London's South Bank, suggests that more subtle and abstract items might be worthy of an exhibition. The items are emotions themselves, presented in a series of rooms, with interactive exercises that evoke particular moods.

In between the rooms are regular "expression points" where signs suggest how we might articulate our feelings. One card says "Scream here." Just after I had been bleeped about a psychiatric admission, I read the notice "Sigh here." Clare Patey, the gallery's artistic director, told me that the public do indeed scream and sigh. One couple were so overcome with the emotions of the "love room" that they proposed to each other there and then. The strange smell in the "lust area" is meant to be chocolate.

Stepping stones, representing the seven stages of grieving, usher you into the crying room. Here you collect drops of water from the "fountain of tears" using a small bottle, which you then label with whatever makes you cry. Among the crowded shelves, where the public have deposited hundreds of bottles of their own, I found one scrawled with "Piles, and Cliff Richard."

General hospitals and clinics themselves could be considered as museums or repositories of feelings, for they contain the extremes of emotion, from the joy of birth to the hopelessness of death. The way in which institutions contain these emotions has profound implications for their denizens. It is curious and worrying that most psychiatric units are emotionally flat and subdued, given that they are meant to care for those suffering from the most extreme of emotional states.

The Museum of Emotions suggests that privacy and concealment are vital in our culture for allowing emotional expression. Such privacy is rarely given to patients in hospital, who are lucky to have a thin curtain around their bed. This lack of seclusion is perhaps intentional, discouraging people from getting too emotional, for the hard pressed staff would then have to control even more chaos.

It is not just patients who are abandoned to cope with their own emotions as best they can. Doctors will identify strongly with the "room of frustration." Here, a fun fair game, in which you throw balls into a clown's open mouth, is totally impossible since the balls are slightly bigger than the holes through which they must pass. The public aren't told this vital piece of information. The smile on the clown's face perfectly captures the attitude of NHS management as they set yet another target.

The gallery is thoroughly involving and entertaining. I left feeling profoundly bolstered by, among other things, the quotation from Emerson on one of the walls: "Sometimes a scream is better than a thesis."

Raj Persaud *consultant psychiatrist, Maudsley Hospital, London*

BOOKCASE

● Scientists, as a breed, are not noted for their modesty. Disputes about priority and authorship are frequent for even the most trivial findings. Joseph Leidy seems to have been an outlier. Denied credit for his discovery that *Trichina spiralis*, the parasitic nematode that causes trichinosis, has part of its life cycle in the pig, he merely commented that the important thing was that the fact was known and that it was of little consequence who found it. This biography (**Joseph Leidy: The last man who knew everything**, Leonard Warren, Yale University Press, £25, ISBN 0 300 07359 3) rescues Leidy, one of the foremost anatomists and microscopists in 19th century America, from undeserved anonymity.

● There is a welcome, if rather belated, shift in the endpoints of clinical trials from an exclusive emphasis on efficacy and safety to outcomes that measure the effect of treatment on functioning and wellbeing. **Quality of Life Assessments in Clinical Trials—methods and practice** (M J Staquet, R D Hays, and P M Fayers, Oxford University Press, £29.50, ISBN 0 19 262785 6) is a comprehensive and fairly non-mathematical introduction to the tools available. It will be a useful supplement to existing books on clinical trial design and analysis.

● All clinicians see a large number of anxious but healthy people, in whatever area of medicine they practise. Glance at **Your Health at Risk: What Doctors and the Government aren't Telling You** (Toni Jeffreys, Thorsons, £9.99, ISBN 0 7225 3925 8) to gain an insight into the sort of things that they worry about. Fluoride, immunisations, and mercury amalgam fillings are old favourites. But if they read this book, your patients' attributions of cause might extend to milk, drinking which, the author claims, will shorten even your cat's life; wearing a bra, which, by artificially constricting the breast, suppresses lymphatic drainage and allows carcinogenic toxins to accumulate; and golf, which exposes its players to dangerous quantities of pesticides, insecticides, and fungicides.

● Many people with epilepsy also have learning difficulties. **Getting on with Epilepsy** (S Hollins, J Bernal, A Thacker, and L Kopper, Gaskell and St George's Hospital Medical School, £10, ISBN 1 901242 39 0) is an imaginative attempt to help them understand their condition. It covers medical investigations, the importance of regular medication, and issues of safety in everyday life. Because the explanations are largely pictorial, it will be especially valuable for people who cannot read easily.

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The steady drip of biased reporting

Steven Harley is a 41 year old man with tongue cancer. According to last week's *Daily Mail* (12 May), he is the victim not of the malignancy itself but of a "cancer blunder." What was the blunder? He had been seen by many different doctors before the final diagnosis was made. The delay was, according to the *Star* (11 May), clear evidence of "scandalous treatment."

The member of parliament for Barnsley, Eric Illsley, raised the issue of misdiagnosis in the House of Commons on 10 May. Mr Illsley spared no detail and declared himself disgusted with the specialists' failure to find the cancer in time. "How did doctors miss my cancer 22 times?" screamed the front page of the *Daily Express* (11 May). On the same day the *Star* contributed "12 docs fail to spot dad's cancer" and declared that the "GPs, hospital medics and specialists … should be sacked." The BBC1 evening news made it their second story, after leading with British troops in Sierra Leone.

As anyone familiar with these stories could have predicted, nowhere in the most prominent coverage were the difficulties of diagnosis discussed. Mr Harley is a non-smoker, which made tongue cancer an unlikely diagnosis even when his sore throat persisted. He was seen by an ear, nose, and throat surgeon four days after requesting the appointment, but nothing was found.

With the benefit of knowing that he had cancer all along, it is easy for the MP and the media to think this was a mistake, but we do not yet know. Steven Harley had "already guessed that he was seriously ill with cancer" (*Star*), but there are many patients with similar symptoms who think they have cancer but are clear of the disease. Steven Harley had several investigations and saw a number of different doctors from different specialties. Some of these were in the private sector. The original working diagnosis was that Mr Harley's symptoms were non-organic in origin. Is it possible that something in the way he or the disease presented made a more serious disorder less obvious?

Eventually, a neurologist found a cervical lymph node. A rapid referral to an ear, nose, and throat surgeon led to the diagnosis being made by a needle biopsy of the tongue. The procedure was ludicrously described by the *Star* as a "simple test." This was typical of the simplification and lack of medical voice in the story—but then the *Express*, *Star*, BBC, and even the *Guardian* reported that Mr Harley might lose his "tongue, larynx and voice box."

There were no ear, nose, and throat specialists on BBC television. The media stories all ended with the unadorned statement from the chief executive of the local NHS trust that there was no evidence of fault. Professors Gordon McVie of the Cancer Research Fund and Michael Richards, the "cancer tsar," used the opportunity to underline our generally poor cancer services and how we have an uphill struggle. We know that already; this was the reason for Professor Richards' appointment.

Even when cancer services are better funded and reorganised and the extra hundreds of oncologists have taken up their posts—perhaps within 10 years from now—cancers will still be missed. We finally got to hear an ear, nose, and throat specialist's view in an interview on *Radio 5 Live*. The surgeon pointed out just how difficult such cases as Steven Harley's can be, and how it is sometimes impossible to locate the primary tumour even when the patient presents with an involved lymph node as the first symptom. The *Guardian* later published a couple of letters sympathetic to doctors' difficulties but "balanced" them with another containing a sarcastic jibe saying that the chief executive had given "hope and inspiration to all patients."

All this was in the same week as the report on dead babies' stolen organs (judging the behaviour of yesterday by the rapidly changing standards of today), a plastic surgeon named in the House of Commons (described under the shield of parliamentary privilege as "a psychopath"), and the neonatal ventilator study in North Staffordshire Hospital (where something does seem to have gone seriously amiss). Countless millions of medical decisions are made every year. The steady drip, drip reporting of every medical misdemeanour that reporters can find is harming the morale of medical staff. The "scandals" are taken up with gusto by politicians desperate to avoid being blamed for the state of an NHS damaged by years of underfunding with staff having to work harder with fewer resources.

We now have promises of more money from Tony Blair and Gordon Brown. We have agreed to systems of reaccreditation and revalidation. The press should give the NHS a chance to put these new systems in place. It is all too easy for the papers to find stories of the small minority of doctors who are uncommunicative and self serving.

Claire Rayner, president of the Patients Association, was commissioned by a newspaper last year to write a story about the NHS. She discussed NHS Direct, and the tone of her piece was optimistic. The paper pulled the story, saying that it was not interested in good news. Ms Rayner's response contains a powerful warning: "Who do these news editors think is going to look after them when they get ill? The consequence is that if the NHS has been fatally flawed by their ill treatment of it, there won't be anyone."

Neville Goodman *consultant anaesthetist, Southmead Hospital, Bristol*

WEBSITE OF THE WEEK

Gulf war syndrome This week the *BMJ* publishes a paper (p 1363) and a linked editorial (p 1351) examining the hypothesis that the accelerated courses of vaccination that Britain's Gulf war troops received may have damaged their long term health. Whatever the science, the supposition that causing an immune response at a time of high stress is a bad idea will find favour among that large and not readily ignored group who prefer intuition to empiricism. Website of the week has considered the issue of Gulf war syndrome in the past (www.bmj.com/cgi/content/full/318/7178/269/a), but on a web that is, for all practical purposes, infinite (72.5 million servers, 800 million web pages) it is not difficult to return and find another viewpoint.

Not surprisingly, the conventional search engines turn up some of the wackier sites: it seems strange that a site designed to campaign for veterans takes a ".com" suffix, but www.gulfwarvets.com seems not to worry. Perhaps more interesting is www.gulfweb.org/tracings/, which encourages individual veterans to submit their experiences of the war, while at www.gulflink.osd.mil/ you can download more formal narratives taken as evidence in military enquiries.

The Veteran's Administration is responsible for the health care of returning servicemen and women in the United States. There are vast amounts of information on its site (www.va.gov/index.htm), which has sophisticated searching and indexing features. The site's text-only version ensures high accessibility to those with sensory impairments—obviously essential with its client group, but good practice in any case as it ensures compatibility with any sort of browser.

The UK Ministry of Defence has a site for its Gulf war veterans at www.mod.uk/policy/gulfwar/index.htm. The design is clear, and the reporting frank—though, in a subject riddled with misinformation, reporting that the National Gulf Veterans and Families Association has cut off relations with the Ministry of Defence with no explanation raises more questions than it answers.

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PERSONAL VIEW

Failures of process at the GMC

The General Medical Council is the organisation which doctors as well as the public are asked to trust to regulate the medical profession. While the members of the public may have doubts about the ability of the profession to regulate itself in their best interests, there are increasing doubts, after the case of the Bristol paediatric surgeons, about the ability of the GMC to be fair in the treatment of individual doctors.

I was privileged to be an elected member of the GMC for five years from 1994 to 1999. I sat on the professional conduct committee (PCC) for two years. For nine out of the 10 weeks I felt comfortable, but one week left me very disturbed. What I considered was my duty to speak led me into conflict with the GMC, which took out an injunction to prevent me from expressing my concerns (25 March, p 822).

It is the first hearing of a case before the PCC which is the most crucial. It is rare for cases to be overturned by the Privy Council on appeal. Initial hearings in any court proceedings have two potential problems. One is lying by the witnesses and the second is prejudice or bias in the jury or panel.

To reduce the influence of lying, witnesses can be crossexamined and evidence produced to support statements. Bias and prejudice in the criminal courts are reduced by having a sufficient number of jurors and by demanding a unanimous decision or at least a 10 to two majority with a standard of proof set at beyond reasonable doubt.

Hearings at appeal seem to assume and indeed seem to want to assume that these safeguards have been in place. I am told that the Privy Council shows great resistance to questioning these basic assumptions and therefore it is only new evidence or breaches in the rules of law that carry any weight at appeal.

The weakness of the PCC proceedings is their susceptibility to prejudice and bias for five reasons. Firstly, the chairmanship is influential and this is a position within the patronage of the president. Secondly, the panels can be too small. I was one of just five, the minimum allowable. Thirdly, a majority decision is sufficient, with no right to a dissenting opinion. Fourthly, there are not enough practising doctors in the common specialties from which to make up the panels. Indeed, during my time on the council one case was heard with no medical member on the panel. Lastly, there is lack of transparency.

My concern was of possible bias. This was also the grounds for appeal in the Bristol case when Dr John Roylance accused the president of the GMC of not declaring the fact that his grandson was undergoing treatment for a heart condition (*BMJ* 1999;318:486). I and those involved with the Bristol appeal thought that access to the in camera minutes would show the injustice. The in camera discussions are concerned with matters of fact and of finding them proved or not. These are recorded verbatim but are considered confidential and protected by privilege from disclosure in cases of appeal.

> PCC procedures need to be more robust and less influenced by individuals

Whereas a policy of transparency and confidence in the system would suggest that there would be no objection to using evidence taken in camera to help decide the issue the GMC and the law lords do not agree. The argument is that this will stifle free and frank discussion. There may be some strength in this argument with a panel of 12 needing unanimity, but in the much flimsier position of needing only three out of five to agree then the argument seems less certain. Once a majority is secured further discussion is unnecessary. The chairman may not feel the need to try to convince the dissenters with reasoned argument, the discussion can just stop, and the muddled logic that might have contributed to decisions can be hidden for ever. If in a particular case the voting was seven to nil for a guilty decision that would carry more conviction and authority than a three to three decision with a casting vote of guilty by the chairman.

What needs to be done? In the interests of justice we should demand that there are larger panels; that decisions should be unanimous or nearly so; that the composition of members must include at least one practising doctor in the relevant specialty; that the in camera sessions must continue to be recorded and a more relaxed approach taken to accessing them in cases of appeal; that the president must not be involved with any part of the procedure as he is ultimately responsible for the integrity of the process and should not compromise his impartiality; and that there must be auditing of chairpersons and members.

Membership of the GMC must be seen as a privilege with responsibilities to the public and the profession. In the interests of justice PCC procedures need to be more robust and less influenced by individuals.

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SOUNDINGS

Happy forms?

I went to a conference recently and found it decidedly hard going. The programme was ominously crammed with one eminent speaker after another. Coffee breaks were repeatedly truncated while the chairman distributed a set of yellow forms on which we were asked to rank each talk in terms of content, relevance, interest, delivery, and handouts, each on a five point scale from poor to excellent. I gave middling to positive responses, since the suits on the podium had clearly worked hard on their offerings and could hardly be blamed for the overpacked timetable, the slack chairing, or the failure of the air conditioning system on the hottest day of the year.

Later, again as an encroachment into the refreshment break (and with instructions to complete them before resuming the programme), we were issued with blue forms asking us to reflect on our overall learning experience thus far. On the second day, we were served with more yellow forms, followed by more blue forms, followed a few hours later by a white form in which we were invited to reflect on the previous day's reflection exercise and say whether we had found it helpful in preparing us for day two.

Don't get me wrong. I am fully signed up to the evaluation agenda. Contracts to evaluate various educational initiatives pay a sizeable fraction of my own salary. But the perceived need to continually evaluate our attempts at evaluation and reflect on our reflections at every interpersonal encounter from the car park committee to the undergraduate tutorial reminds me of a sadomasochistic patient who requested to remain awake during his colonoscopy and spent an ecstatic two hours gazing painfully up his own backside.

When the conference organisers have finished collating the responses on their yellow, blue, and white forms, I suspect they will have learnt three fundamental lessons. Firstly, distributing evaluation forms is like pulling out a video camera—it fundamentally alters the nature of the event you are attempting to capture, and, if overused, the process threatens to destroy the "real" experience altogether. Secondly, the most helpful feedback is almost invariably to be found in the free text responses to questions such as "Are there any other comments you would like to make?" And finally, if you insist on asking vast numbers of closed questions, you will still be analysing your data long after you ceased to care about the answers.

Trisha Greenhalgh *general practitioner, London*