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VIEWS & REVIEWS

Because I'm worth it

PERSONAL VIEW **Robert Mayer**

I'm listening to the consumer programme *You and Yours* on BBC Radio 4, like you do when you have too much time on your hands and an inadequate concentration span for anything purposeful. The programme is about the cost of new anticancer drugs and whether or not the NHS can afford them "at a price that we the taxpayer can afford," as England's cancer tsar, Mike Richards, says.

I was given a diagnosis of metastatic pancreatic adenocarcinoma four months ago, and I've been thinking a lot recently about how much I cost the NHS. Now that I am a patient as well as an "expensive" GP, perhaps I might be, how shall we say . . . a little too pricey now?

Of course, cancer doesn't come cheaply. If you look at my medical record, you will see that very little had been spent on me until I got cancer. A few prescriptions, tonsils and adenoids taken out when I was 7—probably unnecessary by today's standards—and one haemorrhoid injected. A few hundred pounds all in. With an eye to the future, and because we may not be too far away from this scenario, I've done a few back of the envelope calculations of what my treatment might cost: investigations, £9300 (colonoscopy, gastroscopy, scans, computed tomography with biopsy (two), hospital admission with fever and pulmonary embolism, outpatient appointments (weekly)); ongoing drug costs per month—chemotherapy (erlotinib), £1324; bevacizumab, £300; gemcitabine, £450; capecitabine, £300; tinzaparin (to stop blood clots), £300; granisetron (for nausea), £200; other ongoing costs—medical monitoring and scans, one medical meeting a week, medical day unit (one week), computed tomography and magnetic resonance imaging every two months, weekly blood tests. Total: a lot.

Without the medical costs, ongoing drug costs alone are £2874 a month or £34488 a year. So, without too much exaggeration we could say that I am starting to cost the NHS upwards of £40000 a year.

Now, is this expensive? What does the taxpayer get for £40000? I may get six to 12

months (or longer) of high quality life. And my family may get to have me around as a dad and husband. My friends keep me as a friend too. (How much is this worth?) The National Institute for Health and Clinical Excellence (NICE) unofficially says that £20000 to £25000 per quality adjusted life year (or QALY, a measure of useful survival) is the cut-off point for "Am I worth it?" At first sight I am too expensive.

If I go back to work during this time, then of course the UK economy really starts to see some return on its investment. I'll see patients again and make some of them better. That must be worth something—but then I forget they have to pay me at the moment if I'm working or not, although of course that would eventually cease. Paying income tax and national insurance would soon make a dent in the size of my "loan." I'd pay it off in a year.

But in reality there is no loan. If there were, most people would be bankrupt when they got ill. That's why we have an NHS. I'm just exploring the real costs that we don't often think about. And here it gets interesting.

The "standard" and depressingly ineffective treatment for advanced pancreatic cancer is the single agent gemcitabine. NICE approved this more than five years ago and has not returned to the subject since. There is a small amount of evidence for its efficacy but so far only at the "presented in symposiums" level and not formally peer reviewed. This evidence shows a modest but useful survival advantage for the drug with the addition of either capecitabine (a prodrug of fluorouracil) or erlotinib (very expensive).

In my initial conversations with my local oncologist I was told that my primary care trust would not fund capecitabine (in combination with gemcitabine) but that we could apply for special consideration. There was no way the trust would fund erlotinib.

I wondered what form the appeal might take. It would be to a trust committee comprising a public health doctor, a non-executive, and a few managers, most of whom I probably know personally. (Is this good or bad for my chances?) The amount of data is

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restricted to what I already know. So they will be left having to answer the question "Is he worth it?" For six or 12 months? Well, is he?

I offered to pay to save them the embarrassment. Actually I offered to pay for the capecitabine. The bill for erlotinib made even me wonder whether I was worth it. I could get a swanky motorbike, large plasma screen, and a holiday and drive around very fast then retire gracefully to bed—and my family would have some change at the end. Anyway this is not an option in England. I could become a completely private patient, but apparently I am not allowed to just pay for the drugs—it goes against the principles of the NHS. (Although apparently it is possible in Scotland.)

This is, of course, bullshit. As the government knows all too well, an embarrassed Frank Dobson in the early years of the New Labour government had to announce that by and large sildenafil (Viagra) could be made available to NHS patients only if they paid for it. So here we have it: sex is fine for copayment; delaying death is not. And which principle was this?

The moral conundrum so defeated me that I opted for the "opt out" of the clinical trial. Now, I am getting more drugs than either I or the NHS could afford, all courtesy of Roche. Of course the company hopes eventually to expand its market for erlotinib and bevacizumab in the way that it has very successfully for trastuzumab. (Should I have bought shares?) All Roche awaits is a little patient pressure and an announcement from the health secretary to shortcircuit the NICE process. Meanwhile I continue on the trial, happy in the knowledge that at least to Roche—and at least for this year—I'm worth it. This personal view is published posthumously. Robert Mayer, a general practitioner and family therapist in London, died on 21 March 2008. His obituary appears opposite, and extracts from a diary that he kept in the last few months of his life, as well as a comment from his widow, are available on bmj.com.

A personal view by Bruna Carnevale, "I think I'm worth it, why doesn't NICE?" is also available on bmj.com

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Medicine—a victim of fashion?

FROM THE
FRONTLINE
Des Spence



I knew what I wanted to study at university and didn't want to see the careers officer, but I had to go. He looked at my grades, and it was clear that the geek alarm bells had started ringing in his mind. "So you want to do medicine? It is very demanding," he said. "Have you considered law or accountancy?" An imaginary pistol was cocked against my temple. "No," I replied, "I am sure I want to be a doctor." I worked to get the grades I needed for medicine; it was no pick and mix post-results afterthought. It sounds trite, but I did want to be doctor, drawn by the sense of vocation and social duty. The very fact that it was demanding and harsh was the point.

It seems that in recent times some young doctors are leaving medicine at the very start of their careers, no doubt citing "artistic differences." This is extremely disappointing, and I fear that it just reflects the increasing superficiality of our lives. Has a medical degree become a mere fashion accessory? A bauble to be flashed to impress others, with the hope to hear a reverential, "And he is a doctor as well, you know."

It is not the waste of state spending on medical training that is at issue. Nor is it the fact that dedicated clinicians

have supported medical students, sharing their clinical experience and taking time out to teach. It is that patients cooperate in medical training, sharing intimate and personal facts under the implicit and explicit understanding that they do so to help and aid others. When doctors leave, we betray this contract with patients.

I accept that graduates find medicine challenging. And whining about other specialties is an art form in medicine, but in truth we depend completely on our colleagues. No specialty is any more or less worthy than the next. Medicine is a broad and largely egalitarian profession with a vast range of fulfilling jobs, so there seems no need for anyone to leave.

Medicine is not just another degree to be traded in the job market but a vocation. If people don't have this emotional connection with it they will never be happy in the job and should not apply nor be accepted into medicine. The tired and circular argument about gender and ethnicity rolls on, but selection of doctors should be based on two attributes: passion and a sense of duty.

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Publish and be damned

STARTING OUT
Kinesh Patel



"Publish and be damned!" was the Duke of Wellington's famous retort to a former mistress's blackmail attempt by publishing his love letters and declaring their affair to the world. A lesser man than the iron duke would have no doubt quietly acquiesced and paid the money. Moving forward 200 years, the power of publication still seems to have a magic hold over the medical profession, even though its own papers are in large part considerably less entertaining than a 19th century kiss and tell story.

The publications section of every curriculum vitae is examined meticulously for the presence of a suitably large list of entries. Any entry will do for desperate job applicants rather than leave that worst of application form crimes: the empty box.

The deaneries have, of course, conspired to ensure that applicants committing the crime of reducing the size of the box to hide their publication inadequacies are punished by forfeiting their chance

at being shortlisted. And of course there is the publication hierarchy to consider, with case reports beating letters, clinical reviews beating case reports, and papers in which the applicant is the first author surpassing all else.

Why is medicine so obsessed with those who can convince others to read what they have written? Other professions—dentists, lawyers, accountants—are judged on what they can do rather than on how many papers they have published. It is a shame that those who quietly and diligently look after patients, providing high quality care, are deemed less good than those who have spent their time convincing an editor to publish their work.

Does that "interesting" case of xanthogranulomatous pyelonephritis in the *Polynesian Journal of Urology* make the candidate a better doctor? Or is it just a ruse to help whittle down the numbers shortlisted to a manageable few? Granted, a publication history does show some writing skill and

motivation to prepare something worthy of wider dissemination, but these attributes can be demonstrated in countless other ways.

Our love of publications stems from the misguided belief that being scientists and researchers is a critical part of the practice of medicine. Although this may indeed have been true in the past—Paul Langerhans discovered the pancreatic islets while at medical school—the professionalisation of the medical research industry over the past century means that discoveries of such importance are unlikely to be replicated in the future.

So perhaps it is time to move on from "publish and be damned" and look for criteria that really reflect the job the doctors do: looking after the sick. Although more intangible, and certainly more difficult to measure, excellence in caring alone should surely be enough for any prospective employer.

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A pinch of salts

Small details in novels can sometimes evoke a chain of memories. For example, when I read of the smelling salts of Miss Doggett, the elderly spinster in Barbara Pym's novel *Crompton Hodnet* (the last of her novels to be published but among the first to be written), I could not but recall my grandmother.

My memories of her, I must admit, are indistinct, because she died when I was very young, and consist of an almost random concatenation of her characteristics. She wore a fur stole that ended at one end in a bouquet of tails and at the other in a medusoid mass of heads with glass eyes.

She wore hats just like Miss Doggett's, on which were perched stuffed birds, feathers, and fruit, and that were secured with hatpins that nowadays would probably be considered offensive weapons. (I can never hear Eliza Doolittle in *Pygmalion* say "Them she lived with would have killed her for a hatpin, let alone a hat" without thinking of her.)

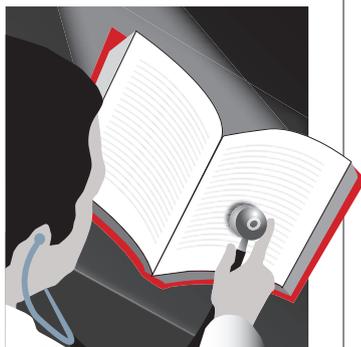
She always smelt of camphor mothballs, and she initiated me into the unfairness of the world. She gave my older brother four shillings, while to me she gave only two. This struck me as unjust: it wasn't my fault that my brother was born before me.

Like Miss Doggett she had a companion. Was she friend, factotum, servant, nurse? I never understood; and now, when I would be in a better position to observe, the whole profession of lady's companion is no more.

My grandmother never went anywhere without her smelling salts—she would have thought it courting disaster to do so. Like Miss Doggett, she kept them in her bag. They were in a little

BETWEEN THE LINES

Theodore Dalrymple



I think it most likely that my grandmother used her smelling salts for the purposes of emotional blackmail, taking them out and narrowly averting a faint with them whenever she was told anything she did not wish to hear

brown bottle, concave on both sides, and I always asked her to let me play with them, which she did.

I didn't actually like the sensation that they provoked. The ammonia made my eyes sting and seemed to swell the lining of my nose and obstruct my breathing. But this I regarded as a challenge: I tried to hold them under my nose as long as I could.

Against what medical emergency did my grandmother believe she was protecting herself or others? Miss Doggett brought out her smelling salts when conveying

to others, with the malicious pleasure of the self righteous, unwelcome news that she hoped might cause the hearer to faint. But from what I have heard I think it most likely that my grandmother used her smelling salts for the purposes of emotional blackmail, taking them out and narrowly averting a faint with them whenever she was told anything she did not wish to hear.

I suppose smelling salts have gone the way of fox furs. The nearest equivalent to them these days is naloxone, which I believe was given out in a trial basis to residents of Glasgow to inject into people who had taken an overdose of heroin. It was claimed that at least two lives were saved by this expedient when the drug was given by passers-by to people found unconscious on the street. I suspect this is more than can be said for Miss Doggett's or my grandmother's smelling salts, although I doubt that proper trials have ever been conducted on their effect.

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MEDICAL CLASSICS

Hall of Mirrors By John Rowan Wilson

First published 1966

In *Hall of Mirrors* a distinguished London physician, Sir Thomas Gilling, sues a professor of surgery for libel. The surgeon's team has developed a computer aided diagnostic machine, and in a public letter he alleges that Gilling was negligent in declining to use it for a difficult case. The title refers to the fairground exhibit where people see themselves in distorting mirrors—a metaphor for how Gilling is presented by the opposing counsel in court. His own barrister presents him as "the perfection of clinical, scientific and administrative medicine." To the other side, however, he is "a rigid, inflexible old man, who can't adapt to new situations."

John Rowan (or Robinson) Wilson trained in surgery before turning to research and later to full time medical journalism and writing. He was an assistant editor at the *BMJ* for several years in the 1960s. *Hall of Mirrors*, which came out in 1966, gives a picture of the contemporary medical establishment, mainly in London.

Younger doctors will find it difficult to believe some of the things that went on at the time. For example, when Gilling has completed his medical house job his consultant arranges a sinecure for him in charge of one of the hospital's convalescent homes so that he can study for his royal college membership. When he gets a job at a London teaching hospital he is quietly told that he will become a resident assistant physician in six months and that he can be virtually assured of being added to the staff after that. As an unwritten condition,

however, he must not get married, as the hospital prefers its resident staff to be single.

Only older doctors will remember when the head porter would take a senior consultant's coat on his arrival at the hospital. Gilling typifies the power of some of the consultants of the time, "the power conferred by age and authority."

These men—for there are no female doctors in the book—controlled the appointments, on the principle that "once you let people argue about who was best for which job, God knows where you'd end up."

Other aspects of the medical profession of the 1960s may, however, still be recognisable. There may yet be occasional surgeons, like the neurosurgeon character, who have a reputation for plain speaking and offensive behaviour. The professor of surgery in the book has always been unpunctual, constantly busy, forgetting times and appointments. He is handsome, with a "diffident charm of manner," but will drop his favourite junior for no obvious reason and then treat him with complete indifference. Perhaps even today such people are not unknown in academic and hospital medicine.

It is sad that such a fine novel seems to have been forgotten, although secondhand copies are easily available. I recommend it as an exciting story and as a portrait of the London medical establishment at a time that is within the memory of older doctors.

Jerry O'Sullivan, retired consultant histopathologist, Chichester, West Sussex

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REVIEW OF THE WEEK

New ways of thinking about autism

Two innovative studies of autism get to the heart of the matter, finds **Iain McClure**

Autism has become a major phenomenon of our time. These two books, in their different ways, explore why this curious condition seems to be becoming commoner, why popular Western culture is almost obsessed with it, and why it is still a shameful diagnosis in many cultures. Furthermore, by considering autism both books address the fundamental question of what it means to be human. A common springboard for the books is that each author is the father of a child with autism. Each has searched for a meaning within his child's condition, so generating two different but similarly innovative and moving accounts.

Roy Richard Grinker is a professor of anthropology who happens to be the son and grandson of eminent American psychiatrists. This background has contributed to his highly readable yet authoritative survey of how autism has become the hot topic that it has, particularly in the United States and United Kingdom. His book is also one of the first serious attempts to survey what autism means to other cultures.

In one of the best studies I have read of this whole field, the first half of *Unstrange Minds* picks its way through the history of autism, considering famous cases such as the 18th century wild boy of Aveyron, through to the 1940s case reports of Kanner and Asperger, and then on to more contemporary authorities, such as Rutter and Wing. In this journey Grinker thoroughly exposes the misguided approach of Bruno Bettelheim. Writing statements such as “the only real difference between the SS guard and the mother of the autistic child is that the mother gets to the child much earlier in life,” Bettelheim, with his massive authority (which was based on minimal experience), is a chilling example of charisma clouding integrity.

Grinker goes on to explain in detail the story of the development of autism classification and why the rise in prevalence is almost certainly due to explicable factors, such as better assessment and wider diagnostic classifications. In this way *Unstrange Minds* serves as a powerful counterblast against those who pursue evidence that environmental insults are the “cause” of autism.

In the book's second part Grinker explores autism's cultural relativism, telling us fascinating true life stories. For example, we learn that even in 2008 raising a child with autism in many Hindu communities in India is “an act of resistance,” that most Navajo families “believe that autism is the manifestation of some kind of spiritual disharmony,” and that the Haredi ultra-Orthodox Jews in Israel believe that children with autism “are former sinners

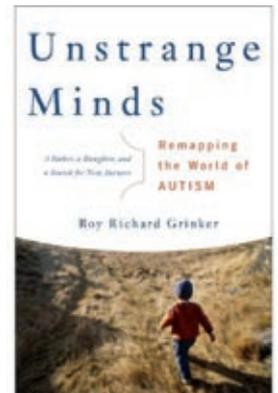
reincarnated.” Although parenting a child with autism in the UK or US is still an ordeal, it seems to be even worse in South Korea. There, as soon as a diagnosis is “made public,” the value of one's house (and possibly those of one's neighbours) “drops a few per cent.” Crushing stigma means that marriage prospects even for siblings of autistic children are instantly “diminished, for who would want to marry into a family with autism?” Intriguingly, Grinker also shows that, even in the West, major discrepancies in the perception of autism still exist. So, in the US, autism is regarded as a neurodevelopmental condition that is amenable to drug treatment, while in France many child psychiatrists still understand it as a psychodynamic disorder arising between parent and child. “Mother blame” in autism is, it seems, still big in France.

Providing an overview of the increasing cultural prominence of autism in less detail than Grinker, Stuart Murray is more interested in how cultures (mainly British and American) perceive and represent the condition and what this tells us about these cultures themselves. For this reason *Representing Autism* is probably less relevant to the medical reader, but it still generates many important points. For example, considering true cases in which a desperate mother has apparently killed herself and her autistic child, Murray exposes the chronic double standards of consequent media coverage, which emphasised the suffering of the affected parent above the unexplained experience of the child. Murray explains how much of our popular culture's consideration of autism—the film *Rain Man*, for example—works mainly in a melodramatic genre, aimed at showing how someone with a disability changes a “normal” person for the better. In such treatments autism is used as a prosthesis rather than being genuinely explored. The one exception to this trend, for Murray, is Mark Haddon's novel *The Curious Incident of the Dog in the Night-Time*, which, he believes, has uniquely achieved huge public interest while allowing its hero's autism to appear normal “within the created world of the fiction.”

Both books are important additions to the autism canon. A key element in their success is the authors' sensitive portrayal of their own autistic children. Isabel and Lucas become powerful offstage presences who remind us that everyone with autism is—first and foremost—an individual, whom we should all try harder to see and hear.

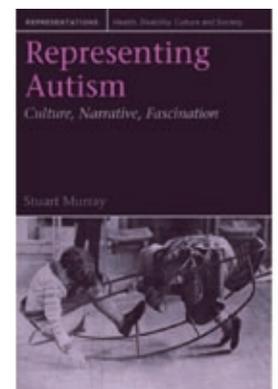
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Unstrange Minds: A Father Remaps the World of Autism

Roy Richard Grinker
Icon Books, £14.99,
pp 401
ISBN: 978 1840468939
Rating: ★★★★★



Representing Autism: Culture, Narrative, Fascination

Stuart Murray
Liverpool University Press,
£16.95, pp 236
ISBN: 978 1846310928
Rating: ★★★★★