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Getting a taste of their own medicine

Daniel Sokol

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VIEWS & REVIEWS

The organ donation debate is long overdue

PERSONAL VIEW **Anonymous**

At 1 am on a Sunday morning in November 2006, my world changed forever. My husband, a 37 year old lecturer at Oxford University, who had been diagnosed with cystic fibrosis at the age of 3, sat up in bed and had a sudden, massive haemoptysis. The events that followed were a blur of blue lights, alarms, and fear. After bagging and BIPAP (bi-level positive airways pressure) failed to reduce his hypercapnia, he was intubated and ventilated. Six hours earlier we had been having dinner with friends.

There followed a nightmare, made survivable only by the support of family, friends, and the wonderful intensive care and cystic fibrosis specialist teams. The odds were poor. I was told that fibrotic lungs respond poorly to ventilation and that it was proving very difficult to ventilate him. A trial extubation failed, a Hayek oscillator was brought in to try and clear the secretions, his CO₂ remained raised, and everyone kept asking whether he was on the lung transplant list, which he was not.

There was some doubt about whether having a tracheostomy would affect his chances of being accepted on to a transplant list. A call to the transplant team confirmed that this was not the case and so on day 10 he had a tracheostomy, and by day 14 he had been weaned off the ventilator on to BIPAP. On 23 December 2006, against the odds, he was discharged home for Christmas.

We were told he would re-bleed again. The question was when. The hope was to get a lung transplant before that happened.

My husband was given an appointment for a consultation with the transplant team in May 2007. It seemed to us a long, long time to wait, but I understand that the shortage of donor organs means the team has to be very selective in

who goes on the list, finding a fine balance between the patient being ill enough to take the risk of transplantation and well enough to survive the procedure. The rehabilitation from having been in intensive care was hard enough. Living with the threat of a re-bleed was terrifying. He continued to have “small” (150 ml) bleeds every few weeks despite embolisation. We employed a live-in nurse, to be available should he have a haemoptysis. I returned to work and, the day before his transplant assessment, got my first consultant post.

After a day of investigations at the transplant centre, we met with the consultant, who described my husband’s case as a “no brainer”: he needed a lung transplant. He had turned his health around after the period in intensive care, and despite needing 24 hour oxygen, had returned to work, making a joke at the start of his lectures about going scuba diving. But we knew he would re-bleed again and that his chances of surviving another massive haemoptysis were slim. His case was fast tracked, and within a week of that consultation he was on the waiting list for a bilateral lung transplant.

Living on the transplant list is a bit like being in suspended animation. There is a need to live every day to the full, but also the sense of the hope of a new, different life hovering somewhere in the future. After a while you stop jumping every time the pager goes off or the phone rings. We followed stories of others who had had successful transplants and sadly of those who died before their call

came. There is a guilt that comes from wishing for something that means someone else’s demise.

There is also a frustration at the statistics: it seems senseless that so many organs go undonated.

I would like to say that this story has a happy ending; that my husband was one of the lives saved every year by someone’s gift of life. I would like to say that

The opt-out proposal will not mean that those who do not wish to donate their organs will have to do so, or that families will not have a choice. What it will mean is that everyone will be prompted to think about that choice

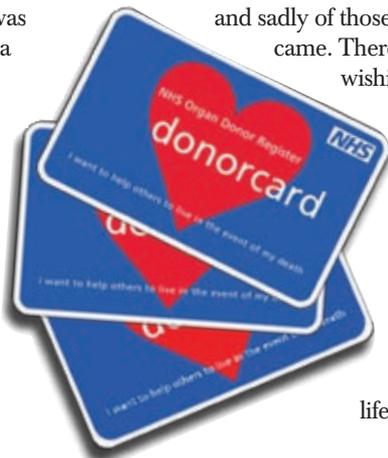
we have moved into the house we were in the process of buying, that he is taking a well earned sabbatical and will be returning to teaching next term. But I can’t. After a series of major bleeds and two further periods in intensive care, he joined the hundreds of people each year who die awaiting organs. Despite the heroic efforts of the intensive care and transplant coordination team, there just weren’t enough donor organs available to secure his survival.

When a loved one dies, so many things go through your mind. One thought has stayed with me. In the hours after my husband’s death, I asked myself whether I would, if it had been possible, said yes to donating his organs. The honest answer is that I do not know if I would have been able to make that decision. I was confused, exhausted, and bereft, and in no state to make a decision about anything. Now, the answer to that question seems like a “no brainer,” but at the time I was dazed.

That is why I think that the organ donation debate is long overdue. Whether to consent is not a decision that can be made easily in those moments of intense shock and grief, and my respect and admiration goes out to the families who have done so. No one likes to talk about death or to imagine their own ending or that of a loved one. The opt-out proposal will not mean that those who do not wish to donate their organs will have to do so, or that families will not have a choice. What it will mean is that everyone will be prompted to think about that choice, to make a decision and discuss it with their loved ones, rather than avoiding the issue and thinking, as is all too easy to do, “there but for the grace of God...”

The author is an NHS doctor

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Arthur Schnitzler's warning to doctors, p 281

REVIEW OF THE WEEK

Getting a taste of their own medicine

What happens when doctors “cross the gulf” into patienthood? **Daniel K Sokol** finds out in a new book of interviews

“One of the hard things to learn in medicine,” wrote the great American doctor Lewis Thomas, “is what it feels like to be a patient.” In the days before the therapeutic revolution of the 1930s, when sulfa drugs gave doctors unprecedented powers over once lethal diseases, most doctors knew about serious illness at first hand. Pneumonia, typhoid, tuberculosis, and poliomyelitis were familiar foes. Today, the experiential divide between doctor and patient has widened. Patienthood is a foreign country.

Robert Klitzman, a psychiatrist practising in New York, lost his sister in the 11 September attacks on the World Trade Center. After organising her memorial service and packing her belongings, he became depressed: “For the first time, I fully appreciated what my patients had to undergo, and how hard it is to put the experience of depression into words.” In *When Doctors become Patients*, Klitzman interviewed 70 doctors who crossed the gulf into patienthood. And so we meet Roxanne, a gastroenterologist with abdominal cancer, who dismissed her epigastric pain as irritable bowel syndrome; Frank, a temperamental surgeon who had a heart attack in the operating theatre; Jeff, a specialist in adolescent medicine with HIV who struggled to tell his doctor of his impotence; and Dan, an oncologist with chest metastases who, refusing to wear patients’ pyjamas, wore surgical scrubs instead. These characters come and go on Klitzman’s stage to recount with humbling candour their views and experiences, based around general themes such as denial, errors, discrimination, and identity.

As doctors are individuals, their responses to serious illness and patienthood vary, but Klitzman identifies common trends. Doctor-patients struggled to come to terms with their illness, often playing down their symptoms and engaging in error prone self doctoring. “We doctors wear magic white coats,” commented Dan the oncologist, as if their healing role made them immune to disease. When denial was no longer possible, the medical and personal selves diverged. On seeing the images of his bone scan, one doctor remarked, “Yup, I’m a dead man,” while another with brain metastases commented, “This is the last weekend with my brain.”

The experiences of these doctor-patients opened their eyes to the impact of seemingly minor matters. Non-specific complaints, side effects such as weight gain and fatigue, fear, humiliation, and spirituality acquired new

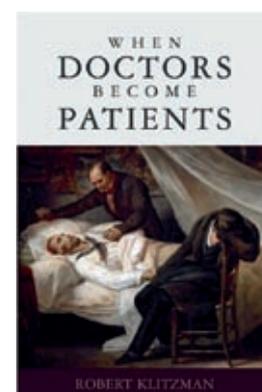
significance. Struggling to adhere to burdensome schedules, they became less draconian about poor adherence to treatment. In presenting medical information, they became aware of the importance of framing the information sensitively. Herb, a neonatologist with a myocardial infarction, recalls a sleepless night before surgery after being told of a 5% chance of death—a 95% chance of success would have been more encouraging. Jacob, a radiologist with skin cancer, drew a distinction between patient time and doctor time and concluded that “a person waiting is a person suffering.” As a result of their own experiences as patients, several doctors tried to return laboratory findings more promptly. One doctor-patient, inspired by a doctor who spent longer in his company by writing the notes in the patient’s room rather than at the nurse’s station, adopted the idea in his own practice. In choosing their own doctor, most interviewees preferred bedside manner over technical skill.

Dealing with the loss of power and fear of discrimination associated with patienthood proved difficult. Some doctor-patients withheld their diagnosis from colleagues and patients through silence or lies, despite concerns about information leaks. As an ethicist I found it alarming to read how little faith these clinicians had in confidentiality. If in theory sacrosanct, in practice confidentiality seems somewhat illusory.

My quibbles are few. The scope of the book is vast, and some topics such as work-related burnout are inevitably glossed over. In only 300 pages, comprehensiveness and depth are hard to reconcile, but Klitzman helpfully points out areas for further research. As this is not an academic social science monograph; Klitzman could have allowed himself more freedom to interpret the data. When he did, I found his analysis insightful.

Klitzman, like Gawande and Groopman, is part of a contemporary group of reflective doctors who, through their writings, contribute to the less palpable but nevertheless crucial moral, social, and experiential dimensions of medicine. Lewis Thomas suggested the development of an “illness simulator” to teach young doctors and medical students about illness, mortality, and good doctoring. Klitzman’s book is a less painful and more ethical alternative.

Daniel K Sokol is lecturer in medical ethics and law, St George’s, University of London daniel.sokol@talk21.com



When Doctors become Patients

Robert Klitzman

Oxford University Press,
£19.99, pp 344

ISBN 978 0 19 532767 0

Rating: ★★☆☆

We meet Dan, an oncologist with chest metastases who, refusing to wear patients’ pyjamas, wore surgical scrubs instead

Beware of expensive imitations

FROM THE
FRONTLINE
Des Spence



Research has established that expensive wine tastes better—even if in fact it is the same wine. I suspect that when you pay a high price for something, and despite evidence to the contrary, you genuinely believe it to be better. This is true of many “luxury” items like gaudy Italian fashion, whose gold buckles and epaulets are found loose in the washing machine. This effect is also true of health care.

I manage to maintain my smile but my feet curl in painful spasm with the attitudes towards our socialised health care from some of our newest economic migrants. Their looks of consternation at the paracetamol for a cold, the huff at the lack of investigation, goggle-eyed head spinning at having to wait to see a specialist, and door slamming “I will go to casualty” when told a specialist consultation is not appropriate. Where I expected stoicism, instead I found strong, health seeking behaviour and doctor dependence even from the citizens from some of the world’s poorest countries. How can this be?

Popular medical logic goes that patients are to blame for health seeking dependence—but this is not the case, for it is doctors and their medical systems that dictate how patients consume services. Most countries have ad hoc private care largely dominated by hospital care, where there is an inherent need for treatment, inven-

tion, and referral, irrespective of need, to maintain income. So this phoney-brand medicine is standard care. Patients are a type of commodity; therefore, promoting dependence on doctors is just good business. So, it seems that, even in developing countries, unfettered medical capitalism is polluting humanity with health anxiety, corroding both self reliance and wellbeing. These distortions will surely worsen with rapid growth and the new wealth that is feeding these unregulated, billowing medical factories.

The NHS, as the son (or daughter) of a Welsh coal miner, is gruff and offhand and has very poor table manners, but it is a diamond. The NHS’s greatest gift after universal coverage is that it has no vested interest in promoting healthseeking behaviour or health consumerism. We cold, wet, and wealthy islanders are still a hardy lot, and stoicism and coping are still prized.

To save humanity from a potential health consumerism hell, there is only one solution. Developing countries should nationalise health care, NHS utility style. This suggestion will cause much door slamming and sneering at our low tech “socialist” care. But in the washing machine of life, never confuse more (expensive) medicine with better medicine. Less is almost always more.

Des Spence is a general practitioner, Glasgow destwo@yahoo.co.uk

We never talk any more

IN AND OUT OF
HOSPITAL
James Owen Drife



Our local theatre, the West Yorkshire Playhouse, is adjacent to one of the national offices of the Department of Health (DH). My only appearance onstage at the Playhouse, so far, has been to give a lunchtime talk to DH staff. One of them had organised a series of lectures in which consultants explained what our jobs involve.

It went reasonably well, as I recall, but it’s hard to remember. It was a long time ago. In the 1990s direct contact between civil servants and doctors was a novel idea. Today it is unthinkable. Taking time out to understand what doctors do would be regarded as a distraction from the job of reforming the health service.

Communication between the NHS and doctors is now unidirectional. “Top down” messages have become public relations exercises. We receive

flashy documents, sometimes fronted by a medical celebrity, featuring trite quotes and mawkish photographs. Doctors, who have no time for falseness, bin them.

Those who run our working lives feel that they know about medicine because they have been to a general practitioner, visited a hospital, or had a baby. Sometimes this, too, was a long time ago. If they want to catch up with modern practice they commission a survey. Or they speak to a medical member of a quango, who will see things as they do.

Genuine dialogue could give the great and good a reality check. It might help them recover the credibility they have lost by instructing general practitioners on when to open their surgeries, telling hospital doctors what to wear, announcing that hand-washing is a great new idea, and compelling

trainees to write creative fiction in job applications.

Can we persuade the DH that there is intelligent life in the medical workforce? It’s a tough assignment. You can talk to people only if they want to listen. We could start surreptitiously by persuading the cleaning contractors to leave the *BMJ* in the coffee rooms.

Then, who knows? Someone might arrange some more lectures. Doctors could tread the boards at the Old Vic (also adjacent to a DH office). But civil servants will point out that all targets and innovations now come from Downing Street. No problem. There’s a playhouse nearby which used to be called the Whitehall Theatre. It’s fondly remembered as the home of British farce.

James Owen Drife is professor of obstetrics and gynaecology, Leeds j.o.drife@leeds.ac.uk

Flaubert and parrotry

When, exactly, did it become a sign of superior sensibility and intellect to decry the bourgeoisie and the bourgeois virtues? No doubt it is impossible to put a date on it as exactly as that of, say, the Battle of Hastings; but there is no doubt that one of the chief critics of the bourgeois mentality was that arch-bourgeois Gustave Flaubert.

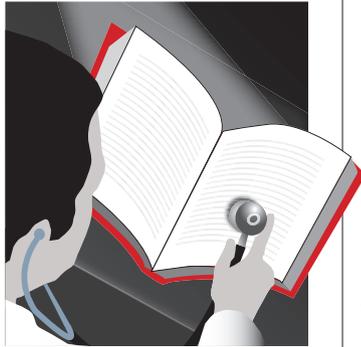
In his *Dictionary of Received Ideas*—which he started in 1849 and never finished, and which was not published until 1911, 30 years after his death—Flaubert makes ironical fun of the bourgeois clichés of his time, among which are many relating to medicine. He disliked intensely the tendency of the virtuous to decry, often on supposedly empirical grounds (but in reality more because they were killjoys) the pleasures of the flesh.

For example, the entry on alcoholism in his dictionary is “the cause of all modern illnesses,” and refers to his entry on absinthe, which is “extra-strong poison: a glass and you are dead. Journalists drink it while writing their articles. Has killed more soldiers than the Bedouin.”

And the entry for tobacco is “cause of all the maladies of the brain and spinal cord.”

Now an idea is not false merely because it is received; it is false because the evidence does not support it. And while one understands very well Flaubert’s detestation of killjoys (there are few illicit pleasures greater than that of preventing someone from enjoying himself), no one could possibly deny that alcoholic excess and smoking are indeed harmful. And while I am rather fond of a drink myself, scarcely ever letting a day go

BETWEEN THE LINES Theodore Dalrymple



Flaubert, it is often said, was violently opposed to conformism, which he mocked and satirised. The problem is that it is not so easy for humans to escape conformism

by without one, the role of alcohol in drumming up customers for our casualty departments has not entirely escaped me.

Flaubert makes fun of the bourgeois who complains (one can just imagine the dying fall of his voice as he describes his last journey in a hot climate) that mosquitoes are more dangerous than any wild beast.

But the bourgeois was more right than either he or Flaubert knew: the French attempt to build a canal through Panama, for example, which was abandoned during the last years of

his life, was defeated not by wild beasts such as jaguars, but by mosquito-borne diseases.

Flaubert, it is often said, was violently opposed to conformism, which he mocked and satirised. The problem is that it is not so easy for humans to escape conformism, if for no other reason than that anti-conformism soon imposes a conformism of its own. Rebels are often only dictators awaiting their chance, and bohemianism only makes sense in a context in which there is a non-Bohemian norm: that is to say, where everyone is a Bohemian, no one is.

The question we should ask of an idea, then, or a work of art, is not whether it is new or old, conventional or unconventional, original or unoriginal, but whether it is any good. Mosquitoes are not wholesome merely because a dull and unimaginative bourgeois complains of their tiresomeness during his latest voyage in the tropics.

Theodore Dalrymple is a writer and retired doctor

MEDICAL CLASSICS

Traumnovelle (Dream Story)

By Arthur Schnitzler

First published 1926

Arthur Schnitzler (1862-1931) knew all about doctors and the temptations they face on their travels—in his words there is a “whiff of freedom, danger and adventure.” His 1926 book *Traumnovelle* (Dream Story)—which Stanley Kubrick made into his 1999 film *Eyes Wide Shut*, starring Nicole Kidman and Tom Cruise—tells the tale of Fridolin, a doctor in Vienna who becomes jealously tormented when he realises that his wife, Albertine, whom he has taken too much for granted, has a secret life. Called out in the middle of an argument, he finds himself on a journey to the end of night, navigating his way through his very own Scylla and Charybdis, a series of hazards that might now be signposted “Warning—GMC ahead.”

He visits a grieving young woman, vulnerably alone. He misreads her excitement as “probable acute bronchitis” and is surprised when she then throws herself at his feet, declaring her love. He narrowly escapes, only to be challenged in the street by some passing young thugs. Refusing to fight, he then worries about his cowardice, which is reinforced when he next encounters a prostitute: “This could end in death he thought, only not quite so quickly!” After dismissing her he meets a friend from medical school, Nachtigall, who did not qualify. Fridolin promptly and insensitively brags about his successful practice and his happy marriage. Nachtigall inadvertently draws him into a meeting of a secret society.

The now costumed Fridolin ignores the warning from a masked beauty to escape the perverse gathering he has gatecrashed. Caught out, he is himself exposed: “Take off your mask!”—a metaphor for his own bourgeois facade, his professional act. He fears exactly what he tells his patients to do every day: to strip, to stand naked for inspection. The woman offers to redeem him, and he escapes.

Once he is home at last, his wife tells him of her dream, in which he has been “buying the most gorgeous things that you could find for me.” The danger on the rocks is surely passed. The masked woman, though, turns up at the morgue; Fridolin charges himself with blame for her death. He comes to the realisation that “all this order, balance and security in his life were really an illusion and a lie.” Schnitzler warns us, as Stanley Kubrick would have it, not to keep our eyes wide shut.

John Quin, consultant physician, Royal Sussex County Hospital, Brighton John.Quin@bsuh.nhs.uk



Nicole Kidman and Tom Cruise in Kubrick’s film *Eyes Wide Shut*