A story of money, drugs, and life: *The Price of Life* reviewed on p 1504

Who would want to be medicine's sacrificial lamb?

PERSONAL VIEW **Julian Sheather**

Audiences can be fickle things. Recently I clambered down from my ivory tower and emerged, blinking, on to a brilliantly lit podium at the Cheltenham science festival. The theme of the evening was "Playing God—risk in surgery." I was on a panel with two surgeons, but my job was to do the ethics. I figured that the live issue would be about balancing paternalism and autonomy. Was there a limit to the amount of risk a patient could be asked to take on? Could illness and the possibility of death be coercive? Could an ambitious surgeon, keen to make a name, lead the desperate into taking impossible and mutilating risks?

How rose tinted must be the windows of the ivory tower. I could not have been more wrong. A charming cardiac surgeon took us on a walk down memory lane, a long, long walk back to the good old, bad old days, the days before the scandals at Alder Hey and Bristol Royal Infirmary had put the spook into medicine, back to the days when surgeons were surgeons and patients were grateful. Back then, apparently, if a surgeon had an idea about a new way of doing things he would run it by his (and I mean "his") team, and, provided that nobody thought it absolutely insane, they would give it a go. On the whole it didn't do to tell patients what you were up to, not a good idea to worry them too much, best just to have a stab at it and see what happened. When it came to looking at the results, the first 30 or so were discounted. These were your "learning curve"—these are not my words—but once the technique had settled down you could begin to assess outcomes.

Medicine has changed incomparably for the better over the past 30 years, and the rise of ethical sensitivity has played a key part in that change

As I listened my blood ran a little colder than usual. I felt the ghosts of ancient wrongs beginning to stir. I thought of the long ethical haul from the Tuskegee syphilis study: black American sharecroppers with the disease were systematically denied penicillin so that researchers could better understand its natural history. What about informed consent, I spluttered? Research equipoise? What about giving people a choice? So far as this audience was concerned, it all fell on deaf ears. Predominantly elderly, they were in nostalgic mood. Several of the surgeon's early patients were present, and they clearly adored him. As a young doctor he had done his best according to the mores of the time. He had also saved their lives. Their questions were not about ethics but about what he "got up to in their chests all those years ago." "We're still here," they chirruped. "In my line of work," he quipped, "your mistakes don't usually come back to complain."

THE GHENT ALTERPIECE HUBERT AND JAN VAN EYCK BRIDGEMAN ART LIBRARY/GETTY IMAGES

That night it wasn't surgery that was in the firing line, it was ethics. A woman came up to me afterwards. It's a pity, she said, you seem like a nice man, but don't you see that you and your ethics are part of the problem? Nobody can move for bureaucracy. Innovation is dying on the vine, choked by the red tape of ethics. There are no pioneers any more. The great surgeons of old have been brought to their knees by Lilliputian ethicists. Ok, so a few patients may have died back then, but think of the thousands saved. You can't make an omelette without breaking some eggs.

If there was a serious point, this was presumably it. In medicine, as in many other walks of life, many could be saved by the sacrifices of the few. Contemporary life, however, puts the one before the many. Treatments and techniques that could save thousands are inhibited out of a squeamish regard for individual rights. A respect for patients' autonomy has brought medicine to a standstill. There is a certain cold utilitarian plausibility about such a stance. But we need to be cautious. Pluck a man at random once a week from a public place and redistribute all his organs: many could be saved for the loss of one. This is facetious, of course, but it makes the opposing point. The public interest is all well and good, but which of us would want to be the sacrificial lamb?

I slunk back to my ivory tower. "Reality in our century," Graham Greene once said, "is not something to be faced." But then his was the 20th century. In my view medicine has changed incomparably for the better over the past 30 years, and the rise of ethical sensitivity has played a key part in that change. It has helped put the patient in the centre. But it seems that not everyone agrees with me. Even, to my continuing surprise, some of the patients.

Julian Sheather is ethics manager, BMA
jsheather@bma.org.uk

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REVIEW OF THE WEEK

If the price is right

Ike Iheanacho is impressed by a gripping documentary on drug rationing

The Price of Life
BBC Two, 17 June at 9 pm
Rating: ★★★★

The rationing of medical treatments can be a fiendishly complex subject. But two quotations encapsulate the tensions at the heart of such decision making:

"If it helps at least one person, then it's worth having."

"… If the price is right."

On one hand is the view that an intervention that has been proved to be effective and tolerably safe should not be withheld from people who might benefit from it. The obvious counterargument is that a taxpayer funded system such as the NHS must decide how far it can afford to help all such individuals.

The two positions may be particularly hard to reconcile when it comes to expensive drugs for extending life in people with terminal diseases. Just how hard is shown in *The Price of Life*, an elegant insight into rationing (and the source of both quotations).

This documentary focuses on the role of the UK National Institute for Health and Clinical Excellence (NICE) in assessing the drug lenalidomide (Revlimid). A treatment for multiple myeloma (a condition underburdened with therapeutic options), this drug can undoubtedly prolong survival. But should the NHS pay for such benefit?

Potential recipients were in no doubt that it should; and who, in their position, wouldn't agree?

However, in October 2008 NICE issued a preliminary recommendation against the drug's use. In these circumstances it is very easy to dismiss rationers as faceless bureaucrats who play with people's lives: easy but wrong. Such a caricature bore no resemblance to Professor David Barnett, chairman of NICE's appraisal committee, who made an eloquent and sensitive case for matching NHS resources to circumstances. Nor did it fit Sophia Christie, chief executive of a primary care trust, who was unafraid to describe the distorting effect of providing costly end of life treatments at the expense of other priorities. One of *The Price of Life*'s many attractive features is its efforts to air and contextualise such views, as well as those of patients and their advocates. This balance is too often missing from public debate about healthcare resources.

It is very easy to dismiss rationers as faceless bureaucrats who play with people's lives: easy but wrong

That's not to say that rationers inevitably make the right choices. Yes, they may be proficient in the black arts of health economics; but this can't disguise the fact that their work is as much influenced by value judgments as by science. And even when it comes to evidence based methods, some of their key tools aren't beyond criticism.

An obvious example is the upper threshold that NICE has used for determining whether an intervention is cost effective (the threshold of £30 000 (€35 000; $49 000) per quality adjusted life year (QALY)). This limit is questionable, not least because it has remained unchanged over the years seemingly oblivious to inflation and other macroeconomic factors.

Yet it is also important to recognise that this widely known cut-off value has provided a transparent, transferable basis for decision making. It was the primary reason for NICE's interim recommendation against lenalidomide (the estimated cost of which was around £47 000 per QALY). To see footage of the appraisal committee as it reached this judgment was fascinating and another neat challenge to those who see only negatives in how NICE conducts its business.

Documentary maker Adam Wishart investigates rationing

Had the story ended there it would have been gripping enough, even without two developments that added a twist to events. One of these was the government's decision to change the criteria for assessing the affordability of treatments at the end of life. As a result NICE can go above the £30 000 threshold when considering such treatments (the assumption being that society may value the benefit of such interventions above that of other treatments). Also, the drug company offered to pay for treatment with lenalidomide once a patient had been taking it for two years, so reducing the projected cost of provision.

These two factors meant that when the appraisal committee discussed the drug again in January this year the drug was recommended (despite the revised estimated cost being £43 000 per QALY). It was close, though, with the committee initially voting nine for and nine against, and the recommendation being carried only on the casting vote of the chair.

Understandably this decision was welcomed enthusiastically by patients with myeloma—and, again, who could begrudge them the hope that lenalidomide brings?

But the uneasy tension remains between such provision and the wider needs of rationing. Indeed, the situation is arguably much worse, because NICE's new policy has introduced another level of arbitrariness into its deliberations. Is that really a price worth paying?

Ike Iheanacho is editor, *Drug and Therapeutics Bulletin* iiheanacho@bmjgroup.com

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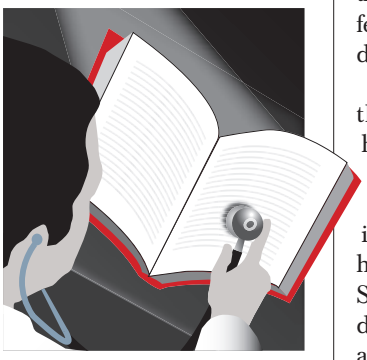
The end of civilisation

BETWEEN THE LINES
Theodore Dalrymple



"The civilization we have introduced has resulted in the country becoming so uncivilized that we have to inflict punishment that we would not have done when it was not at all civilized"

The lot of second-hand booksellers is not a happy one. The trade has nearly gone the way of cooperage or farriery. Customers are growing older and are not being replaced when they die; but many booksellers cannot retire as they would like, because their stock remains unsold. On the contrary it grows as they buy more books than they sell. They know, therefore, that they will die in harness, among the mould, the dust, and the silverfish that inhabit the drier parts of their establishments.

I bought a book from a bookseller for £4. He was delighted, almost triumphant. "I knew I would sell it one day," he said. He spoke as if the book were a puppy that needed a good home. "It's been on the shelf for 10 years, but I always knew someone would buy it."

What was the title that so vindicated his acumen? It was *The White Women's Protection Ordinance: Sexual Anxiety and Politics in Papua*, a subject of extreme specialist interest, I should imagine, by Amirah Inglis. (As I tell booksellers who mark their books "rare," purchasers are even rarer.) But I have long believed that enlightenment is to be sought in the most obscure places.

Extremely well written, this book recounts the agitation in Port Moresby in the 1920s for the protection of Australian women from the sexual advances of the Papuans, who, as primitive men, were thought to have but poor control over their impulses. (Papua was then a territory ruled by Australia.)

The white population was very small, and as writers such as Somerset Maugham, Stefan Zweig, and Graham Greene realised, such communities were like cultures of human nature in a petri dish. Passions were easily inflamed.

The author relates how a new doctor, Mathews by name, arrived in Port Moresby and quickly became a favourite of the women, who preferred him to the other doctors.

He fell foul of the establishment, however, and was barred from treating private patients in the government hospital. A nun, Sister Pascal, went down with malaria, and insisted on none other than Mathews as her doctor, and his partisans had a belligerent confrontation at the hospital with special constables sworn in to prevent him entering. The establishment won: soon afterwards Dr Mathews left.

The ordinance of the book's title provided for the death penalty for rape or attempted rape and for flogging up to three times, 50 strokes each, for lesser offences. Among the members of the territory's unelected legislative council was the chief medical officer, Dr W M Strong, who was also the government anthropologist. He moved unsuccessfully in the council to get the penalty for attempted rape reduced from death. He then tried unsuccessfully to move a reduction in the number of floggings and the number of strokes per flogging for lesser offences. His final ploy was to move that floggings ought to be in public, knowing that if the council accepted this proposal the whole ordinance, which he opposed, would be thrown out by the Australian government.

His final speech was a little gem of irony: "When [Papua] was an uncivilized country these punishments were not needed. The civilization we have introduced has resulted in the country becoming so uncivilized that we have to inflict punishment that we would not have done when it was not at all civilized."

Theodore Dalrymple writer and retired doctor

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MEDICAL CLASSICS

Life & Death

Computer game launched in 1988 by the Software Toolworks

I was 11 years old when I performed my first surgical operation. My hands shook, my incision was a zigzag, and I forgot to sterilise the skin. "Isn't that the chief of surgery coming in?" asked my assistant—and then the screen froze and I was bundled into a lecture theatre and berated on the dangers of infection to which I had exposed my patient. This was *Life & Death*, a computer game featuring reasonably realistic diagnosis and surgery.

The player assumes the role of a surgical resident in a fictional hospital and is presented with an array of patients with acute abdominal problems. After reviewing a patient's chart, the player can conduct an abdominal examination by clicking over each quadrant with the mouse. Some patients were globally tender: these tended to get a diagnosis of "intestinal gas" and were discharged. Those patients with right lower quadrant pain could, after undergoing abdominal radiography, be divided into those with kidney stones, who were turfed to urology, and those with likely appendicitis. This is where the game became truly interesting, as the player could then perform an appendectomy.

In common with most US medical dramas the surgeon was also largely responsible for the anaesthetic—getting the patient to sleep was as simple as turning on the gas. Arrhythmias would occasionally appear on the "EKG" and require prompt treatment with atropine or lidocaine; choosing the incorrect drug led to a trip to the morgue to view your former patient, while the Death March beeped out of the computer's tinny speaker.

The surgery itself, despite the use of low resolution, four colour graphics, was fairly realistic, from the division of the muscle layers to the elevation of the appendix and ligation of the mesoappendix. It was also extremely difficult to perform the operation flawlessly, something the game demanded before the second operation—emergency repair of a leaking abdominal aortic aneurysm—became available.

The game, although now dated, was revolutionary for its time. It remains one of the few games to feature realistic surgery; this realism extended to its copy protection system, which involved having to answer a pager call by finding the correct telephone number from a list. The box also included a pair of surgical gloves and a face mask. The harsh screams of "Ow! Ouch!" from the patients involved creative use of the PC's audio speaker, normally only capable of beeps.

Did *Life & Death* directly inform my decision to become a doctor? I suspect not; however, I did enter medical school with a rudimentary knowledge of the anatomy of the abdominal wall, and I was aware that atropine could be used to treat bradyarrhythmias. Most of the medical computer games of recent years have used fictional medical conditions and operations. These days I suspect that such a game would have to come plastered in warnings: "Do not try this at home."

Roy Williamson specialist registrar in anaesthesia, Leighton Hospital, Crewe **roymwilliamson@msn.com**

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Getting on message

FROM THE FRONTLINE
Des Spence

Concern has been cascading through medical providers recently about the repeated use of meaningless jargon in the ever divergent but occasionally convergent NHS lexicon. In my position as a medical communicator I was included in the loop when a memo was leaked from the office of the health minister Ara Darzi (allegedly), under the heading "Re: The use of "note pads" in the NHS and allied service based agencies." It read:

Hi, all care providers, managers of care, care managers, professions allied to care providers, carers' carers, and stakeholders whose care is in our care. (And a big shout to all those service users who know me.)

We report the findings from a quality based review, with a strong strategic overview, on the use of "note pads" across all service user interfaces. This involved extensive consultation with focus groups and key stakeholders at blue sky thinking events (previously erroneously known as brain storming). This quality assured activity has precipitated some heavy idea showers, allowing opinion leaders to generate a national framework of joined-up thinking. This will take this important quality agenda forward. A 1000 page report is available to cascade to all relevant stakeholders.

The concentric themes underpinning this review are of confidentiality. Notes have been found on the visual interface devices on computers and writing workstations throughout the NHS work space. Although no actual breach of confidentiality has been reported, the independent external consultants reported that note pads "present a clear and present danger" to the NHS, and therefore there is an overarching responsibility to protect service users from scribbled messages in felt tip pen. Accordingly all types of note pads will be phased out in the near time continuum. A validated algorithm is also attached to aid this process going forward.

This modernising framework must deliver a paradigm shift in the use of note pads. Care provider leaders must employ all their influencing and leverage talents to win the hearts and minds of the early adopter. A holistic cradle to grave approach is needed, with ownership being key, and with a 360 degree rethink of the old think. All remaining note pads must be handed over in the next four week "note pad armistice" to be shredded by a facilitator (who is currently undergoing specialist training) and who will sign off and complete the audit trail.

(Please note that the NHS's email system blocks all attachments, so glossy, sustainable, wood based hard copies will be sent directly to everyone's waste recycling receptacles.)

The *BMJ*'s lawyers have insisted that I make it clear that this is a spoof.

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

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Health risks of volunteering

IN AND OUT OF HOSPITAL
James Owen Drife

The urge to do voluntary work overseas is strongest at the extremes of medical life. If, like me, you are an ageing academic, think carefully. Your health is precious, and there are several hazards that aren't mentioned on the Foreign Office website.

Physical violence: The Foreign Office advises you to be sensible and avoid high risk areas, but that isn't always possible. In South Kensington, for example, the desire to throttle someone can become overwhelming as you wait for hours in the visa section of the embassy. Whom to attack first? The couriers ahead of you with their bagfuls of passports? Or the football fans behind, with their obscenity filled discussion of the upcoming away match?

Hyperpyrexia: If you're going somewhere cold you put on warm underwear, forgetting that you're not flying direct. Changing planes involves a sprint along heated walkways in woolly hat and quilted jacket. When you arrive at the gate, bathed in sweat, you are x rayed again and your water bottle is confiscated.

Thromboembolism: As a temporary adviser you will of course be travelling economy class. Remember how it was? Bolt upright at the back of the plane, watching a steward taking forever to dispense teensy weensy drinks in the distance. Next time (if you survive) tell your international sponsor that you don't care if adequate legroom means more expense and a bigger carbon footprint. In the humanitarian jungle, what counts is survival.

Hypochondria: Whatever the clock says, your bowel remains on Greenwich Mean Time. Alone in a hotel room with your laptop and a dicky wifi connection, you become aware of pains, paraesthesias, and pigmented lesions you never noticed before. So this is it. The NHS is thousands of miles away, and here you are, terminally ill. Will you make it to the end of the workshop? Or will there be some corner of a foreign seminar room that is forever England?

Shame: No matter where you go, everyone has heard about the sillier aspects of life in Britain. Don't ask your medical hosts if they've visited London. They will smile regretfully and explain that they tried for months to obtain a UK visitor's visa before deciding not to bother. Your few hours in that Kensington basement fall into perspective. What a paranoid and xenophobic nation we are. Shame won't kill you, but it's still a nasty feeling.

James Owen Drife is a retired professor of obstetrics and gynaecology, Leeds J.O.Drife@leeds.ac.uk

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