Pathology after Alder Hey, p 298

Rationing: it would be NICE to consider patients' views

PERSONAL VIEW **Jane Speight, Matt Reaney**

Cost effectiveness is arguably the most influential factor in the provision of health care in the 21st century. Health technology assessments, performed by organisations such as the UK National Institute for Health and Clinical Excellence (NICE), can make or break a drug—and, consequently, make or break the lives of many people who may benefit from that drug—but NICE is failing to take patients' opinions into consideration when rationing healthcare interventions.

Cost effectiveness analysis compares the costs of an intervention with its benefits to health. The aim is to see whether or not it is worth spending money on this intervention, to maximise health benefits within a resource limited health service.

NICE's appraisals are based primarily on a type of cost effectiveness analysis called cost utility analysis, in which the benefits are expressed in terms of the quality and quantity of life delivered by a given treatment when it is compared to the alternatives—quality adjusted life years (QALYs). NICE's unofficial cost effectiveness threshold range for funding a treatment is £20 000 (€22 000; $31 000) to £30 000 per QALY, although this figure has no basis in either theory or evidence, and you could argue that it is too low when you consider the wider personal and social costs of incapacity. Indeed, research currently being considered by NICE indicates that patients believe that this threshold should range from £35 000 to £70 000.

To paraphrase Albert Einstein, do we really value only the things we can count? Or should we be counting the things that we value?

Cost effectiveness is only one of several criteria that need to be considered when health care is rationed; others include issues of equity, needs, and priorities. Although NICE does not accept or reject treatments on the basis of cost effectiveness alone, it is undoubtedly a major deciding factor. The system has two main problems: it accounts only for costs to the NHS, and it doesn't consider the patients' perspective. In fact NICE prefers that cost utility analyses use utilities deriving from general population values rather than from patients who have direct experience of the particular medical condition.

Pfizer's inhaled insulin preparation Exubera was potentially one of the biggest breakthroughs for people with diabetes since insulin was first isolated in 1921-2. Unfortunately, exogenous insulin that didn't need to be injected was more expensive and no more "effective" at improving health than injected, short acting insulin, so NICE decided that it "was not an effective use of National Health Service resources."

Whatever any of us may think of NICE, it has brought the process of healthcare rationing out into the open. For many years that process had gone largely unchecked behind closed doors, with decisions made on a case by case basis in a "postcode lottery." At least NICE has tried to ensure that such decisions are transparent, independent, and evidence based.

As healthcare resources are limited, someone (or some organisation) has to place a value on health and decide which treatments can be afforded and for whom. The problem comes in defining "health" and deciding whether other factors can and should be part of the cost effectiveness equation. In the case of Exubera the treatment doesn't necessarily improve health (or certainly not in the way it is measured in health technology assessments), but it may improve quality of life and other patient reported outcomes (various outcomes that can be provided only by the patient, such as symptom severity and bothersomeness, perception of daily functioning, feelings of wellbeing, and satisfaction with treatment. NICE's principal choice of generic health status questionnaires, including the EuroQoL 5-Dimension questionnaire (EQ-5D), are unsuitable for measuring the quality of someone's life (a complex construct distinct from health status) and ignore a host of other outcomes of importance to individual patients.

The EQ-5D is often used to provide data on QALYs in NICE's submissions, as it is weighted to the social preferences of the UK population. However, this generic measure evaluates only five dimensions of health status: mobility, self care, usual activities, pain and discomfort, and anxiety and depression. It does not measure the quality of someone's life in a way that is sensitive to a variety of conditions or that allows individuals to indicate what is important to them personally and how their illness affects this. Conditions such as diabetes and breast cancer do not necessarily result in major incapacity (as measured by the EQ-5D), but the impairments that are not measured can be substantial. To paraphrase Albert Einstein, do we really value only the things we can count? Or should we be counting the things that we value? Other patient reported outcomes have been acknowledged as important to drug regulators but are not currently considered by NICE in making decisions on cost effectiveness, despite clear pathways from treatment to cost that incorporate such factors.

In an attempt to speed up the drug approval process, the government recently outlined plans dictating that NHS trusts will no longer be able to refuse to fund drugs on the basis of cost alone. With much recent controversy over the availability of certain cancer drugs, this could be interpreted as long overdue, but it may also seem highly inappropriate in a resource limited NHS. However, it is also clear that the current system of evaluating cost effectiveness in isolation is unsuitable. To maximise the health benefits of treatments available on the NHS, we must consider a condition's effects on the individual's health and on related outcomes. Although the direct costs of some treatments may place a huge burden on society, rationing such treatments places even greater (indirect) costs on individuals, their carers, and the wider population.

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Competing interests: JS and MR work for AHP Research, an independent health research company that provides consultancy, contract research, and training services to the drug industry

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See FEATURES, p 266, HEAD TO HEAD, p 268, ANALYSIS, p 271

REVIEW OF THE WEEK

Pathologists are people too

Pathologists have long been portrayed as "doctors of death." **Debra Milne** asks whether a book can do anything to help make society look on them more favourably

Pathologists have an image problem. We are either social misfits or forensic experts but not ordinary people. At parties I find the most typical reactions to be morbid fascination or politely concealed revulsion. A friend went to enormous lengths to hide his occupation, but eventually the stand-up comedian Ross Noble wheedled it out of him. Paul (not his real name) will never sit in the front row again.

So it was with considerable self interest that I picked up *A Matter of Life and Death*. This book was commissioned by the Pathological Society of Great Britain and Ireland in the wake of the organ retention scandal at Alder Hey Children's Hospital and the resulting negative media portrayal of pathologists as "doctors of death" lurking in the shadowy corners of NHS hospitals. Would this book make society look on pathologists more favourably? Consisting almost entirely of conversations (questions and answers) with pathologists, the format is particularly suited to portraying its subjects sympathetically. The book explores the role of the pathologist and discusses sensitively and in depth such issues as the value of postmortem examinations, tissue retention, and forensic pathology, including the documentation of war crimes and evidence of child abuse. The pathologists that Sue Armstrong has chosen have lived through some of the most momentous political and social changes of the second half of the 20th century, and their individual accounts of dealing with and escaping from oppressive regimes, such as South Africa under apartheid and 1970s Argentina, make fascinating reading.

Although the book's target audience is the general public, it provides valuable insights into the teaching of pathology and its relevance to clinical practice. The importance of pathology as a foundation for understanding medicine in general and for providing the context of much basic scientific research is a recurring theme, as is the lack of pathology teaching in current medical curriculums. Several of the interviewees chose pathology as a career because of the influence of inspirational teachers. But how can today's medical students be inspired to be the pathologists of tomorrow when so little pathology is taught? Some will complete their entire training without meeting a single pathologist. This book may well provide more contact with diagnostic pathologists than they will ever receive as undergraduates.

PHIL NOBLE/PA ARCHIVE/PA PHOTOS

How can pathology counteract the negative media portrayal that has followed scandals such as that at Alder Hey hospital?

The book's contributors also provide useful insights and moral support for practising pathologists, weighed down by rising workloads, multidisciplinary team commitments and diktats from the "specialisation police" (you know who you are). Then there's the bureaucracy associated with Human Tissue Authority licensing, research and ethics committees, and laboratory accreditation. One contributor, Juan Rosai, talks about his enthusiasm for diagnostic pathology, reminding us why we were attracted to it in the first place. He explains how microscopic images can be beautiful and that the core of the diagnostic pathologist's skill will continue to be the recognition and appreciation of complex visual images.

Professor Rosai also gives a historical view of pathology and its contribution to the development of clinical medicine. Pathology emerged in Renaissance Italy, where it was realised that a familiarity with human anatomy was needed to understand disease processes. This coincided with appreciation of the human body among artists, such as Leonardo da Vinci. Physicians and artists of the time worked side by side dissecting corpses in church crypts. The saintly relics so common in Italy must surely represent the earliest examples of officially sanctioned organ retention?

This unusual book draws the reader into the pathologist's world. It succeeds in showing how the study of pathology and the use of stored tissues are an essential part of clinical medicine, basic research, and forensic science. The subjects are engaging and sympathetic, but they are certainly not ordinary people, nor are they typical pathologists. However, their concerns about the practice of pathology and the restrictions placed on it will be shared by hundreds of pathologists working in hospitals and universities across Britain. It is unlikely that *A Matter of Life and Death* will do much to counteract the image of pathologists. But it will be of great use to those who seek a broader, more informed view of pathology and its practitioners.

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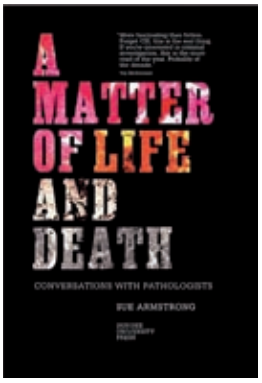


A Matter of Life and Death: Conversations with Pathologists

Sue Armstrong

Dundee University Press, £12.99, pp 240

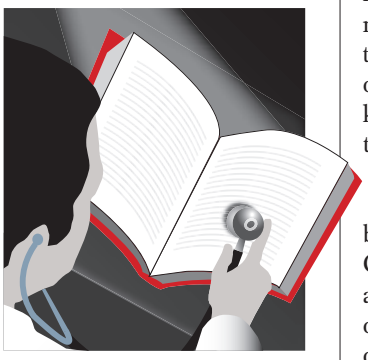
ISBN 978 1845860509

Rating: ★★★★

The saintly relics so common in Italy must surely represent the earliest examples of officially sanctioned organ retention?

A book of quiet heroism

BETWEEN THE LINES
Theodore Dalrymple



Dr Sidibe finishes by recounting the last illnesses of two people 10 years later, one who was tortured and one a torturer. The first died in peace and tranquillity; the other was torn between fear and aggression

The worst dictatorships try to destroy not only people but memory itself; and among the worst dictatorships in a century full of dictatorships was that of Ahmed Sékou Touré, president of the West African state of Guinea for more than a quarter of the 20th century. A third of a population fled his rule, and many thousands were tortured and killed, victims of the dictator's paranoia.

A Guinean doctor, Mandiouf Mauro Sidibe, has recently published a book, *La fin de Sékou Touré* (*The End of Sékou Touré*), which tries to preserve an aspect of that dark period of his country's history. He has kept and transcribed the radio commentary that accompanied the dictator's state funeral, which was attended by many heads of state and government. At this time sycophancy was still the safest policy for Guineans, a sycophancy so extravagant that it was possible only in conditions of extreme terror.

The funeral oration in the stadium given by his successor would have been comic if it were not for the fact that scarcely a family in the country had not lost someone to the insatiable lust for power of the Great Departed, as he was known for a time.

"Eternal glory to President Ahmed Sékou Touré! [the funeral oration began] Eternal glory to President Ahmed Sékou Touré! Eternal glory to President Ahmed Sékou Touré!"

It continued: "Heroic people of Guinea, Ahmed Sékou Touré, to whom today you render your last homage in serenity, order, discipline, and cleanliness of body, heart, and mind, is going to do what he will never do again, take the tour of honour round the stadium, in the atmosphere of the great popular demonstrations which he galvanised as soon as he entered the crowd, amidst the prolonged ovations of his militants, all enthusiasts, giving rise or responding to the very communicative smile of the Supreme Director of the Revolution and the movement, so familiar to the people of Guinea, or to the white handkerchief from which the image of President Ahmed Sékou Touré is inseparable . . . Where, then, Comrade President, are your smile, your optimism that every one of us loved, that remedy for so many ills? Where, then, is your white handkerchief, Comrade President? Wave it to give us back hope."

A week after the death of the "universal genius and giant of history mourned by the people of the whole world" there was a coup d'état. Radio broadcasts then spoke of his ruthless dictatorship, vowed to rid the country of feudalism, corruption, and the abuse of power, and promised to release all political prisoners.

Sékou Touré had left the country in such a state that he himself was a victim of it, Dr Sidibe tells us. During his final illness there was no equipment or drugs in the country with which to treat him. He was flown to the Cleveland Clinic, but he died soon after arrival. Dr Sidibe quotes an African proverb: "When you dig your enemy's grave, do not dig it too deep, or you risk falling into it yourself."

Dr Sidibe finishes his book by recounting the last illnesses that he witnessed of two people 10 years later, one who was tortured and one who was a torturer during the dictatorship. The first died in peace and tranquillity; the other was torn between fear and aggression and bit a nurse looking after him. Fearing that the staff of the hospital would take revenge on him, he left for a foreign country where no one knew him. There he died. Dr Sidibe's book is one of quiet heroism.

Theodore Dalrymple is a writer and retired doctor

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MEDICAL CLASSICS

The Apologie and Treatise of Ambroise Paré

Edited by Geoffrey Keynes, London, 1951

I first read this brilliant translation in its year of publication, 1951. I had just passed my FRCS examination and was completing my two years of national service. I was enthralled. I have dipped into its pages many times over the years, and I have learnt much from my surgical hero.

Ambroise Paré (1510-90) trained as a barber surgeon and spent three or four years as a resident surgeon in that great repository of pathology, the Hôtel-Dieu, in Paris. Aged 26 he began his career in military surgery as a surgeon to the mareschal de Montejan, commander of the French infantry in the campaign in Turin.

This slim book, translated from Paré's medieval French, is in two parts. The first, the Apologie, which was written in 1585, defends Paré's innovation of ligation of the major vessels in limb amputation. It also describes Paré's management of war wounds in his many military campaigns. The book's second half comprises a vivid selection of Paré's other writings, including those on aneurysms, hernias, fractures, cataracts, and lithotomy for bladder stone; there is also an account of his clinical trial of the use of a very valuable bezoar, which had been presented to the Emperor Charles as a specific cure for poisoning. Paré proved that, although expensive, it was quite useless.

Paré's books reveal him as a brilliant innovator. The military surgeons of the 16th century were appalled by the havoc produced by gunshot wounds, in comparison with the lacerated wounds produced by swords, arrows, and spears. The wounds produced by gunpowder became horribly gangrenous and were usually rapidly fatal. We now know, of course, that this was due to clostridial infection of the necrotic tissues—gas gangrene. In those days the phenomenon was ascribed to poisoning by the gunpowder; the remedy: to destroy the poison by cauterising the wound or pouring in boiling oil.

Paré: brilliant innovator

Ambroise recalls how, in his first battle, he exhausted his supply of boiling oil and resorted to a placebo of egg yolk and rose oil. He describes what was, in fact, perhaps the first controlled clinical trial. Unable to sleep, he visited his patients at first light of day, expecting to see his "control group" dead or dying of poison. To his surprise they were all well and rested, while the conventionally treated patients were all "feverish with great pain and swelling." Paré, this young inexperienced surgeon, "then resolved never again so cruelly to burn the poor wounded by gunshot." He went on to show that ligation of major blood vessels could be used in major amputations rather than the advised—and terrible—technique of haemostasis through red hot cautery.

Paré was essentially a kind and humble man. In his first campaign he ends his description of the treatment of a bullet wound of the ankle with perhaps his most famous phrase: "I dressed the wound, and God healed him."

Harold Ellis, emeritus professor of surgery, London

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Everyone hurts

FROM THE FRONTLINE
Des Spence

My head lolled, and the ash from my cigarette flicked onto the carpet tiles of the hospital's doctors' room. My energy and enthusiasm were sucked grey and frail and were about to crumble into dust. This wasn't what I had signed up for. There was no induction course, just "See one, do one, teach one." Mistakes were endemic. The names on the forms were wrong, wrong investigations were ordered, wrong drugs were prescribed, wrong fluids were written up, the wrong procedures were done. Sociopathic seniors appeared at random. The once coveted pager was now the bleeping instrument of my insanity. The zip of the curtain at death was a release for all concerned. All residents were drowning in an ocean of inexperience. We were supposed to care, but caring didn't seem possible; we were sustained only by the darkest humour and a vital camaraderie. But the worst thing was my lack of control and my collusion in the depersonalised medical processing plant. Like everyone, I felt like leaving.

This February many foundation doctors will feel the same way. What does this spoilt generation have to complain about? Shorter hours, better pay, induction courses, mentoring, supervision—they've never it had so good. But such an attitude is merely the foolishness of the old. Every generation is burdened by different challenges, and they are no less irksome. Now there are miserable shifts, unrecognised overtime, confused care, broken firms, a merry go round of political initiatives, and a target driven and "caring" system of indifference. Professionalism is now a mistrusted monster, but at the same time boundaries of professional care and responsibility are cast way beyond what we can deliver. Welcome to the reality of being a doctor.

But anger is better than despair, and we must be wary of the real monster: bitterness. Even in our darkest time hope is revealed in the light cast down from our profession's founding principles. To speak for those with no voice, to stand while others give way, to offer friendship even when none is offered in return, to know when to try but also when to let go, to be aware that clever is no substitute for kind and that the only fool is the hopeless fool. And to do what is right, whatever the cost. Indeed, those who feel they are most on the outside will become the core of the profession. I apologise if this is just condescending sentimentality. But the torch of medicine that passes to each new generation upholds the profession and in the end changes the system. Never forget how you feel now, work hard, but most of all just hold on.

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Fireworks in Iran

IN AND OUT OF HOSPITAL
James Owen Drife

When you say you're going to Tehran in December, your colleagues look worried. This means someone else playing Santa at the Christmas party. And Iran has an image problem. No one actually says "axis of evil," but everyone thinks hostages, and some people just don't like the name. Why can't it still be called Persia?

My visa arrived in the nick of time after increasingly terse emails to and from WHO. As we landed at Imam Khomeini airport the stewardesses covered their hair. I expected hassle from the passport officer, but she almost smiled. Everyone, I found, had a gentle sense of humour under a veneer of caution. Veils were otherwise infrequent.

Anti-Western feeling was notable for its absence. The hospitals have an American feel to them, and doctors rely on standard US textbooks. Dollars (in cash) are the currency for visitors. Television has endless Hollywood movies. Yes, CNN was jammed, at least in my hotel, but there's still the radio, where the Voice of America competes successfully with the BBC.

Having missed the news from Baghdad of the press conference shoe attack, I was surprised to see a chuckling television reporter organising a shoe throwing competition in the street. One almost hit an elderly, burkha clad woman. The crew rushed over to apologise, saying they had mistaken her for President Bush. She laughed and laughed.

The three wise men came from these parts, but Iran's history of learning goes back long before that. These days the country's reorganised primary care system has to cope with a couple of million refugees from its eastern and western neighbours. The local obstetricians, all women, murmur unhappily about the fate awaiting Afghan baby girls once they are taken back home.

Near the end of my stay an explosion went off outside my window. My first thought was that this must be the latest manifestation of Western foreign policy. It turned out to be fireworks celebrating the Eid al Adha festival. Sipping orange juice and watching starbursts on the skyline, I felt as if I were back in Leeds, on call on millennium night.

It was snowing when I left for the airport, wary about returning to all the booze of our own religious festival. My medical host, a good Muslim, said she had just given in to her children's pleas for a Christmas tree. "Axis of evil," my foot.

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