

A good death—but no thanks to the NHS

PERSONAL VIEW **Paula Newton**

A year ago my frail 77 year old father had his renal function checked, on a Friday, by his GP. It was not unreasonable to do such a check, as he had severe cardiac failure, a recurrently infected replacement aortic aneurysm graft, lobectomy for a squamous cell carcinoma (secondary to smoking a pipe since university), and osteoporosis causing severe back pain, to name but a few of his pathologies. Clearly he was living on borrowed time. Despite all this he had enjoyed a weekend away with his wife in the New Forest less than a week before and had a more than reasonable quality of life.

His greatest fear was hospital admission; after all he had been there more times than he could count already, and as each weekend approached the risk loomed of an out of hours admission from which his own GP's wisdom would be absent. If it was a bank holiday weekend then his anxiety levels rose even higher. As I live 130 km away I suggested that a summary of his complex medical condition, and a written statement of his desire to avoid admission, could be kept with him to enable on-call doctors to make an "informed" decision. He really did not want any more heroics; he simply wanted to be at home.

At 7 pm that evening, as my parents enjoyed an early evening glass of wine together, the phone rang and a GP out of hours service told him that his potassium concentration had been rung through to them and that admission was essential. He refused an ambulance, and despite his protests my mother took him to the medical admissions unit, believing this to be the only option. No doctor visited to discuss "options" or "choice," and rather

than being assessed for admission he was admitted to be assessed. His worst fear was to be realised, and he was never to see his home again.

Within 48 hours my father's potassium concentration had fallen, but unfortunately by this time he had been catheterised, not mobilised, and had stopped eating. The family was told that he was a sick man—hardly news—but it was clear that he was sicker now than he had been before admission. His back pain was excruciating, and analgesia was inadequate. I asked for analgesia, but the staff nurse was "too busy" and "having a bad day." We were sorry for her troubles, but this was not our primary concern.

Not much happens at the weekend on an acute ward, and all that occurred was deterioration. We took food in to tempt him and fetched bowls of water to help him wash and shave; nursing care did not stretch anything like that far. A request for a prescription of fentanyl patches, because he was vomiting all medication and in severe pain, took two days to organise. If I had known there would be such a delay I would have sorted the prescription myself and stuck the patches on—the nurses would have been none the wiser. Pity the "ordinary" patient with no medical family to be their advocate. My father's GP was out of the picture: secondary care was in charge. Discharge home with support seemed to be an alien concept.

I was so fearful that my father would die inadequately cared for in an acute hospital bed that I became more assertive. The cardiologist who had treated my father privately in the past agreed to supervise his care in a BUPA

private hospital locally. The family would pay if the insurance would not cover it; he just had to be moved. Within 48 hours of transfer he died peacefully and comfortably in a quiet room, having received hands-on basic nursing care and appropriate analgesia. BUPA health insurance collected the bill. At the end of the day it was a "good death," but no thanks to the NHS, which wasted resources keeping a terminally ill man in an acute bed, provided inadequate care, and did not meet any of his basic needs. Without a medical daughter he would have had a terrible death, though not an exceptional or

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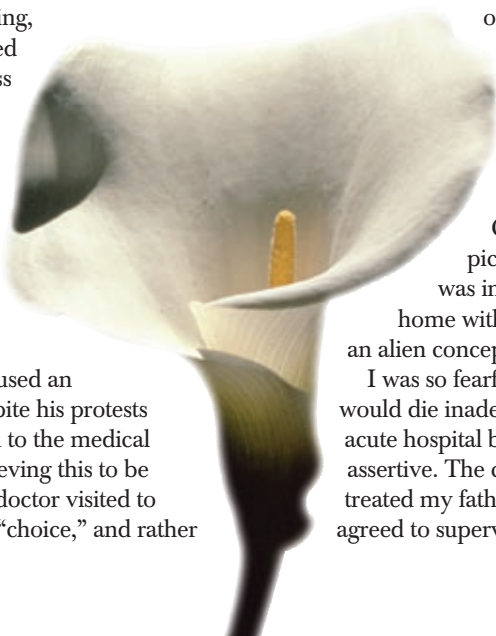
unusual one. The appropriate, cheaper "patient pathway" does not require someone with qualifications in service redesign to fathom out. It probably all went wrong when the "decision" to admit was taken without due thought to the

desirability and consequences.

On 1 November 2005 on an unseasonably sunny day we gave my father the send-off he deserved and would have appreciated. I wrote to thank the consultant for enabling him to die in dignity in the private sector. I tried to write to the NHS hospital to express concern about his care but could not find the words. A year on I just about could, but it is old news to them now. On my return home I did what would have been unthinkable for me a year earlier: I rang BUPA and took advantage of their scheme for doctors and their families. I could no longer gamble with my family's health in the NHS.

Many of you reading this can help to enable this scenario to be avoided in our acute hospitals, especially in the brave new world of practice based commissioning. I challenge you to join me and give it a go, for the sake of all our patients and indeed our own families. Maybe we should also try to avoid requesting unnecessary investigations late in the day—and especially not on a Friday.

Paula Newton is a general practitioner, Papworth Surgery, Cambridge dp31v@yahoo.co.uk



The greatest novel
about medical
research? p 539



REVIEW OF THE WEEK

Making sense of madness

A book that challenges the whole spectrum of psychiatric thinking and practice offers some fresh and modern criticism but falls down on alternative approaches, finds **Iain McClure**

“Let wisdom guide”—what message did the Royal College of Psychiatrists intend by choosing this motto for its coat of arms? “Wisdom” means the ability to make the right use of knowledge, and what constitutes genuine psychiatric knowledge is the main subject of this disturbing (in the positive sense) and edifying little book.

In 12 chapters, 10 contributors challenge the whole spectrum of current psychiatric thinking and practice. The dominance of biomedical psychiatry (which has solidified over the last 50 years) as well as (at the other end of the spectrum) the evolutionary stages of psychotherapy are equally scrutinised. In so doing, *Critical Psychiatry* claims to expose a lack of evidence justifying biological psychiatry’s predominance, rolls in big guns like Kant and Foucault to rough up psychotherapy, and explores the increasing influence of the pharmaceutical industry on psychiatry’s development. Bracken and Thomas’s chapter, explaining how the psychiatric profession was initially reluctant to respond to the overtures of the British government (when the latter sought to develop a new Mental Health Act in the early 20th century) is particularly enlightening. Ensuing decades have witnessed increasing interdependence of government and psychiatry, regarding the management of severe mental illness (the difficult birth of England’s new Mental Health Act), and this chapter alone is essential reading for any trainee psychiatrist.

The book makes several points. It argues that mental illness is a psychological, not a biological, process and that biological psychiatry is excessively reductionist (thereby removing a patient’s free will). It is critical of psychotherapy, describing it as “an exercise of power” whose theories erase all possible differences between people, while elevating its practitioners into the sole arbiters of internal human experience. It then propounds the stimulating argument that psychiatry is a byproduct of Enlightenment thinking—that reason is all—and that we need to adjust such thinking for our emerging, post-Enlightenment era. It also argues that psychiatry’s prevalent subscription to the evidence based rationale needs to be countered by an equal and opposing “values based” approach and that the social dynamics of care (such as the user perspective) must have priority in psychiatric management.

My main criticism of this book is that none of its

contributors clearly define what they mean by “psychological.” At least biopsychiatry attempts to explain what mental illness is (in the—admittedly flawed—DSM-IV and ICD-10 diagnostic systems) and what may cause its manifestations (for example, its claim to have discovered evidence that patients with schizophrenia have associated brain atrophy). Psychotherapies (from psychoanalysis to cognitive behavioural therapy) have ample theoretical foundations, some of which are based on valid scientific observation. *Critical Psychiatry* provides arguments that claim to refute such evidence and approaches, but then fails to offer anything convincing enough to replace them. Simply stating that mental illness is a psychological process seems insufficient.

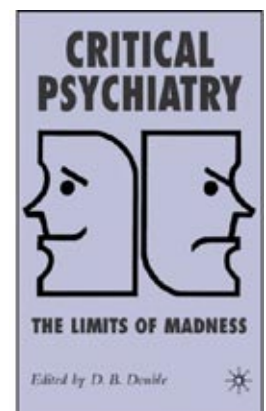
In view of the arguments that the book puts forward, a key question inevitably arises—what does a “critical psychiatrist” do differently from the non-critical psychiatrist? Would critical psychiatric assessment and management of someone with autism, or significant intellectual disability (psychiatric conditions that are commonly regarded as being brain based), or a psychotic patient, be different? Taking things to an extreme, imagine that a psychotic patient has, while mad, murdered her mother and later recovers. How would the critical psychiatrist explain this patient’s aberrant behaviour that was totally out of her (pre-morbid) character? As he presumably couldn’t reassure her, due to his convictions, that her behaviour was caused, in some way, by brain disorder, what explanation could he give that would possibly salve her conscience?

These questions reflect mainstream psychiatry at its most challenging, and critical psychiatry needs to address such issues meaningfully, if it wants to take professional consensus with it; however, such issues are not explored by this book.

Despite these reservations, I recommend *Critical Psychiatry* as a challenging read for anyone interested in mental disorder, even as a reminder of our ethical obligation to clearly define the knowledge that we claim for our discipline and its scientific basis.

Iain McClure is consultant child and adolescent psychiatrist, Vale of Leven Hospital, Alexandria G83 OUA
imcclure@nhs.net

Competing interests: IM was on the Critical Psychiatry Network emailing list (www.criticalpsychiatry.co.uk) from 2003 to mid-2006.



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What does a “critical psychiatrist” do differently from the non-critical psychiatrist?

The inverse care law has had its day

FROM THE
FRONTLINE
Des Spence



Half way through my sixth year at school I received an unconditional acceptance from university. My last few months were spent playing cards, dodging class, sharing cigarettes in the toilets, and attempting to blow up the chemistry equipment. A better preparation for university I could not have had. .

I did learn one thing in those last six months: the inverse square law. This relates to decay in the intensity of electromagnetic waves, so that at twice the distance one receives a quarter the dose. At a certain point, therefore, changes in the power have little impact on the dose of light received. This seemingly irrelevant law of physics actually applies to medicine: beyond a certain point, more resources have a negligible impact on health. Think UK versus USA.

We have another irrefutable medical law: the inverse care law. “The availability of good medical care tends to vary inversely with the need for the population served”—that is, affluent people get better health care than poor people despite being in less need of it. It was Julian Tudor Hart who coined this idea, and a generation of public health consultants have enjoyed surfing the waves caused by his observation. But is it time to question one of the foundations of modern medicine?

The Western world has changed. Absolute poverty has long gone and been replaced by relative poverty. The

most deprived people still have the shortest life span, but the solution to this has nothing to do with medical care and much to do with social issues. The impotence of modern medicine to deliver absolute health improvement is not all that is at issue, though. The reality is that the inverse care law has been turned upside down, with affluent people having worse relative health.

The affluent politely queue for screening that they will never benefit from in a score of lifetimes but are guaranteed overdiagnosis and needless interventions. The sheepdogs of fear and profit herd them into the pens of “pre” diseases (non-disease), restricting their lifestyle unnecessarily, so they are shorn of any enjoyment in life. Cold and bleating, they still gulp down the fix of poly-medication, again oblivious to the infinitesimal benefit to their health. In the grey drizzle of this existence they fail to see that all this intervention is a leap of faith with scarce long term data, especially in low risk herds. The less affluent graze on the hills above the pens, exposed to the elements but warm and above all else free.

Iatrogenic morbidity poses the greatest threat to health in the West. The inverse care law has run its course. Young public health wannabes might consider arguing that we should cap health spending, for the sake of the ailing affluent.

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

Best wishes for your incurable illness

OUTSIDE THE BOX
Trisha Greenhalgh



“Get well soon” is a greeting from a bygone era, in which illness was generally acute and self limiting. These days, those of us on the shady side of 40 are as likely as not to have at least one disease that will not go away, and those over 65 have an average of three. A rising stack of policy documents seeking to address the needs of people who are never going to get better emphasises self efficacy, concordance, expert patienthood, peer support, and personal care plans, while professionals are taught to hang loose, applaud self management, and focus their efforts on the few who have advanced disease and rare complications.

The ill are no longer called “patients,” since this term aligns with an outdated view of the sick role first proposed by Talcott Parsons, in which we took to our beds and exchanged our normal

social duties for the attention of our relatives and the professional services of a physician. Society has moved on. The discourse is now all about accommodating the “ill” individual into a flexible and enabling society.

You know all this. It’s been going on for a good 15 years. It is surprising, then, that it has taken until now for an entrepreneur to come up with a set of greeting cards called “Journeys” designed for people whose most optimistic prognosis is gradual but inexorable deterioration.

Have you got a friend who has been diagnosed with multiple sclerosis? Why not send them a card with “Don’t give up ... you’re not alone. Don’t stop believing ... so many people care. Don’t ever forget how strong you really are ...” Or a colleague struggling with a parent with dementia who may

like to hear: “Watching a parent change can be difficult. Where once stood a tower of strength, there is now a person who needs your care.” Perhaps your friend would benefit from a bumper sticker saying “If you’re handed it you can handle it” or the generic pick-me-up “Don’t give up hope, and it won’t give up on you.”

Hallmark offer their new range of greeting cards as part of “the new normal.” It is, of course, both an idea whose time had come and an innovative way of cashing in on human misery. But if it was OK in the 20th century to make money out of “get well soon,” surely it’s OK in the 21st to help people say, “Hang in there brother/sister.”

Trisha Greenhalgh is professor of primary health care, University College London p.greenhalgh@pcps.ucl.ac.uk

A novel approach to typhus

One of the most famous medical students in all literature is Bazarov, the young nihilist in Turgenev's *Fathers and Sons*. A forerunner of the revolutionary class in Russia, if not of the revolution itself, he accepts nothing, questions everything, and believes with religious intensity in the ability of the natural sciences to answer all questions. He falls in love, and begins to glimpse the inadequacy of his pain-in-the-neck philosophy.

When I was a student, I was a little like Bazarov and thought I was God's gift to philosophy, until it dawned on me that I had never had an original thought in my life and, what was more, that I was never going to have one. But unlike Bazarov, I qualified.

Bazarov dies after performing, while still a student, a post mortem on a peasant who had typhus. Like the discoverer of the agent, Howard Ricketts, but half a century earlier, Bazarov catches typhus—contracting it at the post mortem through a cut finger—and dies from it.

Typhus can be transmitted by blood, I believe, but most likely Bazarov was infected via louse faeces on the dead man's body (so noble a figure as Bazarov couldn't have lice himself). It's striking how accurately Turgenev gives the incubation period, and how well he describes the symptoms, including delirium. Great writers are great observers.

Turgenev mentions typhus in an earlier work, in one of the famous *Sketches from a Hunter's Album*, which played such an important role in the abolition of serfdom in Russia. The narrator, a provincial landowner, describes a visit to a neighbour called Radilov.

BETWEEN THE LINES Theodore Dalrymple



Why should a man who was dying take up a bed when there were people who could benefit from it more? It couldn't happen nowadays

Radilov is a widower whose wife died at home in childbirth. Radilov recounts how, before her burial, he went to look at her corpse once more. "Suddenly I saw ... what do you think? One of her eyes was not quite shut, and on this a fly was moving. I fell down in a heap."

Thus, in a few simple words, the greatest writers convey the deepest emotions and tragedies of human existence.

Radilov had been a soldier in one of the many Russo-Turkish wars, during which he had fallen ill and been admitted to military hospital. Perhaps it was lucky for him that this was in the days before joined-up management and the NHS.

"I recollect that I once lay half dead in hospital ... Suddenly, they bring in more sick—where are they to put them? The doctor goes here and there—there is no room left. [Does it sound familiar, by any chance?]

"So he comes up to me and asks the attendant, 'Is he alive?' He answers, 'He was alive this morning.' The doctor bends down, listens; I am breathing. The good man could not help saying, 'Well, what an absurd constitution; the man's dying; he's certain to die, and he keeps hanging on, lingering, taking up space for nothing, and keeping others out.'"

Here, if anywhere, is a case that needed leaner, more efficient management. And where was the hospital ethicist? Why should a man who was dying take up a bed when there were people who could benefit from it more? It couldn't happen nowadays, thank God: we've progressed a lot.

Theodore Dalrymple is a writer and retired doctor

MEDICAL CLASSICS

Arrowsmith By Sinclair Lewis

First published 1925

Arrowsmith has a claim to be the greatest ever novel about medical research. Writing at the beginning of a revolution in medicine that would yield a generation of powerful drugs, Sinclair Lewis evokes the past, present, and future of the profession, all through the career of Dr Martin Arrowsmith. Informed by Lewis's friend, the ex-Rockefeller Institute scientist Paul De Kruif, the book is based on real characters and actual institutions. It is a cutting satire, but beneath the wit is a powerful call to recognise science as the source of both truth and health. Numerous scientists maturing in the boom of biomedicine after the second world war testified to the book's allure.

Lewis was writing at a time when a drug that would fight the causes of most infection was as yet a vision without substance; penicillin still lay two decades in the future. His adviser, de Kruif, was however closely connected to the research on, and aware of the hopes for, the newly discovered phage viruses as means of destroying bacteria. The apparent success of phage treatment for plague therefore plays a key part in the novel. Indeed the book's invocation of the potential of phage straddles the line between fiction and reality.

If phage seemed to Lewis to be the alluring future, the promotion of sanitary behaviour is presented as the corrupt present. The most humorous part of the book is the description of Arrowsmith's time as assistant to the director of public health in the small town of Nautilus. His boss, Almus Pickerbaugh, is a wonderful rendition of the enthusiast in early 20th century United States. He began January with "Better Babies Week," followed hotly



by "Banish the Booze Week," "Tougher Teeth Week," and "Stop the Spitter Week." This zealous promotion of sanitation is not just funny but also accurate. At the time, the real life Health and Happiness League was asking members to boycott public drinking fountains and to destroy all houseflies.

Arrowsmith fails to cope with the absurdities of the public health department and escapes to the McGurk Institute, modelled on the Rockefeller Institute. Even here, he encounters managers—"men of measured merriment"—as well as his hero, the truth-seeking Max Gottlieb (modelled in part on Jacques Loeb). He is caught in the tensions between pure and applied science, yet there Arrowsmith can aspire to use fundamental knowledge to make great advances.

Since the book's publication, McGurk and its real life analogues have served as the cradles of hopes for better health. Yet, at the beginning of the 21st century, the issues dealt with by that public health department in Nautilus have fresh importance. The relations between prevention, cure, and citizenship are again being renegotiated. So, although it is now more than 80 years old, *Arrowsmith* speaks to contemporary concerns—and fortunately this classic is still regularly reprinted.

Robert Bud, principle curator of medicine, Science Museum, London r.bud@ntlworld.com