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VIEWS & REVIEWS

I was misquoted over very premature babies

PERSONAL VIEW **Daphne Austin**

Months ago I agreed to take part in a television documentary that the UK film maker Adam Wishart was making about premature babies.

Adam and I met on a couple of occasions over a period of weeks. At this time the documentary was a work in progress, so I didn't know where and how I would fit in. The final product was *23 Week Babies: The Price of Life*, recently on BBC Two.

Media interest was generated before the documentary was aired. My first outing was on *The Big Questions*. I was introduced as "the doctor who thought babies born at 23 weeks should be left to die." That's not quite how I would have put my position, but there was, fortunately, enough opportunity during the programme to convey the ethical complexity.

A completely different and also unique experience in my career was the *Daily Mail's* contribution and its consequences. An article appeared the day after *The Big Questions* that focused almost exclusively on my views ("Are doctors defying nature by keeping premature babies alive?" 8 Mar 2011, www.dailymail.co.uk/health/article-1364007/Are-doctors-defying-nature-keeping-premature-babies-alive.html). I had not been interviewed, and the article contained many errors, including misattributed quotes and presumed positions that I do not hold. Of particular note is that on the matter of finances I have been clear in all my discussions relating to extreme prematurity that the money spent on neonatal intensive care is not the issue, yet the article implied that this was my main concern.

Unfortunately this article was cut and pasted within 24 hours by other journalists—and with it the mistakes. One unintended consequence is

that I have become an argument in the campaign in the United States against the health reforms, because it would appear that my "views" illustrate the dangers of socialised healthcare.

So what is my position? It is true: I would not wish intervention to take place for a baby of mine born at 23 weeks. Having looked at the evidence I am not even sure I would want this at 24 or 25 weeks. Survival may have slightly improved, but long term outcomes have not.

Paediatricians following up these children report financial problems, divorce, mental health problems, and a lack of services. No two families will be affected in the same way. Even a mild learning difficulty can have a profound long term consequence for a child born into a poor and vulnerable household (and we must not forget that prematurity is linked with poverty (*BMJ* 2009;339:b4702)). The impact of a disability is likely to increase when the individual hits adulthood, as the documentary attests. Without this being fully documented, can anyone be said to make a truly informed decision?

When society wishes medicine to intervene, as it does in extreme prematurity, then surely some form of social contract is established between society and any individual who may need long term support and care as a result. All the signs are that society is not currently meeting its end of the deal. Having been in the thick of priority setting for more than 20 years, I find that nothing gives me reason to hope that things will radically change. The cancer drug will always beat healthcare and social care for disabled people. We could do more, but we choose not to. It is an ugly truth. And as the population ages and the number of severely disabled people grows, there will come a time when we cannot afford to

Has our relentless pursuit of improving survival left us so immune to the consequences of our actions?

support everyone even if we choose to.

What has been evident in the public debate is the desire to separate the ethics of intervening in extreme prematurity from the ethics of adequately funding care. Even the healthcare professionals working in this area separate the two issues (see <http://bit.ly/dHth6>). Separating the action from the consequence might ease the conscience, but it is a cop out.

I have heard many noble sentiments expressed recently. Noble sentiments do not require society to sacrifice anything—but their delivery does. Ask who will give up something to fulfil this social contract and you will be met with an uncomfortable silence. The answer is that nobody will. The measure of medical success appears to be survival and survival alone. This is true of many areas of healthcare, not just neonatal intensive care.

Has our relentless pursuit of improving survival left us so immune to the consequences of our actions? Is ready acceptance of severe disability really a price worth paying by those individuals and their families so that another family can have the chance of a normal child? Given that we do not and are unlikely to provide necessary lifelong care and support, should we continue on the same path? Can the NHS and society really continue to act with such impunity? And if we are to leave it to the parents to make the decision, how can we assure ourselves that informed consent is truly informed, including an understanding that the support they and their child might need will not always be provided?

I do not in any way regret my involvement in the documentary. I consider it to be a sensitive and courageous documentary, raising important issues that go beyond the very premature baby. I participated in the hope that it would lead to a better and sustained debate. Will we get one?

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Read James Owen Drife's review of the documentary (*BMJ* 2011;342:d1681)



REVIEW OF THE WEEK

Research misconduct revisited

What have we learnt about scientific misconduct? **Michael Fitzpatrick** reviews a two part documentary that puts the Andrew Wakefield vaccine debacle in a broader context

Science Betrayed

A radio documentary by Adam Rutherford

BBC Radio 4; 17 and 24 March 2011

www.bbc.co.uk/programmes/b00zn98

Rating: ★★☆☆

Because scientific research relies on trust, and misconduct is rare, mechanisms for detecting and dealing with it tend to be cumbersome and inefficient. In a two part Radio 4 documentary Adam Rutherford examines the controversy surrounding Andrew Wakefield, in the context of scientific scandals from the Piltdown man hoax of 1912 to the furore over the sacking of the Harvard animal behaviour researcher Marc Hauser in 2010.

Rutherford examines the key roles of the relevant institutions and journals in two recent cases of scientific misconduct that were resolved briskly and efficiently. In the case of the Korean biotechnology researcher Hwang Woo-suk, the revelation that his claims for the therapeutic value of human embryonic stem cells published in *Science* in 2005 were based on fabricated data led to his prompt dismissal from his academic post at the Seoul National University (*BMJ* 2006;332:7). When it was revealed that the South African oncologist Werner Bezwoda's claims for the spectacular success of a combination of high dose chemotherapy and autologous stem cell transplantation in advanced breast cancer were fraudulent in 2000, he was immediately fired by the University of Witwatersrand (*BMJ* 2000;320:398).

In these cases the damage caused by scientific misconduct was limited by the fact that the perpetrators made early public admissions of their responsibility. The contrast with the combined measles, mumps, and rubella (MMR) vaccine and autism scandal is immediately apparent: in the "extended interview" provided

So many were "ready to be taken in": they "wanted to believe" in Piltdown man because he seemed to confirm prevailing prejudices about human evolution. In a similar way many people wanted to believe in Wakefield

by Andrew Wakefield for this programme, the "continuing lack of insight" into his conduct that so horrified the members of the General Medical Council's inquiry team is once again put on public display. In response to persistent questioning from Rutherford, Wakefield is incapable of recognising the difference between disinterested scientific research pursuing a null hypothesis and research commissioned by a lawyer to produce findings congenial to the pursuit of litigation.

There are other substantial differences between the Wakefield case and other recent scandals. In an interview with Rutherford, *Nature's* editor, Philip Campbell, emphasises the key responsibility of coauthors to check data submitted for publication: they are in a position to detect fraud (and indeed error) in a way that peer reviewers cannot. It emerged at the GMC's inquiry that John Walker-Smith, the most senior of Wakefield's 12 coauthors, had not even read the final draft of the paper submitted to the *Lancet*. Wakefield's supervisor at the Royal Free, Roy Pounder—later shown by the investigative journalist Brian Deer to be engaged in commercial enterprises with Wakefield—failed to detect his misconduct.

When Deer presented evidence of Wakefield's misconduct to the *Lancet* in February 2004 the journal's editor collaborated with senior figures at the Royal Free in a cursory investigation. As the *BMJ's* editor in chief, Fiona Godlee, explains to Rutherford, the result of this failure by the responsible journal to pursue alleged misconduct meant that it "joined with the authors in reassuring" the public that Wakefield's paper was based on sound science. The rigorous investigation by the GMC culminated six years later in the vindication of Deer and the disgrace of Wakefield.

Mark Pepys, head of the new University College London medical school consortium,

tells Rutherford how in 2000 he called Wakefield's bluff, demanding that he produce some evidence for his hypothesis of an association between MMR vaccine and autism or quit. Notoriously he quit. Yet the public influence of Wakefield's allegations continued to grow, leading thousands of parents of children with autism in the United Kingdom and the United States into the futile pursuit of litigation and leading many more to refuse vaccination of their children. It is only now—13 years after the *Lancet* paper—that University College London is pursuing a formal inquiry into Wakefield's research (*BMJ* 2011;342:d2010). It is extraordinary to hear that Pepys considers that the college has dealt "admirably" with this affair and that he remains "unrepentant" about the delay in the public exposure of Wakefield's misconduct.

To answer the question of why it took so long for Wakefield to be exposed, we can return to Piltdown man. It took half a century for the truth to emerge that decayed bones discovered in a Sussex gravel pit were not those of a missing link between humans and apes but a combination of recent orangutan and human remains. As the geneticist Steve Jones explains, this was because so many were "ready to be taken in": they "wanted to believe" in Piltdown man because he seemed to confirm pre-

vailing prejudices



Brian Deer (right) tries to talk to Andrew Wakefield

about human evolution. In a similar way many people—parents desperate for an explanation of their children's difficulties, journalists eager for a story about a maverick scientist taking on the medical establishment, and, no doubt, others with more venal motives—wanted to believe in Wakefield. Like the ill fated Walker-Smith, also struck off by the GMC, they "trusted Andy." We have all paid a high price for this misplaced trust.

Competing interests: MF is author of *MMR and Autism: What Parents Need To Know*, Routledge, 2004.

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See **NEWS**, p 729

► bmj.com/archive Read Brian Deer's three recent features on the MMR vaccine (*BMJ* 2011;342:c5258, c5347, and c7001)

BETWEEN THE LINES Theodore Dalrymple

Bad style

John Gross, who died recently, was said to be the best read person in England. Certainly, no person I ever met knew more about English literature—and many other things besides—than he. But his vast knowledge, the fruit of prodigious reading and prodigious memory, was not that of a pedant; everything he knew, he knew because he delighted in knowledge for its own sake. He had the gift of conveying that delight to others.

He was, among other things, the finest anthologist of his age. His *The New Oxford Book of English Prose* is an indispensable source for those who would write well, in whatever style they would like to write. Gross knew that there were many fine styles, none of them suitable to all occasions. He wanted, he says in the introduction, “to illustrate the resources and achievements of English prose as an artistic medium and an instrument of expression.”

It is pleasing to note that, of 490 writers anthologised, at least 11 are doctors (I might have missed some), surely a much higher percentage than could be expected by chance. They are Sir Thomas Browne, John Locke, Bernard Mandeville, Tobias Smollett, Oliver Goldsmith, Oliver Wendell Holmes, David Livingstone, Charles Sherrington, Arthur Conan Doyle, William Somerset Maugham, and Oliver Sacks. There are also at least two former medical students, John Keats and J G Ballard, and one other Nobel prize winner in medicine,



“Doubleplusgood duckspeak,” as Orwell might have described the GMC’s document

Social historians of the future will marvel that eminent educated people should have consented to put their names to such a document

Peter Medawar. And many of the extracts of other authors concern matters medical. Ours is a literary as well as a scientific profession, and if you want your doctor-son to be a writer, call him Oliver.

Not surprisingly the anthology has extracts on language and prose style. Hilaire Belloc, praising Cardinal Newman, says, “[He,] having to tell a certain number of facts, and to express a certain number of ideas, does so with the best choice of words in the best order—and that is prose.” George Orwell describes the purpose of Newspeak: “The intention was to make speech on any subject not ideologically neutral, as nearly as possible independent of consciousness.”

I turn now to a document I received from the General Medical Council recently through the post. Gross would surely have anthologised it if he had lived, because it certainly shows one of the resources of English prose. Here is what the UK Revalidation Programme Board will do: “(a) Clarify the assumptions and context for delivery; (b) Confirm the scope of the programme and its major interdependencies, including managing performance concerns in relation to doctors; (c) Define the workstreams needed to deliver all aspects of the model and identify who is responsible for delivery; (d) Provide a clear timetable and key milestones for starting revalidation and incremental implementation; (e) Ensure that all key interests are confident that readiness is being assessed on a robust and consistent basis against UK wide criteria; (f) Outline an end state picture across the UK as a part of the planning process for roll out and implementation.”

Social historians of the future will marvel that eminent, educated people should have consented to put their names to such a document, which in Newspeak would be esteemed as “doubleplusgood duckspeak.” Thomas Carlyle (not a doctor, though a hypochondriacal frequenter of doctors) asked his friend John Stirling in 1835, “Do you reckon this really a time for purism of style?” And he answered, “I do not.”

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MEDICAL CLASSICS

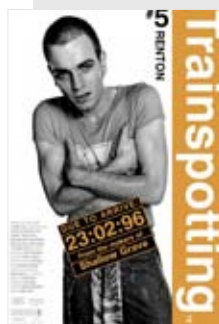
Trainspotting

A novel by Irvine Welsh, first published 1993, and a film directed by Danny Boyle, released 1996

Trainspotting’s shifting narrative focus and Scottish vernacular, its cast of rather unpalatable characters, and its multitude of themes, from Scottish national identity to drug addiction (almost a metaphor for all that was wrong with Edinburgh in the late 1980s), hailed the arrival of a new talent. The eponymous 1996 film by Danny Boyle distilled these themes and characters.

The film’s main theme is drug addiction in young people. The main narrative is provided by Mark Renton, who seems a more positive character in the film. The ending, when he “chooses life,” followed by the same monologue that opens the film, seems to bear hope. In the book, however, he escapes to Amsterdam, and it seems inevitable that the vicious cycle—addiction-withdrawal-abstinence-thrill seeking—will repeat. The film’s repeated sequence of Renton and pals running along Edinburgh’s Princes Street also hints at this vicious cycle. But we follow Renton and friends through voluntary withdrawal, overdose, and cold turkey to, at least in Renton’s case, a possibly more sober and grown up life in London.

The film seems to portray great camaraderie among those injecting drugs, but it’s obvious that the experience is solitary and isolating, and mostly people don’t communicate while under the influence. The starkest reminder of this is when baby Dawn is found dead, although we never find out the cause—perhaps simple neglect.



In the novel the physical ravages of heroin addiction and the drastic behaviours it prompts are described in detail; the film uses occasional surreal visuals to depict the physical horrors. We see characters cook up heroin in spoons, apply tourniquets and inject, fall over backwards, and withdraw into their own private trip. When Renton overdoses, he literally disappears into a hole in the floor, and when undergoing sudden withdrawal at his parents’ house the bed turns into

a threatening place, full of angles and unwanted intruders. The pinnacle of his horror is the dead baby, who seems to crawl along his bedroom ceiling.

Constipation as the addict’s curse affects several characters—Spud soils his girlfriend’s bed in a scene that is as disgusting as it is comic, and Renton himself, in a phantasmagoric sequence, actually disappears down the “worst toilet in Scotland,” swimming about in dark waters to retrieve two opium suppositories. HIV seems merely a spectre on the horizon until Tommy, the only character who is not even a junkie at the outset, contracts the virus from a dirty needle, develops full blown AIDS, and dies.

In the book Welsh gives a convincing depiction of injecting drug use. One of the characters says, after listing a pharmacy of substances that the characters regularly steal, beg, or borrow, “We’d have injected vitamin C if only they’d made it illegal.” Although the film is funny and energetic, the overall message seems rather more negative: drug misuse is physically abhorrent, isolates you from your peers, and leads to a long, grim cycle of criminality—a dark masterpiece.

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Bad medicine: sports medicine

FROM THE
FRONTLINE

Des Spence



At school I wore plimsolls for football, and I slipped and skidded across the mud in a drenched, freezing cotton T shirt. But when I returned to exercise 25 years later, sports science had banished plimsolls as a fashion accessory. I listened to the chatter of the exercising classes: shoes, insoles, isotonic drinks, physiotherapy, personal trainers, heart rate monitors, massive watches, diets, and massages. But for all their physical strength, sports people are the zenith of vulnerable neuroticism. And everything is gospel from the mouths of evangelical sports scientists, supported by a global industry that is worth billions of pounds. Patients have unshakable beliefs and respond with anger if you suggest that what they have been told makes no intuitive, physiological, or scientific sense. So what about the science?

There is no evidence base of benefit for those £100 (€115; \$160) technological “pronation control, elevated cushioned heel” running shoes,¹ and indeed the fad is now for non-padding and barefoot running. Compression leg-wear is all the rage and claims a range of performance improving effects, but again evidence of any benefit, even at elite level, is scant.²

As for expensive isotonic sports drinks, the evidence is sketchy. Firstly, the advice to load with fluid during exercise is linked to a serious condition, exercise associated hyponatraemia,³ and indeed taking fluids during vigorous exercise for an hour has no effect on performance.⁴ Perhaps for most sports we do not need fluids, and any fluid replacement should be

driven by thirst. As for dietary supplements, a billion dollar business, I could find no robust evidence of any benefit at all.

Deep massage and ultrasound treatment don’t seem to have any benefit (it is illogical that external forces could affect a molecular physiological healing process).⁵⁻⁷ “Biomechanics” is the new musculoskeletal cure all, and expensive moulded shoe insoles are sold to treat back pain and knee pain and to correct a “tilted pelvis,” but no functional benefit has been proved.^{8,9} Orthopaedic surgeons fare little better. Sports medicine trials are of poor quality, with small numbers, selective groups, and limited follow-up. So the outcomes from use of rotator cuff operations and arthroscopic decompression seem no better than from conservative treatments.¹⁰ Even cruciate repair has a poor evidence base and limited follow-up.¹¹ As for the rest of sports surgery, most is but emotion and mere opinion. One fact is certain, however: these inventions are highly profitable.

The body has had been honed by millions of years of rigorous evolutionary pressure, so thirst, breathlessness, and, most importantly, pain have an important purpose. Sporting performance is clearly psychological as well as physical. Sports medicine comprises some science, much pseudoscience, and a fair amount of quackery—bad medicine by any measure.

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References are on bmj.com

Let’s talk about pensions

STARTING OUT
Kinesh Patel



If you remember The Beatles growing up, you’re probably okay. If Led Zeppelin is more your thing then you’re probably going to be disappointed. And if it’s Kylie Minogue, well you’re doomed on many levels.

Yes: it’s the big issue that everyone avoided talking about until the recent Hutton report. Out goes the gold plated final salary scheme, and in comes a new scheme based on career average earnings, which will put an end to that merit award in the last few years of service topping up the pension. Out goes retirement at age 60; in comes retirement at 68 (for anyone who has qualified in the past 10 years).

Older doctors will be allowed to work a year or two less than this. And for all this you have the privilege of paying higher contributions, with less tax relief. Everyone’s up in arms. The BMA, the trade union Unison, and the Trades Union Congress are all incensed. Talk is rife of strike action

and protests in the street. “We will not take this lying down,” is a familiar cry.

But what will actually happen? I’m not usually the soothsaying type, mainly because I don’t like being wrong, but this one is easy to call. We will roll over and take it, just like we take everything else handed out to us—from pay freezes to deteriorations in terms and conditions of service—with some disgruntlement but little else. Yes, we’ll moan and groan and there will be rumblings of mass defections to the private sector and abroad, but nothing of any great note will happen.

The only people unaffected by the reforms, those consultants near the end of their careers, may well jump ship while they can, into an easy retirement and with their pension preserved. With salaries frozen for the foreseeable future but pensions still rising with inflation (currently running above 4%), many are asking: why work longer for less?

It’s the solution to the workforce problem that no one expected. Junior doctors waiting for consultant posts, but disappointed by the sudden arrest in consultant expansion due to the financial crisis, will suddenly find jobs. Trusts will find that those older consultants, the awkward ones who were trained to have some independence of thought and the management unfriendly ability to say no, will leave en masse.

There is only one way to effect real change here. The prospect of paying large amounts for a pension of uncertain value 50 years in the future may be too much for some doctors to stomach, and we may see an exodus from the NHS scheme. That would turn far more heads than the usual vociferous but ultimately futile trade union protestations.

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bmj.com/archive

- News: BMA warns of mass retirement after Hutton recommends end to final salary pensions (*BMJ* 2011;342:d1596)
- Trisha Greenhalgh on working harder for longer (*BMJ* 2011;342:d1616)