We need a simple test for prosopagnosia

PERSONAL VIEW David R Fine

He is a distinguished colleague and I am proud we are on first name terms: had I met him at the conference rather than the airport I would not have walked past. I was embarrassed, so my wife explained my problem, and his reply was unusual: “You must write a review for the BMJ so that others can understand your problem and benefit from your experience. Accounts of disability and how people cope are uplifting and help even those not afflicted.”

I have severe inherited (developmental) prosopagnosia, or face blindness. The term prosopagnosia was coined in 1947, but it has been widely recognised outside the context of brain injury only in the past decade. Its purest form is limited to facial recognition, but I also have problems with inanimate and animate objects and in interpreting facial signs of emotion and sex. I often fail to recognise my children or even my wife.

Prosopagnosia has shaped my life. At every stage I have failed to acknowledge friends and, more distressingly, those in authority. At school I would get lines for not raising my cap to a teacher or be shouted at (and worse) for ignoring a classmate. As a young man I ignored girls whom I had met the night before—not a good mating strategy. As a houseman I knew the patients by their beds; if the nurses moved them I would present the wrong case on the round. I find networking all but impossible, and social situations, from parties to conferences, may cause acute anxiety. Ward parties are the worst because I know other staff members by their uniforms and badges; in party clothes, with different hairstyles, they are strangers to me.

Even worse than ignoring someone you know is recognising someone you don’t. Depending on the circumstances this can be interpreted as rude, deranged, or predatory. I have long learnt to smile politely at people who smile at me but to let them make the first moves in conversation.

How do I function personally and professionally? A look at my life reveals strategies. I have a limited number of friends, many of whom are physically distinctive: I suspect that is because I was able to recognise them at an early stage, allowing acquaintance to develop into friendship. I work in a hospital, so fellow workers are labelled and patients either come to me by appointment with notes, or are in a specific and allotted place. I memorise hair, jewellery, and favourite clothes. I recognise gait, tics, and voices. The fashion for tattoos and piercings can help, but they are often hidden in daily encounters. Above all I rely on context: a person of a certain type in our corridor is my colleague—but in the supermarket is probably a stranger. Professionally I have limited myself to a small subspecialty, with a couple of hundred colleagues worldwide. Being diagnosed helped. A friend used the term prosopagnosia in 1996, but only in 2005, when I found Brad Duchaine, then at the institute of cognitive neuroscience at University College London, did I realise how disabled I am. The news that I am “in the bottom 15%” sounded all right, until I realised that Duchaine was referring to the affected population rather than the general population (I’m eight standard deviations away from the mean). I then became a bore, telling everybody about it. Now I try to tell people on first acquaintance and only reinforce it if they say, “I’ve got that too”—most sufferers forget names but recognise friends and family without difficulty. Many people now reintroduce themselves when we meet. One exposes her tattoo, normally only visible in a low cut dress, which raises eyebrows.

Early on I would tell people how I recognised them, until my wife, who has an astonishing memory for faces, cautioned that inevitably I identified their worst features. Now I tell people who are difficult to remember that this is a compliment, because good looks are symmetrical (would that I had known that line as a single man).

I have done well enough in life, but I believe that I would have achieved more professionally had I been better able to network. My hope is for a simple test to identify prosopagnosia in childhood (as for colour blindness), so that the next generation of sufferers grows up in a society that understands and recognises our disability. Meanwhile, if you think you may be affected you can check your facial recognition ability at www.faceblind.org.

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Obmj.com/archive Oliver Sacks describes his own prosopagnosia in his latest book, The Mind’s Eye (BMJ 2011;342:c7110)
As a newly qualified doctor in 1967 Jack Wennberg was employed to ensure that the citizens of Vermont had access to advances in treatment for heart disease, cancers, and stroke. His study of the delivery of healthcare, with the aim of identifying communities that were underserved, found extensive evidence of variation in the treatment of many medical conditions in the state. This was exemplified by the rate of tonsillectomy in children younger than 15 being 60% and 20% in two neighbouring communities with similar populations.

More than 40 years later Atul Gawande reported wide variation in healthcare delivery in a much cited article in the New Yorker. He compared two communities in Texas and found that one spent twice as much as the other per person on Medicare, a difference that could not be accounted for by population need and that was unrelated to the quality of care delivered. The higher cost community was among the most expensive healthcare markets in the United States, and Gawande argued that this was due to its overuse of most kinds of healthcare, driven by a payment system that rewarded doctors for doing more.

In fact, international comparisons indicate that financial incentives only partly explain persistent variations in healthcare delivery. Forty years before Wennberg’s work in Vermont, J Alison Glover found that tonsillectomy rates in some school districts in England and Wales were four times those in others. The main reason for the difference was the judgment of the school doctors who referred pupils for surgery, not the way doctors were paid or other factors. Glover illustrated this by reference to a London borough where a change in the school doctor led to a considerable fall in the tonsillectomy rate.

Wennberg’s work went beyond describing variation in care to explore what could be done to change patterns of medical practice. This included working with the Vermont State Medical Society to introduce second opinions into decisions on whether to undertake tonsillectomies. As a result the tonsillectomy rate fell from 60% to less than 10% in the community with high levels of intervention. Reductions in hysterectomy rates were also brought about in Maine through use of data on variations and the support of the state medical association.

Variation in tonsillectomy rates is an example of variation in “preference sensitive conditions” that occurs when more than one treatment option exists and there is often scientific uncertainty about the outcomes of different options. Tackling such variation calls for investment in comparative effectiveness research to reduce uncertainty and for much greater involvement of patients in choosing treatments. Promoting shared decision making and informed patient choice are at the heart of Wennberg’s agenda for reform, not least because involving patients in treatment decisions is one way of reducing costly and inappropriate overuse of healthcare.

Variation in preference sensitive care coexists with variation in “supply sensitive care,” which results from the availability of doctors, hospitals, and other facilities. This is illustrated by Roemer’s law, which states that a built hospital bed will be used almost regardless of need.

Even more important is evidence that for supply sensitive care more is not better. As Wennberg and colleagues have shown, outcomes (as measured by death rates and patients’ satisfaction with hospital care) are worse in areas with high care intensity. It follows that improving outcomes does not always require additional investment and increased supply but rather the adoption of patterns of practice seen in areas and hospitals that deliver the best value for money.

This is shown by research into variation in care at the end of life at academic medical centres in the United States. The cost and intensity of care, measured by time spent in hospital and the number of visits by doctors, varied widely between these centres.

One of the strong messages from this book is that integrated delivery systems such as Mayo Clinic, Kaiser Permanente, Intermountain Healthcare, and Group Health Cooperative are “a compelling American success story” that have shown what can be achieved when doctors are fully engaged in quality improvement and incentives are aligned to support their efforts. Wennberg sees hope for taking forward these ideas in proposals for accountable care organisations in the United States that have emerged as part of debate about reform of healthcare in that country.

The argument for integrated delivery systems is at least as compelling in England, at a time when healthcare reform is again centre stage. Such systems could emerge from the nascent general practice commissioning consortiums, as long as specialists as well as general practitioners are fully involved in the work of these groups, and groups are enabled to provide as well as commission services. There is a huge opportunity for multispeciality medical groups working with capitated budgets to be in the vanguard of improvement through reducing surplus hospital capacity and strengthening primary care and community services.

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The arguments for integrated delivery systems, shared decision making, informed patient choice, and investment in comparative effectiveness research, as set out by Wennberg in this book, should be compulsory reading for policy makers and healthcare leaders. In putting forward these arguments he throws down the gauntlet to the medical profession to act on evidence of variation or else have others who are less well qualified do so instead.

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See EDITORIAL, p 665, ANALYSIS, p 687, FEATURE, p 682, MEDICAL CLASSICS, p 713
Filming the foundation years

This television series follows seven newly qualified doctors working in hospital for the first time, but Yusuf Mirza finds it lacks authenticity.

Junior Doctors: Your Life in Their Hands
A documentary series on BBC Three
www.bbc.co.uk/programmes/b00yb30f
Rating: ★★★☆☆

Should you believe everything you see on television? Certainly not, as Dr Keir Shiels exclaims in the opening scenes of Junior Doctors: Your Life in Their Hands. This docusoap follows six foundation programme trainees at the Royal Victoria Infirmary and the Newcastle General as they work, rest, and play.

In this slickly edited series, we meet seven junior doctors who are also housemates. Adam is the handsome extrovert; Katherine is the Cambridge graduate; Lucy’s sister has been diagnosed as having cystic fibrosis; Suzi is a self described Barbie girl; John is a rugby player; Keir is enterprising; and Andy wants to be a surgeon. They are introduced as warriors in the fight against disease, as they get to grips with the demands of medicine on the wards and their life outside of work.

Some of the realities of being a junior doctor are well captured. The camera records Suzi’s rapid initiation to the emergency department, contrasting this to the purgatory of Adam’s “bloods or paperwork” in the chest medicine department. Everyone will also recall Katherine’s choice: as a lone houseman should you take bloods, clerk a preoperative patient, or complete the discharge letters on the surgical ward? Adam makes the wrong choice, and a blood sample for the measurement of gentamicin concentration misses a delivery deadline, and he incurs sister’s ire. The sight of a patient falling in the background as John is interviewed before he clocks off succinctly captures the constant hum of medicine. John disregards the European Working Time Directive and attends to the fallen woman. And when Lucy cares for a woman with pancreatic cancer she is visibly upset when the consultant breaks bad news, telling the patient about her poor prognosis.

Junior Doctors wants to debunk the notion of doctors as automatons, constantly on the job, and offers insight into the personal lives of our subjects. We see the seven at home, where they let off steam about various aspects of their day, something which is instantly recognisable to me as a junior doctor, and we witness their pastimes. The series is on BBC Three, and the channel bills itself as being “shamelessly and directly influenced by you.” So the desire to expand the public’s understanding of junior doctors is obstructed by what the film makers must see as the public desire for sensationalism. So Junior Doctors revisits the tired topics of the per rectal examination and patients who present with various appliances in their back passages.

The need for hyperbole is also sated, and the film is edited in a way that suggests it is giddy with excitement for its own subject matter. Quotes are used out of context to increase the drama, and the camera cuts between the doctors to a persistent soundtrack, encouraging the appropriate emotion in the viewer.

So does this capture the life of a junior doctor?

Where is the interdisciplinary rivalry, where the medics dislike the surgeons and the surgeons reciprocate?

To a degree, yes. It shows the monotony of ward life interspersed with the rhythm of being on call. Here is the excitement of making your first correct diagnosis and managing it appropriately; the shame at having to ask for a senior colleague to take some blood on your behalf; and the panic at a cardiac arrest call as you run to a ward that you didn’t know existed. All are instantly familiar.

But the documentary misses the opportunity to delve a little deeper into life as a foundation trainee. There is no explanation of foundation training and how this has changed medicine, in terms of the rapid turnover of doctors in teams. Neither is there an explanation of the fallout on training or of the impact of European law on junior doctors’ working hours and what this means.

There is no insight into why junior doctors decide to be surgeons, physicians, or general practitioners. I wanted to be a physician after university. The contrast between my first medical job and my first surgical job blew away any such aspirations. The documentary also smirks benignly at all professions and disciplines. Where is the interdisciplinary rivalry, where the medics dislike the surgeons and the surgeons reciprocate? Where is the interprofessional rivalry between nurses and doctors? The series hints at the solitude of a junior doctor on busy wards as one becomes overstretched, but it never fully captures it.

Series like the inspirational Doctors To Be, motivated me to a medical career. I was struck by the engaging personalities and their struggles through undergraduate and postgraduate medicine. I hope Junior Doctors, the child of Doctors To Be, will inspire the next generation of medics just as Doctors To Be encouraged me. The protagonists come across as enthusiastic, knowledgeable professionals who will be competent physicians, surgeons, and so on, despite attempts to cast them otherwise. But I must concur with Dr Shiels: although enjoyable, you can’t believe what you see on television, and this is not an accurate representation of the life of a junior doctor.

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BETWEEN THE LINES Theodore Dalrymple

Shakespeare on alcohol

Shakespeare knew all about drinking; he liked a drink himself. Indeed, we are told that he died after a drinking session in Stratford with Ben Jonson, though whether from alcohol poisoning, an epidemic brought on by the recent flooding in Stratford, or as a matter of coincidence, we do not know.

Perhaps, then, the scenes enacted in the centre of every British town and city on Friday and Saturday nights would not altogether have surprised him because, as Iago says to Cassio in Othello, “They [the English] are most potent in potting. Your Dane, your German, and your swaggellied Hollander—drink, ho!—are nothing to your English.”

Cassio, in fact, has a low tolerance for alcohol: “I have very poor and unhappy brains for drinking. I have drunk but alcohol: “I have very poor and unhappy brains for drinking. I have drunk but alcohol: “I have very poor and unhappy brains for drinking. I have drunk but...”

Sherris sack gives Dutch courage to the consummate coward who is Falstaff: “It illumineth the face, which as a beacon gives warning to all the rest of this little kingdom, man, to arm; and then the vital commoners and inland petty spirits must me all to their captain, the heart, who, great and puffed up with this retinue, doth any deed of courage; and this valour comes of sherris.”

Shakespeare even describes a rare condition, alcoholic hallucinosis; in The Tempest, while drinking, Stephano hears a voice (actually that of the invisible Ariel) accusing him of lying. Trinculo says to him, “Out o’ your wits, and hear too? A pox on your bottle! This can think that he is being witty?” Falstaff, in Henry IV Part II

Incidentally, in The Tempest Caliban is often taken to symbolise a man in a state of nature. But really he is a psychopath, not a savage, noble or otherwise; as Prospero says of him, “A devil, a born devil, on whose nature / Nurture can never stick; whose nature / Nurture can never stick;...”

The solution to these variations, argues Wennberg, is to promote organised systems of care; to establish fully informed patient choice as the legal standard; to improve the science of capacity and spending. We have a long way to go.

MEDICAL CLASSICS

Dartmouth Atlas of Health Care

By John E Wennberg and Megan McAndrew Cooper First published 1996

It is not wholly fanciful to compare the Dartmouth Atlas of Health Care with On the Origin of Species. Both books resulted from a rigorous accumulation of data and fundamentally changed our world view. Darwin’s book showed our descent from apes. The atlas exploded the belief that medicine is based firmly on science. The first Dartmouth Atlas was published in 1996, and it is now a rich website with well presented maps and publications on healthcare in the United States. “Jack” Wennberg (as he is known) is the main author but was not the first to identify variations. The atlas pays tribute to the British paediatrician J Alison Glover, who observed in the 1930s that the proportion of children who had received tonsillectomies varied from 10% to 50% in different school districts. Wennberg himself discovered big variations in numbers of hospital beds and physicians in Vermont in the 1970s.

The atlas grew out of failure of the Clinton health reforms when funds for studies to inform the reforms were diverted to creating the atlas. Wennberg and his team used Medicare and Medicaid data to produce the atlas but have shown a close correlation between all activities and those funded by Medicare and Medicaid.

Variation occurs in all of healthcare. The original atlas showed, for example, a twofold variation in numbers of hospital beds, a threefold variation in numbers of doctors, fourfold variation in rates of coronary bypass surgery, and eightfold variation in radical prostatectomy. Importantly, more hospitals and doctors did not mean better outcomes.

Politicians are fascinated by these data because of the huge savings that can be made if unwarranted variation can be eliminated. The first atlas calculated that if every region in the country was like Minneapolis, then 120 000 beds could be closed and $32.6bn (£20.2bn; €23.2bn, at current exchange rates) saved without any deterioration in outcomes.

Wennberg’s recent book, Tracking Medicine, tells the whole story and spells out the responses that are needed. He divides healthcare into the 15% that is effective and necessary, the 25% that is preference sensitive (do patients really want that operation?), and the 60% that is supply sensitive—driven by how many hospitals and doctors a region has. He thinks that the UK is a little different from the US. The NHS Atlas of Variation in Healthcare, published in 2010, shows, for example, a near 30-fold variation in the percentage of patients in primary care trusts who receive all nine key care processes recommended for people with diabetes (www.rightcare.nhs.uk/atlas).

The solution to these variations, argues Wennberg, is to promote organised systems of care; to establish fully informed patient choice as the legal standard; to improve the science of capacity and spending. We have a long way to go.

Competing interests: RS is employed by the UnitedHealth Group and company’s foundation is one of the atlas’s many sponsors. Richard Smith, director, UnitedHealth Chronic Disease Initiative, London richardswsmith@yahoo.co.uk

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See EDITORIAL, p 665, ANALYSIS, p 687, REVIEW, p 711

Alternatives to audit

Set standards, review, change, and re-review: these fab four once rocked the medical world. This was “audit.” They rattled out simple quick numbers. From humble beginnings the tunes echoed around the world. For the first time audit attempted to systematically improve care at all levels of practice. Audit had merchandising, pens, calendars, and T-shirts, and middle aged men screamed and fainted at the royal college command performance. Fan clubs formed throughout the country. The audit cycles were easy to write and so flexible that we thought they would play out forever.

I was more a fan of evidence based medicine, though I admired the power of audit. But “audit” experimented with drugs, firstly with soft generic switches but later with more confusing psychedelic care pathways, which sounded great but actually didn’t make any sense. So things changed, and corporate medicine took over audit, making it standard, formatted, repetitive, and compulsory. Audit became profligate and boring, just a system, losing its creativity and many loyal fans.

The backbeat of medicine constantly changes, however, and the new fashion is to compare medicine to aviation. So “significant event analysis” (SEA, aka screw ups) and clinical risk assessment are the new pretty young things. SEA is useful but not new: sharing at the medical confessional in small confidential groups is a timeless medical classic. And all the talk of a “no blame culture” is a lie—blame is alive and well in the NHS. Doctors are fearful of being honest in the written word. Indeed I have more significant events washing my hair than in some of the SEAs I have read. As for clinical risk assessment and “global trigger tools,” these seem to be ramping up to being the next big thing. But I fear the language, “drilling down” and “closing the loop,” because it is the jargon of management and self help books. I am happy to work with these ideas but need to be convinced that producing meaningful improvements in care isn’t just more meaningless activity. I also fear that they will shift from being a useful voluntary exercise to compulsory recordable box ticking.

All these system approaches improve care but are limited to measuring what is measurable; this is only a fraction of care. We shouldn’t be seduced by and put all our faith in systems and checklists, because then we diminish the role of the individual doctor. Personal responsibility is the key to quality of care, and those obsessive non-systematic traits that drive us as doctors are more important than any system. Improvements in care are born of creative and reflective thinking, and we should remember that systems can systematically inhibit innovation.

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A tax on the English

Not long now: in a little over 16 months the world’s greatest sporting event will be in London. Hosting the Olympic Games is a huge burden for a country. But undeniable too are the benefits, not least the near certain boost to the tally of medals won by the UK’s athletes (or, if you must, “Team GB”).

The happy prospect of victorious competitors draping themselves in the Union Flag doesn’t necessarily chime though with the United Kingdom’s tendency to devolution in other aspects of life. With regard to medical care, for instance, references to the National Health Service often need to be qualified by saying exactly which nation or nations you’re talking about.

Take the prescription charge. Scotland’s decision to get rid of this from next month leaves England as the last of the four UK countries to retain it. And, as if to rub things in, the charge is going up this year (as usual) to £7.40 (£8.50; $11.90).

The justifications for this tax (“charge” is a poor euphemism) have always been threadbare. But at least when there was a more unified NHS and, crucially, meek tolerance of its Byzantine workings, the public would have had less focus for objecting to paying for prescribed treatments. They may even have believed that the tax represented a ringfenced so called contribution to the NHS or even for drugs specifically—cosy but entirely bogus notions.

The suggestion that the tax helps to curb inappropriate demand for drugs and their prescribing by doctors also looks hollow when, by implication, it’s supposedly only those in England who need such a deterrent. Likewise, why do the citizens of only one country need a token reminder that prescription drugs cost money?

The arbitrary and iniquitous application of the tax doesn’t help either. Its defenders, including the (English) Department of Health, sometimes highlight that roughly 90% of prescriptions don’t attract the payment, which must be a great consolation to those payers who have long term medical conditions that are not on the list of exemptions. In 2010, Professor Ian Gilmore’s Prescription Charges Review (www.dh.gov.uk/en/DH_116366) offered sensible approaches for lancing this particular boil and also asked ministers to think about scrapping the tax altogether.

But its measured recommendations were to no avail, given the torpedoing they suffered in the government’s subsequent 2010 Spending Review (www.hm-treasury.gov.uk/spend_index.htm). Inevitably, the current harsh economic environment provides a haven for taxes: but surely not those as odd, illogical, unfair, and anachronistic as the prescription charge.

It’s 63 years since the Olympics were last in London. Coincidentally, the same year saw the founding of the NHS, which initially didn’t employ prescription charges.

Perhaps, eventually, history will repeat itself in that way too.

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