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VIEWS & REVIEWS

Where are the clinicians when you need them?

PERSONAL VIEW Emma Halls

Having spent the past 12 months working with patient groups and clinicians on a project to identify treatment uncertainties in prostate cancer, I have been amazed at the way people and organisations working in the same field don't speak to each other. Have we become so competitive that we can't see that working together is good, if not essential?

My frustration is growing, and the *BMJ* seems a good place to ask doctors: "Why the lack of communication?" Where is your culture of collaboration in my field of prostate cancer? Do you feel you have your own show, and all the answers?

We're currently fighting our way towards an exciting collaboration between patients and clinicians designed to agree priorities in treatment research. There is so much we don't understand about prostate cancer and no agreement as to the most important research. Our partners are the James Lind Alliance (an organisation established to help identify and confront the uncertainties about the effects of treatment), several other prostate cancer charities, the main patient support groups, and the Prostate Cancer Charter for Action. Progress is now being made, but getting to this point has been uniquely painful.

Our initial attempt to identify the big treatment questions in prostate cancer comprised asking 50 of the top researchers in the field to come up with 10 questions each. They gave us a total of 42. Encouraging.

We took this list to the Prostate Cancer Support Federation, an organisation of patient led support groups, to see if we could combine patients' questions with those from our "top minds." We were amazed when only four people

responded. But it soon became clear that these patients weren't opening up because they couldn't—they didn't have a clue what the experts were saying.

That was when we decided to follow the model used by the James Lind Alliance: forget researchers for the time being and concentrate on finding consensus between clinicians and patients.

We invited 90 organisations to an initial meeting to find out more about the James Lind Alliance and to become involved in our project.

About half replied—a poor response rate given that all these organisations have a vested interest in this work. Surely most, if not all, these organisations would have felt duty bound to reply? And more importantly, why didn't large organisations that represent research and patient interests want to join in?

Undeterred, we arranged to gather in London a group of the most enthusiastic supporters. We inadvertently picked a tube strike day in June. Thirty people turned up, but only one a clinician. I tried hard to believe doctors are more affected by a tube strike than the rest of us, and then I stopped making excuses for them.

I'm known for being rather enthusiastic and energetic. Given this constitution and despite a growing sense of despair, when we met in London I was again convinced that our project was interesting, exciting, and vital to drive the research agenda forward. We might only have one clinician, but we were at least giving patients a voice they'd never had before.

It didn't take long for my enthusiasm to wane. Many of the patients came with personal questions centred only on their diagnosis, which made life difficult for those of us trying to see the bigger picture. The researchers were clearly apprehensive, and the appearance of one valiant

clinician can hardly be called "involvement."

It quickly became clear that guiding these disparate voices would be tough. I'm eternally grateful to one patient who pointed out that this piece of work may not help those in the room who had prostate cancer—indeed, he would be dead before any substantive results emerged—but he was still interested. And similarly appreciative of the man worried about the poor communication with black and minority ethnic groups about their increased risk of prostate cancer (it's three times more common in black than white men) and their treatment options. By the end of the day I still believed, as I do today, that this work could mean only good things for prostate cancer and those it affects.

We continue to collect research questions that could address treatment uncertainty, but we are still struggling hard to get clinicians to participate. I really do get the point about busy work loads, but there's no reason to assume that it is tougher for doctors to get involved than for patients, many of whom have been so easy and keen to engage. Indeed, for this latter group, prostate cancer is not the day job. For doctors who work in the field of prostate cancer it is. Where do you lie on this spectrum?

We set out to make our project an equal partnership between patients and clinicians, but doctors won't come to the party. Do I still believe in collaboration? You bet, and by hook or by crook we plan to have our top 10 jointly agreed research priorities by summer 2010.

We need to be answerable to our stakeholders—patients, families, and those who donate money—and fund the best research. For so long, what we do with our funds has been decided by "professionals" who take little heed of those who have lived with prostate cancer.

Do you just not like us treading on your turf? Is guarding your territory paramount? We have more than fully engaged a wonderful Cambridge clinician, Vincent Gnanapragasam, and he's as baffled as we are as to why his medical colleagues don't seem to want a say in what we're getting up to with—and for—their patients. Emma Halls is chief executive, Prostate Cancer Research Foundation, London ehalls@thepcrf.org

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REVIEW OF THE WEEK

Great Ormond Street: great expectations

Sophie Cook reviews a documentary about a world class hospital where clinicians are often expected to work “miracles” in cases of last resort, often against the odds

Great Ormond Street

A series of three documentaries, BBC2, 6-13 April

Available free on BBC iPlayer
(www.bbc.co.uk/iplayer)

Rating: ★★★★★

Few hospitals are as internationally renowned as Great Ormond Street Hospital for Children, London. This three part BBC documentary, which was a year in the making, explores how such worldwide recognition can lead to high expectations among patients and their families and how reality can't always measure up.

The documentaries highlight how, as scientific and clinical knowledge rapidly accumulates, parents often arrive with high hopes that the expert staff and new technologies can help, but sadly this is not always the case. Just a few years ago many of these children would have died, but as medicine advances and children with previously fatal conditions continue to defy the odds, it becomes all the more difficult for staff and parents when there is nothing more to offer. The programmes show how parents will desperately fight for their children to be treated and the ethical dilemmas that this poses to health professionals who often disagree that further invasive treatment is in the child's best interest. They also touch on the delicate issue of how difficult it can be to justify financially some of these costly, cutting edge procedures in children unlikely to survive. We see how staff deal with these sensitive clinical and ethical difficulties on a daily basis and the personal cost of such work.

The series follows doctors and several children and their parents in the hospital's intensive care, renal, and cardiac departments. The opening programme, “Pushing the Boundaries,” follows the cardiac team at Great Ormond Street, the largest paediatric cardiac unit in the country. It looks at the delicate interface between medicine and surgery and shows how successful truly multidisciplinary team working can be, if executed well. Four children and their families feature in this episode, and through them we see the success of surgery performed by the cardiothoracic surgeons Victor Tsang and Martin Elliot, what happens when parents cannot accept the answers they are given, and how even the most technologically advanced operations sometimes fail or result in further complications. We also see the consultant cardiologist Phil Rees, the cardiac department's longest serving doctor, eloquently and honestly explain to a 9 year old that he must have a cardiac transplant—a must see scene for clinicians to learn about effective communication.

The second episode, “Caught in the Machine,” features the intensive care unit and deals with some of the delicate ethical dilemmas doctors face. These include when to withdraw care from a child and when it is right to continue to attempt procedures on a child whose prognosis is already poor or when to say enough is enough. Another issue raised is what happens when a local hospital says that nothing more can be done but a second opinion at Great Ormond Street suggests otherwise. Through one child's story we see the psychological effects

that such a scenario can have on the parents.

The final documentary, “An Imperfect Cure,” follows patients in the renal unit. In contrast to the other episodes, where the patients have been much younger, we hear from some teenagers who give frank accounts of what it is like to be on dialysis three times a week and to have been through multiple unsuccessful renal transplantations. These adolescent patients display such wisdom about their conditions and strong opinions on their management that you might not realise they were the voices of children if you couldn't see their faces. We see how difficult it can be to work with adolescent patients who refuse to undergo lifesaving treatments, how intense and long the preparation for renal transplantation is, how patients are prioritised amid a shortage of organs, and what happens when lines and catheters fail.

A theme running through the series is that although vast improvements have been made in paediatrics nobody can work miracles. The programmes focus on the sickest children, some of whom live and some of whom die. So often programmes like this highlight only the success stories, but this series doesn't shy away from those who weren't so lucky.

I enjoyed this snapshot of Great Ormond Street and found the issues thought provoking. As someone who once briefly entertained the idea of a career in paediatrics it made me very glad that I opted for general practice. Although I recognise that the children depicted in the documentary represent the minority and that most paediatric patients will do well, these programmes attempt to highlight how emotionally difficult it can be for health professionals to care for sick children and how devastating it is for families to lose a child they have spent many years caring for. Many of the children with chronic illnesses have been attending the hospital for a large proportion of their lives, making it difficult for those involved in their care to remain emotionally detached when difficult decisions need to be made. Some of the doctors mention emotional attachments to the children, and we are left wondering how they manage to switch off from their day jobs or whether, indeed, they can.

As expectations of medicine continue to grow, it is good for us all to be reminded that despite all the advances of the past years we cannot, as much as we would like to, cure everyone and that, sometimes, enough is enough.

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BBC/FILMS OF RECORD

How long is a life?

Not long ago I was asked (being a doctor) to appear in a public discussion on the subject of longevity.

One of the proposed panellists was an eminent scientist who believed that we were on the verge of abolishing death; which abolition, were it ever to be brought about, would be grossly unfair to all those people who had died in the previous centuries.

However, I suspected (without having an evidence base for my suspicion) that the scientist was talking nonsense. Of

course, the natural span of human life has long been a matter of speculation. For example, Lionel Arthur Tollemache (1838-1919) wrote an essay in the 1870s on the question of whether or not there were any true centenarians and, if there were, how many there were.

Tollemache is described in the *Dictionary of National Biography* as “a man of leisure,” but he was also a litterateur who had the ambition to be something of a Boswell to Gladstone’s Johnson. He had his books privately printed and sold them at cost price; but even this was not enough to bring him lasting literary fame.

Longevity was a pet subject of his, and his essay in a book entitled *Safe Studies* was a meditation on the views of George Cornwall Lewis, a dull polymath who was also interested in longevity. Lewis wrote on Roman history, the interpretation of hieroglyphics, and the Phoenician voyages of discovery. While chancellor of the exchequer he controversially raised the rate of income tax during the Crimean war from 6.66% to 8.33%. Increases in income tax have certainly proved to be long lived.

Tollemache attributed the increased life expectancy of the Victorians to the fact that doctors now advocated port wine and

BETWEEN THE LINES Theodore Dalrymple



Tollemache attributed the increased life expectancy of the Victorians to the fact that doctors now advocated port wine and quinine rather than bleeding and starvation

quinine rather than bleeding and starvation. He was agnostic as to whether there was a natural span of human life and about what, if anything, concluded to centenarianism. He pointed out that “in those who have attained to an unusually great age, nothing is more natural than that they should take to their own wisdom the credit of their happy condition, and should urge their crotchets on all the world.” Unfortunately these crotchets, or quirky enthusiasms, were either implausible—for example, dining off roast turnips for 40

years—or contradictory, one centenarian attributing his long life to abstinence and another to drunkenness.

Oddly enough, Tollemache’s interest in longevity was equalled by his interest in euthanasia. The cure he advocated in “The Cure for Incurables,” privately printed in 1883 in a book called *Stones of Stumbling*, was an overdose of chloroform under medical supervision. This, he thought, would start a laudable fashion for “legalized Hara-kari”; those who committed it would be public benefactors.

Tollemache thought that the knowledge that one could end one’s life at any time would act as “an anti-preventive of exertion” among those with a morbid fear of invalidity; while those many Britons abroad who, for fear of premature burial, gave an advance directive that a dagger should be thrust into their chests prior to their interment in the Middle East within 24 hours of their death of plague “had already committed euthanasia in their hearts” and therefore could not object to euthanasia on abstract principle.

Tollemache died, aged 80, from natural causes, though he had been an invalid, and nearly blind, for much of his life.

Theodore Dalrymple is a writer and retired doctor

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MEDICAL CLASSICS

On Liberty

By John Stuart Mill Published 1859

Last year marked the 150th anniversary of the publication of John Stuart Mill’s seminal work, *On Liberty*. In it he states that “the people who exercise power are not always the same people with those over whom it is exercised.” In a properly functioning democracy power can be exercised only by the majority, and the majority might arbitrarily discriminate against a minority.

This led Mills to create the concept of the “tyranny of the majority.” This has very practical implications: the medical profession has a duty to stand up against any form of tyranny that serves to hamper the provision of an equitable and just healthcare service. In Mill’s view it is difficult to protect “against the tyranny of the prevailing opinion and feeling,” but it is in this very instance that our voices should be loudest.

Swathes of society have been allowed to be led astray by those who have an unfortunate sway in shaping public opinion. Humans are subject to the prevailing view in society—and will rightly or wrongly be fashioned by it.

Doctors have the backing of science when dealing with uncertainties that face the public; but while we do rely on evidence based medicine as individuals, we are not fluent in the art of public relations when trying to get this message across. It is a difficult and often thankless job, but it is essential that we remain stoical in the face of such adversity. For example, we should be willing to advocate the importance of evidence based medicine when dealing with any form of media frenzy and not be overrun by a wave of myopic policies. We should be steadfast

when dealing with issues of medical education and training and not allow the attainment of appropriate qualifications to be dictated by limitations set on us by bureaucracy.

On a more personal level Mill believed that “the only purpose for which power can be rightfully exercised over any member of a civilised community, against his will, is to prevent harm to others.” However, a caveat is added: those who are incapable of protecting themselves should be given liberty from authority only when they have shown

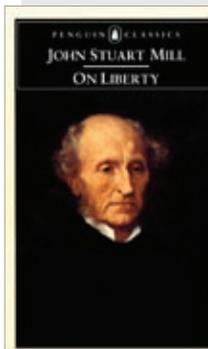
that they are capable of making just decisions for themselves.

This is similar to choice for patients. But this ideal should be offset against everyday pragmatism—not every patient is able to make an informed choice, nor is every special interest group able to argue its case in a manner that is balanced against the infinite needs of a healthcare service with finite resources.

This is not a rallying call to return to the age of paternalistic medicine, but doctors should remind patients to take control of their wellbeing. We should guide them with timely and evidence based information that will allow them to fulfil their role as partners in their management. After all, Mill did warn that the tyranny of the majority can be just as dangerous and damaging to society as any individual or oligarchic despotism.

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Be wary of patients bearing gifts

FROM THE
FRONTLINE
Des Spence



The NHS has a no fault, open approach to complaints; it is an organisation with “memory.” This, of course, is utter nonsense, and in reality there are witch hunts and ritualistic drownings. Obviously some complaints are justified, while others are wholly unjustified. The NHS struggles to distinguish between the two, because these are the days of health consumerism and patient power. So now doctors run scared of complaints, because they take a professional lifetime to resolve and because, irrespective of the circumstances, the professional is always criticised. Doctors accept complaints as a fact of modern professional life. But in truth patients sometimes use the threat of complaint to manipulate doctors to get what they want, not what they need. Sometimes I hold my ground despite the wielding of a threat of complaint because it is the right thing to do.

But what of gifts? Surely these are a marker of good care. Glasgow may be among the poorest cities in western Europe but also seems, paradoxically, to be among the most generous. Our cupboards are full not of important medical paraphernalia but straw donkeys, holy water, Old Spice after shave, Tweed perfume, and litre bottles of vodka. At Christmas the surgery is swamped by chocolates that everyone denies they will eat; they disappear

nonetheless. These are tokens and an honest response to the support we have given, especially in a medical system that demands no fees. It is reassuring that patients view us as normal people: unwashed, pagan binge eaters and drinkers.

But my unease radar starts bleeping with the regular gift givers, non-seasonal givers, and gift voucher givers. Gifts engender a sense of control and beholding, and if complaints are the sticks, then gifts are the carrots of manipulation. So in the encyclopaedia of unsolicited advice that I flog door to door to polite but uninterested junior doctors I warn of patients who claim, “You’re the best doctor I ever met,” or, “You’re the only doctor who ever listens.” I always add, “Be wary of patients bearing gifts.” It is hard to say no to the givers of presents, because few can resist the puffing of egos. So perhaps the NHS should meet criticism and praise a little more equally. Contrary to the populist political slogans being broadcast on a megaphone near you now, sometimes there is a fundamental professional duty to refuse to give people what they want, however they might try to play us.

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The Black knights

IN AND OUT OF
HOSPITAL
James Owen Drife



I never met Sir James Black, who died last month aged 85, but I used to worry that I might. Not that I move in Nobel prizewinning circles, but we ageing Scottish doctors tend to hang out in the same places from time to time.

What worried me was that I might have a senior moment and congratulate him on the Black report, a public health document written 30 years ago by a completely different Scotsman, Sir Douglas Black, who died in 2002 aged 89 (*BMJ* 2002;325:661). I’ve always been prone to such gaffes, muddling up friends who share similar faces, ages, sexes, and orders of chivalry.

With the Blacks it wasn’t just the name and the knighthoods. Both were graduates of St Andrews, and both came from archetypal Scottish backgrounds. James, born in a mining village, was the son of an engineer, and Douglas, born in Shetland, was the son of a minister. They also shared an aversion to political correctness and would no

doubt scorn the labels “left” and “right” that people love to apply, particularly this month.

James worked in big pharma, the *bête noire* of lefties everywhere, and invented two drugs that became world best sellers. His *Daily Telegraph* obituary said that “no man on earth earned more for the international pharmaceutical industry.” He made little money himself, however, and his Nobel prize horrified him. He was afraid it might persuade him that he had something important to say.

Douglas did have something important to say but fell foul of right wingers. A lifelong NHS supporter, in 1977 he was commissioned by a Labour government to report on social class differences in health. Then there was a general election. Only 260 copies of the Black report were printed, and the new government, under Margaret Thatcher, disowned it.

How quickly we forget. Last

month we Brits affected amused disbelief at the way the Americans fought over President Obama’s health proposals. How can the United States tolerate disparities such as a fourfold difference in maternal mortality between African American women and white women?

As Douglas might have reminded us, the United Kingdom has similar discrepancies. For example, maternal mortality among black African women in the UK is six times that among white women. But independent thinkers like the Blacks are out of fashion. As we endure another election campaign, I look back with envy at the slugfest surrounding the US health bill. There, unlike here, you could see some substance underneath the spin.

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See **OBITUARIES**, p 867