Fathers—good for families, bad for patients?

This year in the UK, doctors have faced resounding criticism from the media and parliamentarians (although patients still seem quite kindly disposed towards their physicians). Two words crop up with monotonous regularity, so I have sought to assist readers by quoting their meanings as offered in The New Shorter Oxford English Dictionary (Oxford: OUP, 1993).

Paternal: of, pertaining to, or characteristic of a father or fathers.

Paternalism: the principle or practice of behaving in a paternal manner towards others, specifically the claim or attempt by a government, company etc., to take responsibility for the welfare of its people or to regulate their life for their benefit.*

Medical paternalism, which has a long history, has become a subject of extreme obloquy. I am more than a little puzzled, being lucky to have had a father who taught me a valuable moral and ethical code and whose actions always appeared designed for the benefit of his family. Probably many of our colleagues have had equal good fortune, so it is hardly surprising that we have attempted to mimic this behaviour when dealing with distressed patients. This year we have learned, with discomfiture and surprise, that such an ostensibly benevolent approach is not seen as necessarily in our patients’ interests. Consequently, this month, ADC publishes an editorial by Professor David Hall, president of the Royal College of Paediatrics and Child Health, with a commentary by Professor John Lilleyman, his pathologist equivalent, reflecting on what we can learn from this year’s causes celebres (page 455). They deal with issues of consent, information, and partnership. Both express concern about the future of paediatric histopathology.

In a companion piece (page 457), two paediatric histopathologists remind us that more than 25% of NHS consultant posts in their specialty are unfilled with only a single trainee waiting in the wings. Can the service be saved? Lilleyman certainly believes so, although he predicts a struggle ahead. Meanwhile, optimism prevails from an unexpected source: Lishimpi and others from the University of Zambia, working with colleagues from the UK, examined why so many bereaved parents refused consent for necropsy (page 463). The reasons are surprisingly similar to what one might discover in the developed world, as are the suggested solutions. Perhaps, while we shrug off our fatherliness—some more regretfully than others—we need to decide just who it should be that explains to parents the whys and wherefores of necropsies. Many trainees in the UK have never seen a post mortem examination, yet are often given the task of obtaining consent; histopathologists, whom one might reasonably consider to know best, are rarely offered or have an opportunity to meet parents before the examination takes place. The debate is an important one and we look forward to readers’ comments via our rapid response system: log on to our website (www.archdischild.com), find the paper that interests you, click on “abstract” or “full text” and send your response by email by clicking on “submit a response”.

Screening—what next?

Paternalism aside, the UK media are also obsessed with what they are told is a massive rise in the prevalence of autism: a tenfold increase in recent years is the usual declaration. The evidence is thin; diagnostic labels, especially when applied to behavioural or psychiatric disorders can be victims of fashion. When the NHS was introduced, children with disabilities had to be categorised according to a set list, including severely subnormal, educationally subnormal, deaf, blind, maladjusted, delicate, and so on. There was a (pink?) form to be duly completed which enabled the child to attend a school designed for his category. Autism was not one of these defined categories so there was little incentive to diagnose it. The seventies brought an end to such medical rigidity—the terms used were seen as pejorative and integration in mainstream schools became de rigueur while the law now required a statement of a child’s special educational needs and proposals for meeting them. The special schools began to close; labelling, including that of autism, was regarded as unhelpful medicalisation of educational and social issues.

As political correctness waned and community paediatricians spread throughout the land, (note: an association, not causative) diagnosis became fashionable again. Paediatricians were no longer scared of diagnosing autism and a speciality had arisen who knew how to do it. Thus did a rare disease become less rare.

But how rare? It is important to know, both to direct appropriate help at those who need it and to provide facts with which to counter the wilder allegations about possible causes of autism, not least the misdirected campaign against the use of MMR vaccine.

A long preamble, but one that invites readers not to miss Dr Gillian Baird and colleagues’ important review of screening and surveillance for pervasive developmental disorders, published on page 468.

Screening—can we do it?

Ades and others at Great Ormond Street and the Institute of Child Health, London have audited coverage of neonatal blood screening in 14 health districts, covering over 90 000 births. Their paper (page 476) is essential reading for those to whom a Guthrie card is a slip of bloodstained blotting paper that vanishes into an unknown black hole, never to be seen again. In half the districts the national gold standard of over 99.5% coverage is exceeded and in the remainder the information systems make it difficult to know whether there is a failure of screening or just of recording. The new NHS number project, due for completion by the end of 2002, could solve remaining uncertainty.

Surveillance—where?

It is early summer in the UK and birds have flown the nest. A successful nest, with lots of fertile eggs, is the Welsh Paediatric Surveillance Unit. Sibert and colleagues, in a short report (page 486), demonstrate its effectiveness and that being “nested” in its national equivalent has proved a disadvantage for neither.

* Incidentally linguistic pedantry allows no escape for female colleagues: at one point in his report on organ retention at the Royal Liverpool Children’s Hospital, Michael Redfern QC referred to the paternalistic attitude of four women.

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