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BMJ

A wake up call for sleep disordered breathing

Evidence of ill effects is conflicting and inconclusive

See pp 851, 860

Sleep disordered breathing is characterised by recurrent obstruction of the upper airway, which results in episodic asphyxia and interruption of the normal sleep pattern. Although manifestations of sleep disordered breathing have been described for many years, the condition has achieved wider recognition only in the past decade.[1-3] It comprises a continuum—from chronic snoring to obstructive sleep hypopnoea to severe obstructive sleep apnoea—associated with progressively increasing clinical consequences.[4]

In this week's *BMJ* Ohayon and colleagues present data from questionnaires which confirm that sleep disordered breathing is common in Britain and is associated with increased use of medical care (p 860).[5] The reported prevalence depends on the recognition threshold. A community based study by Young *et al* found that 2% of women and 4% of men had both daytime sleepiness and an apnoea and hypopnoea index greater than five episodes per hour.[6] Thus, sleep disordered breathing is as prevalent as diseases such as asthma and diabetes, and some consider it to rival smoking as a major public health problem.[7]

Sleep disordered breathing remains undiagnosed in most patients, and doctors should routinely ask patients and their bed partners about snoring, interruption of breathing, and daytime sleepiness. Other symptoms include nocturnal choking, nocturnal awakenings, unrefreshing sleep, morning headache, and daytime fatigue. Most patients show no abnormality while awake, making it necessary to study sleeping patients. Increased awareness of the condition has increased demand for overnight sleep monitoring. Weight reduction, avoidance of alcohol, and relief of nasal obstruction should be addressed in every patient with sleep disordered breathing. For those who fail to improve on conservative treatment, a variety of treatments have been developed. Nasal continuous positive airway pressure (CPAP) is generally accepted as the first option, but oral appliances and corrective upper airway surgery are also widely used.

Increased demand for both diagnostic and therapeutic services prompted the systematic review published in this week's *BMJ* (p 851).[8 9] This evaluated all studies published between 1966 and 1995 on the association between obstructive sleep apnoea and mortality and morbidity, and on the efficacy of nasal continuous positive airways pressure. The authors concluded that there was limited evidence of increased mortality or morbidity in patients with obstructive sleep apnoea, and that the evidence linking the condition to cardiac arrhythmias, ischaemic heart disease, left and right ventricular dysfunction, systemic and pulmonary hypertension, stroke, and automobile accidents was conflicting and inconclusive. They thought that most of the studies failed to adequately take into account the confounding factors of obesity, smoking, age, and alcohol consumption and that few were of sufficient quality to be able to determine the effectiveness of treatment. They concluded that, although nasal continuous positive airways pressure had been shown to improve objective daytime sleepiness, there were insufficient data to determine its effect on quality of life, morbidity, or mortality.

In our understanding of the natural history of sleep disordered breathing and the impact of treatment, we are at a similar stage as we were with systemic hypertension and hypercholesterolaemia several decades ago. There is clearly enough observational evidence of the ill effects of sleep disordered breathing and the benefits of treatment to justify further research. We now need long term population based prospective cohort studies, with stratification by severity of sleep disordered breathing and risk factors, to examine the association with morbidity and mortality. More studies are needed on the link between sleep disordered breathing and road traffic accidents, taking into account the potential confounding factors of shift work, alcohol and drug use, and annual distance travelled. Well designed randomised controlled trials with adequate sample sizes are needed to further determine the indications, benefits, and risks of each of the currently proposed treatments. These studies should include quality of life measurements, objective assessment of daytime performance, covert monitoring of compliance, and long term follow up.

The quality of research into sleep disordered breathing is becoming more rigorous as it moves up the hierarchy of study design.[10] A short term randomised placebo controlled crossover study of nasal continuous positive airways pressure has shown improvement in daytime sleepiness.[11] A short term randomised crossover study has demonstrated that oral appliances are an effective treatment in some patients with mild to moderate obstructive sleep apnoea.[12] The United States National Institute of Health has recently funded a long term multicentre prospective study to examine the cardiovascular and cerebrovascular mortality and morbidity associated with sleep disordered breathing.

Sleep disordered breathing is common and has important implications for the population's health. Wright and Dye's recent systematic review has highlighted the limitations of current data about its associations and the effectiveness of treatment.[8 9] Agencies funding health services, in collaboration with the manufacturers of the different treatments, need to fund well designed studies of the effects of sleep disordered breathing and the benefits of treatment.

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Scientific imperialism

If they won't benefit from the findings, poor people in the developing world shouldn't be used in research

See p 887

This week the *BMJ* carries a debate on whether drug companies conducting clinical trials on patients infected with HIV in South Africa should continue to supply the drugs after the trial ends to the subjects who show benefit and who cannot afford to buy them (p 887).[1] Dr Peter King of Roche Products concedes that subjects in clinical trials in Britain may be treated differently from those in Africa and South America (p 890). This inequality of treatment prompts other questions. Should research be conducted in a country where the people are unlikely to benefit from the findings because most of the population is too poor to buy effective treatment? Are poor people in developing countries being exploited in research for the benefit of patients in the developed world where subject recruitment to a randomised trial would be difficult?

The marketing policies of multinational drug companies proves that they do not treat developed and developing countries equally. The Medical Lobby for Appropriate Marketing, an international lobby group based in Australia, repeatedly criticises companies which market in developing countries drugs that are denied a product licence in the developed world because of lack of efficacy or safety, or both.[2] A multinational drug company continued to market a drug as "an over the counter product" and advertised it directly to the public in Africa and rural areas of the Philippines years after admitting to the Food and Drug Administration that the drug was unsafe and long after its withdrawal from sale even on a doctor's prescription in the developed world.[2]

If poor people in a developing country have adverse effects from an unsafe drug, they are unlikely to sue a multinational company. If they sue, litigation costs will be less than in the developed world. Either the poor of developing countries differ dramatically in their pharmacological handling of drugs or their lives are valued lower by risk analysts and policy makers, including doctors, in some drug companies.

These double standards extend to drug research. Drug companies have performed research on children and adults in countries such as Thailand and the Philippines that do not conform to the Declaration of Helsinki and could not be conducted in the developed world.[3] Reasons quoted for conducting research in Africa rather than developed countries are lower costs, lower risk of litigation, less stringent ethical review, the availability of populations prepared to give unquestioning consent, anticipated underreporting of side effects because of lower consumer awareness, the desire for personal advancement by participants, and the desire to create new markets for drugs.[4 5] These reasons apply in other developing countries. The commercial secrecy that surrounds early clinical research, and safety and dose ranging in phase I trials in paid normal volunteers (that is, poor volunteers), means that much preliminary research is unpublished, particularly when adverse effects are high and further development is abandoned. Therefore, the extent of exploitation of poor people cannot be gauged easily.

Drug companies are not alone. I am aware of a researcher from a British institution who has conducted invasive research abroad after the morality of similar research in his own institution was challenged. The chairman of the ethics committee at the institution has assured me that such research would no longer be permitted at their institution. Doctors from academic institutions in the developed world travel to developing countries to perform invasive research in specialties such as cardiology and oncology when subjects with the same disease exist in their own country.[6-8]

The requirement that visiting foreign researchers obtain ethics approval from their employing institution as well as from the institution they are visiting may be inadequate. The Indian government recently announced that it will no longer tolerate trials of new or unproved treatments by foreign organisations when they are carried out exclusively on Indian subjects. This announcement came after the Indian Council of Medical Research rejected an application for funding of fetal tissue transplantation in retinitis pigmentosa to be performed only on Indian patients by American and Indian doctors.[9] There remain a large number of developing countries that will permit their citizens to be subjects in foreign trials.

In some experiments in developing countries it is difficult for patients to refuse to participate. In the developed world most patients can refuse to take part in randomised trials and opt for the best available proved treatment instead. In developing countries participation in a trial may be the only chance of receiving any treatment.

If investigators are unable to obtain ethical approval for a research project in an institution in their own country is it acceptable for them to perform the research in another country that has less stringent requirements? Do trials performed exclusively in developing countries, when the disease is also prevalent in the researchers' own country, confirm that researchers attach different values to some lives? Do trials which require participants to be foreign and poor differ ethically from experiments such as American radiation experiments in which the subjects were chosen because they were poor, black, uneducated, or sick?[10]

Rules are required to govern the way that international research may be performed ethically. Licencing authorities refuse to accept data from overseas research unless they are satisfied that it is scientifically sound. They must also insist that its ethical integrity is above reproach. Attempts to prevent unethical trials being conducted on subjects in developing countries will face opposition from those profiting from the research. Paradoxically, developing countries which are former colonies of an overseas power may resent a return to imposition of external controls.[11] Such objections must be overcome by universal agreement. The scientific community has a responsibility to ensure that all scientific research is conducted ethically.

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All doctors are problem doctors

Doctors worldwide must do better with managing problem colleagues

See pp 847, 910

Britain has in the past few weeks heard much about "problem doctors,"[1 2] and a book has just been published on the subject.[3] The public reaction to the cases reminds us that self regulation for doctors is not a right but a privilege that has to be deserved every day. And the book makes clear that doctors worldwide do badly with managing their problem colleagues. It also shows that in a sense all doctors are problem doctors. That is why we do so badly.

A fatal accident inquiry in Scotland heard how surgeon Gerald Davies operated on patients when he had a blood alcohol concentration that was probably twice the legal limit for driving[1]; while Britain's General Medical Council struck off obstetrician and gynaecologist Patrick Ngosa for continuing to treat patients when he was infected with HIV.[2] Both cases led to calls for compulsory testing of doctors for alcohol or HIV, and the sheriff hearing the Scottish case observed: "There appears to be a culture among members of the medical profession where it is regarded as inappropriate ... to report on certain matters, including in particular a colleague's apparent excessive drinking."[1] *Sun* columnist Anne Robinson put it more starkly: "In truth there is not a single reason to suppose these days that doctors can be trusted any more than you can trust British Gas, double glazing salesmen, or the man in the pub."

We shouldn't be surprised by problem doctors. Why wouldn't they exist? Think how surprised we would be by a community of 130 000 people (the number of doctors in Britain) where nobody committed terrible crimes, went mad, misused drugs, slacked on the job, became corrupt, lost competence, or exploited their position. Such a community cannot be imagined. And yet doctors often behave as if they are surprised by the existence of problem doctors. We choose to turn the other way rather than understand and develop ways of responding.

The new book shows that no country has an adequate system for managing problem doctors. British doctors, for instance, have been regulated by the General Medical Council for well over a century, but the council is only now introducing a system for

dealing with poorly performing doctors. In the United States problem doctors can skip from state to state, always one jump ahead of the regulatory machinery. Swedish researchers conclude that there has not been enough emphasis in the Nordic countries on tracking problem doctors and taking preventive action. The Canadians observe that bad doctors are insensitive to the threat of discipline whereas good doctors are needlessly worried by it.

Self regulation is the main distinguishing feature of a profession. The unwritten social contract says: "You have special skills and wisdom. You have unequalled access into the intimacies of people's lives. It is important that the state should not seek to control the development of your professional wisdom or interfere as you deal with the most profound of human difficulties. We therefore trust you to regulate yourselves. These special privileges are given in exchange for special service."

And perhaps self regulation is part of the problem as well as part of the solution. Doctors are set apart. We are a priesthood with our own rites, beliefs, systems of initiation, and tribal practices. And we have special powers. The public turns to us in moments of extremity and expects an answer, even a solution. Often we cannot provide it. We cannot defeat death, sickness, and pain. Everybody within the priesthood knows its vulnerability. But the public doesn't want to know too much about that vulnerability. They hope we can deliver, and we want to. Indeed, our privileges depend to some extent on us being able to. We are thus permanently conflicted: expected and wanting to deliver but often not able to.

Against this backcloth we can understand why doctors have such difficulties dealing with problem doctors. We are all problem doctors. And even if we aren't problem doctors today we might be tomorrow. Who wants to criticise a colleague in such circumstances? We understand how they grapple with the most awful difficulties with limited means, and we don't want to condemn them. We would rather turn away until we are forced—by criminal proceedings, publicity, or ghastly consequences for a patient—to act. Then we will, but reluctantly.

Marilynn Rosenthal—a sociologist who has made a special study of problems doctors in Britain, the United States, and Sweden—describes this phenomenon in the book. Through her ethnographic studies she has identified how doctors practice in a state of "permanent uncertainty" and must accept that "fallibility ... [is] an intrinsic part of the practice of medicine." All doctors have made mistakes, often serious ones, and their experiences "create a powerful pool of mutual empathy and an unforgettable sense of shared personal vulnerability." Living this way, doctors are unsurprisingly "quick to forgive," and "non-criticism" is the norm. "Where uncertainty surrounds all members of the profession daily and all see themselves vulnerable to accidents," writes Professor Rosenthal, "it is not difficult to understand a tacit norm of non-criticism, a conspiracy of tolerance."

Although readers of the book will understand why the medical profession has dealt so badly with problem doctors, that understanding cannot be an excuse. Doctors have to do better, and they need help from managers, lawyers, and sociologists. As always, the first step must be to acknowledge, understand, and define the problem. Next must come prevention. Although each country must have good systems for detecting, helping, managing, and sometimes removing doctors with serious problems, the main emphasis must be on preventing the development of serious problems in doctors.

The most crucial step in prevention is to recognise that, far from being less likely than ordinary members of the public to develop serious problems, doctors are in some ways more likely to. Doctors have the good health that goes with wealth, status, and rewarding employment. But young people are sometimes attracted to medicine by the care they have received when ill themselves. It may be that those who are afraid of death gravitate towards a profession that seems to be trying to defeat death, or that those with poor mental health want to join a group trying to understand the vagaries of the mind.

Once they arrive, medical students are put through a gruelling course and exposed younger than most of their non-medical friends to death, pain, sickness, and what the great doctor William Osler called the perplexity of the soul. And all this within an environment where "real doctors" get on with the job and only the weak weep or feel distressed. After qualification, doctors work absurdly hard, are encouraged to tackle horrible problems with inadequate support, and then face a lifetime of pretending that they have more powers than they actually do. And all this within an environment where narcotics and the means to kill yourself are readily available. No wonder some doctors develop serious problems.

The medical profession in each country needs to develop a long term strategy for preventing or at least reducing problems in doctors. One strand of the strategy should be to help the public and applicants to medical school understand better the limitations of medicine. This should reduce the pressures on doctors but also help people recognise the need to take more responsibility for their own health. Those who seek a career in medicine because of some special vulnerability should not be denied entry but should be given greater support from the beginning. We need to move from a culture that encourages doctors to hide distress and difficulties to one where we learn to share them and ask for help. Perhaps this will happen inevitably as medicine becomes less male dominated. Medicine also needs to move to a culture that encourages healthier working patterns, with shorter hours, better appraisal and guidance, and more flexibility.

Developments like these should help both doctors and patients, because problem doctors—as the two recent cases show—harm not only themselves but also their patients.

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This editorial is adapted from the introduction to the new book. I received no fee and will receive no royalties.

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Sudden cardiac death in the young

A family history of sudden death needs investigation

The sudden death from cardiac causes in a young, active, and apparently healthy adolescent or young adult is a major catastrophe. Of the several cardiac causes—including congenital heart disease, congenital anomalies of the coronary arteries, Marfan syndrome, and myocarditis—the commonest cause in young sports people is hypertrophic cardiomyopathy.[1] In one study 70% of patients with hypertrophic cardiomyopathy who died suddenly did so before the age of 30 years, and 40% died during or after exertion.[2] Such deaths are preventable, so why are they not prevented?

The incidence of hypertrophic cardiomyopathy in the United States is about 1 in 500,[3] which suggests that there are likely to be at least 100 000 cases in Britain. However, this is an underestimate because many people have mild disease and live for many years unrecognised. For them, the sudden death of an offspring is likely to be the first "symptom."

Hypertrophic cardiomyopathy is usually, if not always, familial.[4] In the familial form, mutations are present in genes coding for sarcomeric contractile proteins. In sporadic hypertrophic cardiomyopathy, de novo mutations occur in the same genes, indicating that the sporadic and familial forms have the same disease process.

Identifying people at risk is vital for effective intervention. Widespread population screening is not appropriate, but individuals with a family history of sudden cardiac death and/or cardiomyopathy must be carefully examined for evidence of disease. The first clue usually comes from the family history, but suspicious symptoms reinforce the need for investigation. Careful clinical examination, electrocardiography, and echocardiography will detect most cases.

In some cases echocardiography is normal but the electrocardiogram is mildly abnormal, perhaps because myocardial disarray can occur in the absence of hypertrophy. A few patients may need more specialised investigations such as effort testing and blood pressure responses to vascular manoeuvres, especially when there are signs that overlap with those of the athletic heart. Factors suggesting a high risk of sudden death are young age, history of aborted sudden death, strong family history of sudden death, syncope, abnormal blood pressure response to effort, and arrhythmias including occult conduction disease.[5] People with such risk factors need accurate diagnosis, and Holter monitoring to detect arrhythmias is essential to guide appropriate treatment.

Although there is as yet no cure, there is much that can be done to improve symptoms and prognosis and reduce the risk of sudden death. Advice on lifestyle and drugs such as β adrenergic blockers and calcium channel blockers can improve symptoms, while amiodarone can improve prognosis by controlling arrhythmias.[6] Implantable cardioverter defibrillators may prevent sudden death in patients with intractable arrhythmias, while dual chamber pacemakers may improve symptoms and effort tolerance.[7] Surgical treatment, including transplantation, may be useful for a small proportion of cases with special indications.

Two other cardiomyopathies—dilated cardiomyopathy and arrhythmogenic right ventricular dysplasia—are also important causes of sudden death.The incidence of dilated cardiomyopathy in the United States is 3-10 per 10 000, with 20 000 new cases being diagnosed annually.[8] It is now known that more than 20% of cases of dilated cardiomyopathy are familial,[9] and molecular genetic abnormalities have been found. Pathogenesis remains uncertain, but there is an association with enteroviral infection as well as evidence of autoimmunity, including the presence of disease specific antibodies that recognise cardiac α and β myosin heavy chain and other as yet unidentified antigens.

Early diagnosis has greatly improved the prognosis of dilated cardiomyopathy, as have better understanding of the disease, more sensitive diagnostic tools, better treatments, and greater awareness of the indications for cardiac transplantation and its timing. Four year survival increased from 54% in patients diagnosed during 1978-82 to 83% in those diagnosed during 1988-92.[10]

The detection of hypertrophic cardiomyopathy, dilated cardiomyopathy, or arrhythmogenic right ventricular dysplasia offers the prospect of treatment that will improve symptoms and prolong life. All those who are involved in the care of the young should be aware of these conditions. Failure to take notice when a young person reports a family history of sudden death demonstrates a serious lack of appropriate medical care. Screening for cardiomyopathy by experienced staff is accurate and readily available. Treatment improves symptoms and saves lives.

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Maternity services: the Audit Commission reports

Listen to women, especially after delivery

See p 845

Maternity care in England and Wales costs £1.1bn a year, an average of £1700 per pregnancy. The Audit Commission has the responsibility for checking that money is being spent wisely by local authorities and by the NHS. Its national report on maternity services was published last week.[1] A team from the commission visited 13 NHS trusts and collected information from 12 health authorities and 500 general practitioners. Through MORI, it surveyed a national sample of recent mothers: questionnaires were sent to 3570 women 16-18 weeks after delivery and 2375 (67%) responded.

The report concludes that although maternity services are becoming more "woman centred," further improvements are possible. For example, it recommends that women should receive better information about options for care; that midwives' work should be organised to maximise continuity of care in labour; and that problems with postnatal care should be rectified. It believes this can be achieved without increased funding. "Trusts can make better use of resources" by moving more antenatal care into the community, by employing staff flexibly, and by targeting specialist care.

The commission found wide variations in the number of routine antenatal visits and estimated that £10m could be saved by a reduced schedule. Research suggests, however, that women are less satisfied with fewer visits[2] and compensate by making extra appointments. The most difficult issue in antenatal care at present is screening for fetal abnormality. The commission did not include this in its cost calculations, recommending instead that purchasers should decide, after talking to clinicians, which screening procedures to include in their contracts.

Regarding care in labour, the commission recommends that women should have continuous midwifery support and should be fully involved in decision making. Many of the women surveyed had not felt involved in decisions about, for example, monitoring or episiotomy. Some women may not want a detailed description of an episiotomy, but in general clinicians are likely to agree with these recommendations.

More difficult is the recommendation that the level of intervention in labour should be "appropriate." What is "appropriate"? The commission found instrumental delivery rates varying between 5% and 13%; and while noting "concern" about high caesarean section rates (between 11% and 18%), the report does not specify an optimum figure. Nevertheless it points out that a caesarean section costs £760 more than a vaginal delivery, so a 1% increase in the rate costs the NHS over £5m a year. It would be a pity if these cost considerations led to pressure on obstetric registrars to avoid emergency caesarean sections. Litigation arises more often from delaying operation than from unnecessary intervention,[3] and four or five successful lawsuits for "brain damaged babies" could cost more than £5m.

The postnatal ward has always been the Cinderella of the obstetric unit, and the commission notes that "women make more negative comments about hospital postnatal services than any other aspects of their maternity care." Recommendations include flexibility regarding length of hospital stay, consistent advice breastfeeding, and a good environment on the postnatal ward, including facilities for families whose baby has died. One of the more specific recommendations relates to neonatal intensive care: a minimum of 500 intensive care days a year is necessary to maintain staff skills, otherwise health authorities and trusts should rationalise service provision.

Overall the report is balanced and constructive. Obstetricians will criticise the fact that details of the survey will be published several months after the results and recommendations. It is also disappointing that safety is mentioned only briefly. Safe childbirth has been hard won and is available to only a tiny proportion of the world's women. Women do not take safety for granted but the commission tends to do so.

Other recent surveys of maternity services have generally assumed that when women have more say in their care, intervention rates will fall. This report is more realistic. Women are even less inclined than doctors to take risks with the baby,[4] and as we learn more about how normal delivery can affect the pelvic floor,[5] well informed women are starting to request intervention.[6] American experience suggests that caesarean section rates may plateau between 17% and 25%.[7] When, earlier this month, a British newspaper asked "Should caesareans be available on demand?" it received a bulging postbag and remarked: "Somewhat to our surprise, those who favoured technology over nature were comfortably in the majority."[8] Hence the commission's comment that "cost and effectiveness issues need to be considered alongside women's views." If the two conflict, obstetricians should support the women, not the auditors.

The report is available from Audit Commission Publications, Bookpoint Ltd. 39 Milton Park, Abingdon, Oxon OX14 4TD (Freephone 0800 502030), £15.

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