

successful treatment has on quality of life as well as on mental and physical health.

The immediate challenge posed by sildenafil in the United Kingdom involves the need for rational decision making about availability on the NHS or from medical insurers. The challenge for clinicians, mainly general practitioners, is to be adequately informed, which will require urgent availability of information and education, usually sadly lacking in the field of sexual health. Although sildenafil seems to be a simple solution to a common problem, it should not be prescribed without assessment of the patient's physical and mental health and his sexual and general relationships, followed by management of underlying causes, such as diabetes, cardiovascular disease, or change to antihypertensive, antipsychotic, or antidepressant drug treatment. Smoking and alcohol consumption can have a profound adverse effect on erections. Patients may have severe relationship or personal difficulties, requiring counselling or therapy. The various treatment alternatives⁹ need to be discussed with the patient and preferably his partner before one is chosen.

Erectile dysfunction is a cause of misery, relationship difficulties, and significantly reduced quality of life for many men and their partners. Whatever the availability of sildenafil in the NHS, the effectiveness of

this treatment and the high prevalence of this distressing disorder make it inevitable that it will be taken by large numbers of men. The medical profession must respond with acceptable standards of assessment, followed by regular monitoring of continued effectiveness, appropriateness, and, above all, safety.

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Viagra and rationing

Let the sunlight in, let the people speak

The inability of Britain's government to come to terms with rationing is exposed by this week's "interim guidance" that doctors should not prescribe sildenafil (Viagra) (pp 000, 000).^{1,2} The government should use this opportunity to lead the debate that Britain needs on what will be provided on the NHS, who will decide, and how.

The fiction of the NHS, encouraged by this government and the last, is that the NHS can provide a comprehensive, high quality service that is free at the point of delivery and covers everybody. The reality, well recognised by most of those working in the service, is that health systems cannot meet all four principles.³ Something has to give. The United States has never had universal coverage. Britain has had continuing slippage in comprehensiveness, quality, and free access at the point of delivery, and now comprehensiveness is abandoned to a blare of trumpets.

"Media coverage of this drug to date," said Frank Dobson, secretary of state for health (recognising an opportunity to try and pin the blame elsewhere), "has created expectations that could prove a serious drain on the funds of the NHS. If this were to happen, other patients could be denied the treatment they need. I cannot allow this to happen." The reality is that patients are denied the treatment they need every day of the week. What's more, coming through the pipeline are a series of "lifestyle" drugs that will be attractive to those who want to be thinner or to soup up their slowing brains. Recognising that the founding principles of the NHS cannot be maintained, many would opt for abandoning

comprehensiveness rather than universal coverage, quality, and free access at the point of delivery.

Mr Dobson might thus find considerable support for the painful decisions that have to be made. What is unacceptable is that these decisions are made piecemeal, on the hoof, behind closed doors, according to unknown criteria. We need a comprehensive, transparent, continuing debate that is based on evidence and values. Almost certainly Britain needs an institution—perhaps a version of the Royal College of Physicians' National Council for Health Care Priorities⁴—that can hold the debate. There will be no end to the debate and no neat resolution, but the process will be of vital and continuing importance.

Instead, Mr Dobson is seeking "further expert advice" and "discussions with the manufacturer." No doubt he will try to bully the manufacturer into reducing the price. Good luck. But this won't solve the problem. Nor will "expert advice." There are no technical fixes for rationing. No expert can trade a man's impotence against a couple's infertility against adequate care for psychogeriatric patients against chemotherapy for childhood cancer. These trade offs depend on the values of our society, the agreed purposes of the NHS, and many other issues laid out in the agenda for the rationing debate published by the Rationing Agenda Group in the *BMJ*.⁵ The government has never taken up the agenda offered by the Rationing Agenda group, but now would be a good time to do so. The government cannot be blamed for failing to provide, but it can be blamed for obscuring and avoiding the debate.

*Editorial p 759
News p 765
Medicine and the
media p 824*

BMJ 1998;317:760-1



Will Gaylin, president of the Hastings Centre, bemoaned that in the United States that “What could have been a wide open, far ranging public debate about the deeper issues of health care—our attitudes toward life and death, the goals of medicine, the meaning of “health,” suffering versus survival, who shall live and who shall die (and who shall decide)—has been supplanted by relatively narrow quibbles over policy.”⁶ Britain should accept George Eliot’s invitation and take up the “the labour of choice.” And the government must lead.

Richard Smith *Editor, BMJ*

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The *BMJ* will be hosting the second international conference on priority setting in London on 8-10 October. For more information call Elaine Oliver 44 171 383 6137 or email her eoliver@bma.org.uk

Thalassaemia in Britain: a tale of two communities

Births are rising among British Asians but falling in Cypriots*

General practice
p 788

The thalassaemias are recessively inherited haemoglobin disorders with profound implications for individuals, families, and health services.¹ In the United Kingdom they occur mainly in certain minority ethnic communities, but prevalence varies within these communities. Around 3-10% of Indians, 4.5% of Pakistanis, 8% of Bangladeshis, 17% of Cypriots, 0.5-1% of Afro-Caribbeans, and 0.1% of the indigenous British carry thalassaemia.² Carrier couples have a one in four chance in every pregnancy of having a child with a major thalassaemia. Unlike some other genetic disorders, the thalassaemias are common and manageable, requiring, as a minimum, regular blood transfusions and iron chelation treatment to prevent iron overload. The cost of supporting a patient from birth to 30 years is estimated at about £250 000.³ Haemoglobin disorders can be prevented by carrier screening and genetic counselling, with the option of prenatal diagnosis, and antenatal carrier screening is recommended practice in the UK.¹ First trimester prenatal diagnosis is feasible in all at risk pregnancies,⁴ but a recent national audit has shown it is seriously underused.⁵

Uptake of early prenatal diagnosis by informed couples at risk for thalassaemia is high: when counselled in the first trimester over 90% of British Cypriots⁶ and over 70% of British Indians and Pakistanis request prenatal diagnosis.^{5,7} Informing couples later in pregnancy leads to lower uptake of prenatal diagnosis by British Pakistanis.⁷ With optimal carrier screening and counselling, this high uptake should be reflected in the number of prenatal diagnoses actually done, but the national audit showed that this is the case only for British Cypriots. Only 50% of Indian couples at risk and 33% of Pakistani couples actually had a prenatal diagnosis, the proportion for Pakistanis ranging from 0% to 60% by regional health authority.⁵

What underlies these discrepancies, and what can be done about them? Cypriots are distinguished from other groups by a high level of awareness of thalassaemia among health workers and the community. Historically, thalassaemia major has been seen as a problem for Mediterranean populations, and con-

certed awareness campaigns have greatly reduced its birth prevalence in the Mediterranean area.⁸ For example, in Cyprus there are now almost no new affected births.⁹ The messages from the intensive Cypriot education campaign have washed over to the UK and have been reinforced by support groups and local health services. Most British Cypriots request carrier testing before marriage or in early pregnancy, so community awareness reinforces health workers' awareness. Though prenatal diagnosis is available in India and Pakistan,¹⁰ there have been no education campaigns in these countries that might raise community awareness in the United Kingdom. Health workers are usually not aware that Asians are at risk of thalassaemia. The recently completed thalassaemia module of the Royal College of Physicians' confidential inquiry into counselling for genetic disorders¹¹ has shown that many districts with a large Asian population have inadequate screening policies, so that risk is often not identified or is identified too late in pregnancy for prenatal diagnosis to be acceptable. Hence most new thalassaemic births are now among the British Asian community.

Clearly, increased awareness among health workers and populations at risk is required for services to improve. In particular, primary health care providers need to become more involved in screening and counselling for haemoglobin disorders than they are at present. On p 788 Modell et al report a study aimed at promoting community based screening, and conclude that it is both feasible and desirable for primary care teams to provide this service, supported by a sympathetic haematology laboratory.¹² Appropriate information materials for carriers are now widely available on the internet.¹³

So what can individual doctors do? Firstly, be aware of the high frequency of haemoglobin disorders among minority ethnic groups. In particular, recognise that births affected by thalassaemia major are now commoner in the Asian than in the Cypriot community. Secondly, offer carrier screening to all British Asians of reproductive age. Finally, know where to refer people for screening and counselling. If levels of awareness are raised in this way then British Asians may become as