

Rationing: the search for sunlight

Rationing decisions should be explicit and rational

“Every choice involves a sacrifice,” said Søren Kierkegaard. Economists recognise this truth with their concept of “opportunity cost”: the cost of building a hospital is measured not merely in money but more broadly in the opportunities forgone. These might include better housing, a job creation scheme, or an antismoking campaign. Suddenly within health services we are becoming much more aware of having to make choices between different treatments, services, facilities, and patients. The word that has been attached to this activity is rationing—with its depressing overtones of queues and denial—but what is happening is less that people are being denied and more that the choices are becoming more explicit; in addition, broader sections of the community are taking an interest. These are healthy developments.

Doctors are less shocked by rationing than is the public. They have been at it for years. Decisions have regularly been taken not to continue treatment of terminally ill people not only because it would be kinder for the patient but also because it would be a waste of resources. Patients above a certain age have been denied admission to intensive care units; diabetic patients have been refused renal dialysis; and alcohol misusers have been turned down for liver transplants.¹ Often the rationale for these decisions has been clinical—because doctors feel happier making clinical rather than ethical decisions. But by converting ethical decisions into clinical ones they are deluding themselves, a process in which managers and politicians are happy to collude: taking such decisions in full public view is acutely uncomfortable.

Although most doctors recognise the inevitability of rationing, many people still believe that another chunk of the gross national product would solve the problem. The macrostatistics of Sir Bryan Thwaites and others showing the widening gap between what could be done and what can be afforded is one way to refute this optimistic notion,² but a better way may be to consider particular problems. We know that rates of coronary artery bypass surgery are lower in Britain than in many other developed countries, but this is only the tip of an iceberg of unmet need. John Hampton, professor of cardiology in Nottingham, gives a powerful lecture in which he illustrates how many patients with angina never consult a doctor; many are not treated when they do; many are never referred for exercise testing or angiography; and many don't make it to a bypass operation even when their symptoms would be much improved if they did. Professor Hampton ends his lecture with a picture of a dam, asking the audience to imagine what might happen if it burst. Or consider infertility treatment:

Robert Winston, professor of obstetrics and gynaecology at Hammersmith Hospital, estimates that less than 3% of those who might benefit from the new techniques of assisted conception are actually receiving treatment—and most of them are paying. Rehabilitation services have always been sparse, while the biggest unmet need of all is probably among those caring for disabled people in the community. Here deprivation is the rule.

Most health authorities around the world are still busy fudging the issue of rationing and hoping (in vain) that it will go away, but some have now become brave enough to make explicit the tough choices that must be made in health care. First of the brave is the Oregon Health Services Commission.³ Like most of the American states Oregon has insufficient funds to meet in full the health needs of those eligible for Medicaid. One response from Oregon was to decide that it would not pay for transplants, but this provoked an outcry from the media and a response from experts that transplantation is actually more cost effective than many other less dramatic interventions. Consequently Oregon started down the path of trying to rank medical interventions by combining the public's opinions with technical measures of cost and effectiveness. The first round threw up some bizarre suggestions, and the whole process has been conducted under a hail of criticism.⁴

But many have admired the courage of Oregon and its doctor-senator John Kitzhaber. Daniel Fox, a Harvard historian, has said: “What really astonished me. . . was the wide open manner in which the rationing debate is being carried out there. If one was searching for a classic exercise of American democracy, in the sunlight, it is Oregon's debate.”⁵ Together with Howard Leichter, a political scientist from Oregon, he adds: “the events in Oregon occurred mainly because health professionals who believed that these problems could be solved by reason, frankness, and good will occupied positions of authority. . . . The people who created and are implementing the Oregon plan assume that that the problems of cost and access can be solved by community discussion, by the application to policy of research based knowledge about assessing opinions and values and weighing the costs and benefits of medical intervention, and by legislative decisions that are accountable to voters. . . . The leadership of health professionals is not the whole story in Oregon, but it is the major, and largely unreported, story.”⁶ Nowhere else has begun to tackle this issue with anything like the same degree of openness or rationality.

The key questions about rationing once its inevitability has been accepted are who should do it and how it should be done. The BMA's document *Leading for Health* asks both of these questions.⁷ Traditionally, doctors have taken the lead but at the operating table and the bedside rather than in open forums. Sir Raymond Hoffenberg stated clearly the traditional view in this year's Harveian oration: "If services are to be limited," he said, "I would rather see it done implicitly—unstated, unwritten, unacknowledged—in the curious and not inhumane way in which such matters are managed in the United Kingdom."

Sir Raymond has misread the zeitgeist. Democracy in all its messy splendour is taking over everywhere; older democracies like Britain are talking of citizen's charters; and professions are suspect. The decline of paternalism and the rightful increase in demands for accountability mean that doctors cannot take such decisions alone or simply within the profession. Nurses and other health professionals must be involved and so must managers; they at least are used to working within environments where resources are never adequate to pursue all projects. The difficult people to involve in the decisions are those who in the end matter most: politicians and the public. Politicians are scared by explicit rationing and become vulnerable if they run too far ahead of the electorate, but they must begin to draw the public into the debate. Their problem is that the public is more likely to accuse them of meanness than admire them for forward thinking. But some politicians have begun to speak about the issue.⁸

Especially difficult is to involve the public in detailed decision making in the way that was achieved at least partially in Oregon. Health authorities may need to be much more accountable than they are at the moment if they are to make their difficult decisions with confidence, and authorities may need to look at devices like opinion polls if they are to find out what the public really thinks.⁹

The two disciplines that have the most to offer to the how of rationing are philosophy and economics, and both are building up considerable bodies of thought on the subject. Ideas that judgments might be made in terms of gender, age, income, economic value, or moral worthiness (as has often happened) become hard to sustain in the sandblaster of ethical argument,

and the debate inevitably drifts back to some sort of utilitarianism or cost-benefit analysis.

Many people accept that it feels ethically doubtful to devote large amounts of resources to achieve small benefit (even if that benefit is something as precious as prolonging the life of a child) when much greater benefit could be achieved by spending those resources elsewhere. Yet many people who would accept this general line of argument become upset by the thought of using techniques like QALYs (quality adjusted life years) to help make these difficult decisions. But often the worry is misplaced: even the greatest enthusiasts for QALYs argue that they are aids to analysis, not substitutes for thought.¹⁰ Better than abandoning them because of their many technical imperfections is struggling to improve them and to develop other techniques that will help allocate resources in a fairer and more rational way.

The debate on rationing health care in Britain has still to get fully underway in the community at large. The BMA has put it on the agenda in *Leading for Health*, but little is likely to be heard on the subject before the election. The debate should move beyond whether there is a need to make difficult decisions on allocating resources and concentrate on who should make them and how. Although it is tempting to leave the decisions to be fudged by kindly professionals, I believe that we should follow the Oregonians into the sunlight. Ways need to be found of combining public opinion with improved technical measures of cost and effectiveness to make the difficult choices inherent in allocating resources.

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Physicians for Human Rights (UK)

Showing early promise

Physicians for Human Rights (UK) was launched two years ago. Its constitution, drafted by a steering committee chaired by a former editor of the *Lancet*, Ian Munro, was approved at its first annual general meeting 12 months later. Is there really room for another medical group promoting human rights?

Doctors are singularly well suited to investigating abuses of human rights. They are perceived as independent, intelligent, and conscientious professionals, and the medical code of ethics is universally respected. Such a reputation encourages victims and witnesses to offer information, it discourages bureaucratic obstruction, and it lends authority to what doctors say.

But there is much more to it than that. People are accustomed to trust doctors with sensitive information, and doctors are experienced at dealing with distress. They are trained to evaluate information impartially, even in difficult circumstances, and to perform physical examinations and

take specimens. Medical specialists are responsible for more specialised investigations such as necropsy, psychiatric assessment, and biochemical analyses. And importantly for the success of campaigns condemning medical participation in abuse, peer group assessment is required before pressure can be exerted, which has occurred in response to the abuse in Soviet psychiatry.¹

The principal purpose of Physicians for Human Rights is to exploit these unique characteristics in investigating abuse of human rights. The four other aims are of similar importance: to defend health care workers persecuted for their beliefs or for practising ethically; to educate people about the physical and psychological consequences of abuse; to expose medical participation in abuse; and to promote cooperation between medical and other human rights organisations.

These are fine ideals, but what has the group achieved one year on from its first Annual General Meeting? Most notably,