

ECONOMIC AND POLITICAL PRESSURES AND THE RIGHTS OF THE PATIENT*

D. J. Hunter,† Nuffield Institute for Health, University of Leeds

This paper considers the economic and political pressures operating in and on the National Health Service (NHS) and their implications for the future direction of health care in the UK. The rights of the patient have to be analysed in the context of these economic and political pressures and their implications for the future of health care considered. If one was to distil this contribution into one word, it would be 'rationing'. But I have resisted using this term as it arouses all kinds of emotions which do not contribute to a cool consideration of the arguments at hand; in any event the issues are rather more complex than many commentators on rationing concede.

Economic and political pressures

Various economic and political pressures have always been a feature in the NHS and have underpinned and informed, indirectly or directly, successive reorganisations of the service from the 1970s on.^{1,2} The economic pressures are at heart political pressures because decisions on the money spent on health care are essentially political in a system centrally financed through taxation.

Arguably, these pressures are becoming more acute given the social and economic trends now in evidence. The key economic trends are an increasing national wealth, more women at work, greater career flexibility, more part-time employment, wider income disparities and continued public spending capping. Key social trends are an ageing population, a less community-minded population, more crime and violence as a consequence of a growing urban under-class, more fragmentation of families with smaller households, rising levels of education and changing attitudes to health. Moreover, these trends are occurring in a hostile political context where the priority is to cap, and preferably reduce, public spending aimed at lowering taxes and induce a 'feel good factor' in the run-up to the general election. No political party is openly advocating increased public spending through taxes, even though public surveys suggest that people would be prepared to pay higher taxes for better health and education services. Whether politicians are simply out of step with public opinion or whether they know something the rest of us do not, spending on the NHS looks set to remain static at best or at worst to fall slightly.

Regardless of what is actually spent on health care, all health care systems are subject to trade-offs between competing goals (Fig 1) and to some form of rationing whether implicit or explicit at various levels (Table 1). This leaves some key questions to address, including who decides, and on what basis (Table 2). Medical administrators, as Archie Cochrane pointed out almost a quarter of a century ago, have had a major responsibility for exercising choice.³

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†Professor and Director.

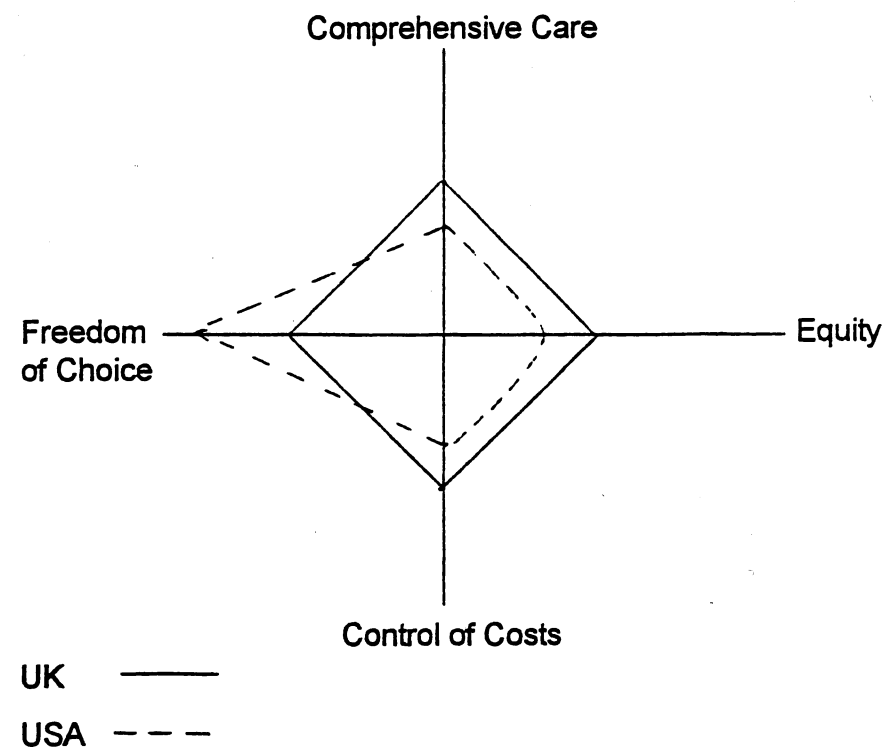


FIGURE 1
Objectives of a health care system.

The main job of medical administrators is to make choices between alternatives. To enable them to make the correct choices they must have accurate comparable data about the benefit and cost of the alternatives.

Government strategy has attempted to squeeze more out of existing resources and finances through numerous measures on the supply side leading to greater efficiency, including cost improvement programmes, value for money initiatives, bed closures, capping of management costs, and a greater emphasis on evidence based medicine resulting in the formulation of clinical guidelines and a move towards knowledge-based decision-making. All these measures—especially evidence based medicine (EBM)—are designed to avoid the need for rationing health care. Any required rationing should be based not on an arbitrary withdrawal of treatments but on a termination of those of proven ineffectiveness.⁴ The challenge of EBM is huge; it is, as Haines and Jones put it,⁵

To promote the uptake of innovations that have been shown to be effective, to delay the spread of those that have not yet been shown to be effective, and to prevent the uptake of ineffective innovations.

One estimate puts the savings to be achieved from ending ineffective procedures in excess of £1 billion and, it is claimed, this would comfortably cope with the newer challenges facing the NHS from developments in medical technology and demography.⁶

The NHS research and development (R&D) strategy, introduced in 1991, has proved to be an important instrument in achieving a reallocation of existing

TABLE 1
Levels of rationing.

| | |
|--------------|---|
| <i>Macro</i> | Deciding how much to devote to health care Deciding priorities between services and health care groups |
| <i>Meso</i> | Deciding priorities within services and health care groups |
| <i>Micro</i> | Deciding who to treat and how |

TABLE 2
Key questions.

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| What outcome 'descriptors' should be used? |
| Whose preferences should be used to determine policies for allocating resources? |
| Can individual preferences be aggregated? |
| Should rationing be implicit or explicit? |
| Does the public have a role in setting priorities? |
| Do professionals have a similar role? |

resources. The main objectives of the strategy are: (1) to base decisions—clinical, managerial and policy—on research-based information, (2) to provide the NHS with the capacity to identify problems that may be appropriate for research, and (3) to improve relations between the health service and the science base, with the key challenge being to get R into D, that is, to effect change in practice and behaviour. This has resulted in a profusion of bodies and initiatives aimed at implementation of these objectives (Table 3)

TABLE 3
Evidence based complex.

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|--|
| Health Technology Assessment programme |
| NHS Centre for Reviews and Dissemination |
| Effective Health Care Bulletins |
| UK Cochrane Centre/Collaboration |
| UK Clearing House on Health Outcomes |
| National Clinical Audit Information and Dissemination Centre |
| Central Health Outcomes Unit |
| Centre for Evidence-Based Medicine |

The emphasis on evidence based medicine is welcome and sensible but we should be wary of unrealistic expectations and should not ignore the lack of evidence concerning what works and does not work in medicine. Ministers are attracted to EBM because it offers a seemingly rational, scientific approach to making decisions; this, in their view, conveniently depoliticises decisions and therefore deflects any criticism that they are rationing health care on a crude, ill-informed, arbitrary basis. And, of course, health economists welcome the arrival of EBM—there are careers to be made, reputations to be shaped, new jobs to be

had and new riches to be amassed from the sudden profusion of research grants. Such investment in R&D is both welcome and overdue only if it succeeds in making a difference, and if research does affect development and ultimately practice.

Less convinced and impressed by the R&D strategy with its emphasis on EBM are those doctors who actually see patients and have to make complex decisions daily, which require finely balanced judgements on individual patients who vary enormously from one to another. Moreover, doctors frequently disagree among themselves, e.g., in the role of hysterectomys as a treatment of gynaecological problems, where some doctors reach for the knife at the earliest opportunity while others resist this option in favour of discussing others available with individual patients thereby allowing them to choose. The dynamic and changing nature of doctors' knowledge is well highlighted by a small anthropological study undertaken by Tanenbaum.⁸ She wrote,

Some of what (doctors) know is certain, all of it is changeable and some of what is known is always incidental to the sense of a case.

Arguably, patients and the public are also somewhat less than reassured by these developments which, far from engaging them in mutual discussion, often appear to marginalise them further, thereby reducing what are essentially political, value-based, ethical issues to ones of technical knowledge founded for the most part on randomised controlled trials. Such trials represent the gold standard research methodology, which may seem to bear little resemblance to the world a patient actually inhabits.

An example of spurious scientism is the Quality Adjusted Life Year (QALY) approach which raises all kinds of concerns (Table 4).⁹ What appears and is portrayed as a technical aid to decision-making, on closer inspection may prove to be riddled with assumptions and be quite misleading or simply wrong.

TABLE 4
Problems with QALY approach.

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| Variability of the valuations across different individuals |
| Potential for discrimination against certain patient groups |
| Meaning of the information that QALYs yield |
| Data are aggregated and this fails to allow for individual diversity and uniqueness |
| Medicine equated with the ability to benefit |

A growing concern is that 'cook book medicine' may be the outcome, i.e. medicine as a form of 'painting by numbers' in which professionals are reduced to the status of technicians following guidelines and protocols and so becoming less and less skilled at the art and craft of medicine where judgement and experience count for so much with individual patients.

Under the cloak of this new narrow scientism, political decisions affecting individual patients and communities may be transferred to a new breed of so-called experts and managers, thereby adding to the 'democratic deficit' in public policy observed by Stewart.¹⁰ Soothing words from politicians to the contrary offer little solace. Indeed, the more they protest their innocence the more one is inclined to conclude that their real wish is to contain costs and diffuse blame rather than to improve quality.

For their part patients may be suspicious too, for they may interpret the EBM approach as a denial of treatments which they feel they need and have a right to. The importance of the 'rescue principle' in medicine whereby something must be done at all costs in the event of a crisis (e.g. an air/sea rescue) should not be overlooked.¹¹ Considerations of cost and efficiency are not the dominant concern for the public, nor is it believed that the best interests of the individual should always be secondary to those of the group. The utilitarian credo, the greatest good for the greatest number, is not a dictum which the public would wish to follow unreservedly because it dilutes concern for the individual. The recent Child 'B' Case in Cambridge illustrates the dilemma.¹²

A rights based approach

Patient's rights can be considered as substantive and procedural.¹³ Substantive rights are to actual services and facilities, while procedural rights are to ensure that individuals are dealt with fairly when they come into contact with services.

The Patient's Charter talks about substantive rights but these are not enforceable. Those enshrined in the Charter are to receive health care based on clinical need and regardless of ability to pay and to receive emergency medical care at any time. If one does not get what the Charter promises, one can only complain, with the health service commissioner or ombudsman acting as a last resort. As the Child 'B' Case demonstrated, there is no enforceable right to health care under NHS legislation. Nor is it realistic or reasonable when resources are constrained to envisage all UK citizens having substantive rights to health care enforceable through the courts. How would this affect priority setting and rationing and, therefore, the allocation of resources? When there are competing needs and limited resources, whose rights would take precedence? Who would decide? The courts? If so, on what criteria? Would there be drawbacks in making political decisions subject to litigation?

Rather than empowering citizens in the rationing process, the attempt to establish substantive rights would cut right across it. The NHS has been founded on the principles of solidarity and collectivism. This ethic has been put under severe strain of late by the rise of consumerism (of which the Patient's Charter is a manifestation) and also a more assertive individualistic ethos. Balancing the needs of society with the needs of the individual has become fraught with acute tension.

Procedural rights pose fewer problems, although it would be unfortunate if the courts became too involved in making decisions in this area. The only beneficiaries, as ever, would be lawyers.

The Patient's Charter lays down the following procedural rights: a right to be registered with a GP; to be given a clear explanation for any treatment proposed; to have access to personal health records; detailed information on local health services, including quality standards and maximum waiting times, and to be guaranteed admission for virtually all treatments within two years of being placed on a waiting list. Overall, rights should not be seen as a substitute for collective decision making which constitutes the unique strength of the NHS. Rather, they should be seen as complementary.

If, as I have argued, priority setting and rationing are matters for collective rather than individual decision making, it is still important that they are perceived as fair and that, as far as possible, decisions are transparent and can be defended. Accountability is clearly central to this process but there are other mechanisms

and instruments which may lend themselves to both strengthening public involvement in the NHS and offering alternatives to be considered; open governance, public meetings, user groups, health panels/focus groups, electronic democracy, citizens' juries, and elected authorities with perhaps a new role for local government. There must be limits on how far the public can, should, or even wants to, be involved in setting priorities at a 'micro' level. Rationing at this level is probably best left to clinicians and patients. This is not to defend a sometimes paternalistic system in which doctors may claim that they always know best. Far from it, as the British Medical Association has recently acknowledged.¹⁵ But 'health fascism' is to be avoided whereby those with the loudest voice get their way.

I support Julian Tudor Hart's notion of seeing patients as co-producers of their health care together with their doctor.¹⁶ Redefining the doctor-patient relationship in this way may be a more effective means of proceeding than simply seeking to introduce a rights based approach to health care in a context where there is no tradition or history of one.

Of course, this still leaves open the problem of political accountability at higher levels. To address this issue, I favour some form of local government control over health care.¹⁷ The NHS is profoundly undemocratic, being part of what is known as the quango culture. Setting priorities for the NHS requires decisions but these are largely political, not technical. Evidence based medicine is now contributing to many decisions and hopefully to more in the future, but it cannot be a substitute for greater political accountability. There is a need for strengthened democratic institutions through which economic and political pressures can find expression. As Rudolph Virchow, the famous pathologist, who was also at one time leader of the liberal opposition to Bismarck in the Prussian Diet,¹⁸ expressed it over a century ago,

Medicine is a social science and politics nothing else but medicine on a large scale.

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