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Healthcare Rationing and Patient Rights

All modern healthcare systems face growing gaps between funding and treatment possibilities. Societal expectations call for decisions on whether to relax or accept resource constraints and how to deal with the respective consequences. The following article compares the different ways in which the healthcare systems in the USA, Germany and the UK have dealt with these problems to date.

Current healthcare reforms in the USA, Germany and the UK, representing significantly different funding conditions, reflect a common interest in market-driven cost containment. At present, US healthcare outlays amount to 2½ times the OECD norm in purchasing power parity terms and, failing corrective actions, are projected to swell to more than one third of GDP by 2030. Aiming to curb the public share of this, the 2003/4 Bush Administration's Medicare bill offers $500 billion prescription drug benefits to motivate pensioners to join a for-profit health maintenance plan that manages costs by substituting fixed-price budgets for fee-for-service arrangements. Germany's 2003/4 healthcare reforms, a key plank of Chancellor Schröder's Agenda 2010 to kick-start the economy, are to cut health spending by €20 billion by 2007. As part of this, German sickness funds are induced to pool chronically ill patients in specialised disease management programmes, replacing itemised reimbursement by global budgets. Strict enforcement of budget limits across the UK National Health Service (NHS) has contained total national healthcare expenditure to presently around 7% of GDP, but it has also positioned the UK close to the bottom of the OECD in terms of its overall capacity and perceived willingness to respond to patient needs. Initiatives presently under discussion in Parliament, if enacted, would offer more managerial autonomy to primary and hospital care and effectively disintegrate the NHS to obtain competitive performance contracts.

Each reform project embraces fixed-price, prospective contracts to deal with shortcomings of the respective current approaches. In each case, economic motives affect clinical autonomy and treatment decisions and limit patients' choice and payers' financial commitment. In each case, cost containment however may also result in unwarranted exclusions from vital cures and generally sub-optimal healthcare supply. Regulatory responses to evident risks differ in substance, each suffering from some acute shortcomings. The US relies on decentralised market and judicial reactions to challenge healthcare performance, but the system is severely hampered by unclear procedural and substantive standards. UK healthcare authorities insist on a national system of clinical governance, but treatment standards and performance guidelines continue to differ by regions. Germany's healthcare reform de facto "renewed" the country's reliance on corporate self-regulation, but there is clear concern about the legitimacy and anticompetitive impact of rules and a need for external supervision. Put this way, the three healthcare projects are in fact rather similar: in each case, political authorities effectively displace the responsibility for actually "managing care" without having set effective substantive and procedural standards.

But quality norms and treatment standards are essential to distinguish proper treatment from malpractice, and the wrongful from the justified denial of service. Clarity about the legal status of managed care organisation, contractors and patients is vital in determining the extent and allocation of liabilities, rights and obligations. Murky standards at each level hamper operational and regulatory governance and fuel concerns for legitimacy. How can patients/consumers, managed care suppliers and authorities determine whether a given service is fairly offered in competitive markets, or requires suppliers to be controlled by incentive contracts, or demands internalisation and direct regulatory control? How should courts pass judgment? What ultimately legitimises healthcare markets?

If these concerns are self-evident, why are responses to them not patently obvious? As is argued next, the explanation has three elements.

- Like most OECD countries, the USA, the UK and Germany do not face up to the essence of "managing care."
- Dodging the facts has fuelled the delegation of de facto decision-making to healthcare suppliers and manifests itself in a diluted system of governance and cost control.
- Growing demand-side concerns are being "dealt" with through the promotion of patient rights, which, how-

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ever, de facto are, and for all practical purposes should be, of little legal significance. There may be a right to "healthcare" but there cannot be an inalienable right to treatment. The question is how to advance from the current state of affairs.

Rationing Health Benefits

Managing care means rationing health benefits. Growing gaps between funding and treatment possibilities and societal expectations call for decisions on whether to relax or accept resource constraints and how to deal with the respective consequences. Relaxing constraints requires mobilising opportunities for productivity increases and/or diverting funds from alternative investments. "Value-based competition" and the development of new drugs and treatment methods may help to curb hospital bills, but their combined effect is unlikely to compensate for the total consumption growth that is driven by the demographic profile of most developed economies.[1] Hence, recognising the limits of growing healthcare at the expense of alternative consumption let alone investment requires accepting healthcare rationing as unavoidable. Healthcare rationing, that is allocating healthcare resources in the face of limited availability, means withholding beneficial interventions from some individuals. It is socially inevitable and prevalent. It is implicit in co-payment schedules, gatekeeper decisions, utilisation reviews and capitation contracts. Yet, it is also politically difficult. When in 1995 the French Prime Minister Alan Juppé tried to introduce explicit rationing of health services the country went on strike for five weeks. Few policy-makers dare to make choices explicit; most prefer to use euphemistic phrases such as "emphasising truly beneficial services". In the process, allocation decisions are clandestinely delegated to providers and performance expectations are raised that cannot be met. The discussion cannot be about *whether* to ration but *how* to make it explicit and do it well. As D. A. Barr says, "You can treat some people some time, but you cannot treat all people all the time."[2] Or to quote D. Callahan, "Medicine cannot conquer death or old age, but it can bankrupt us trying to do so."[3]

Explicit, Efficient and Legitimate Rules

Healthcare rationing requires explicit, efficient, and legitimate rules. In the ideal, rules are efficient to the extent that they fit specific circumstances and can be easily and broadly applied. In reality, there are trade-offs to be made. *Per se* rules are simply and broadly applicable, but they may not do justice to a specific circumstance; rule of reason decisions, by contrast, may only reflect a specific case, are completely discretionary and entail no regularity or rule at all. In the former, rule writing is separated from rule application; in the latter, decision-makers, in the extreme, set their own rules of action. Both face specific problems of legitimacy. In the case of healthcare, this translates into decisions on *what and who* is being treated, *how* decisions are made, by *whom*, and subject to *which* review?

Answering the first question, *what and who*, may result in listing the types of intervention for which society is willing or unwilling to pay and/or a set of criteria, such as age, prior health behaviour, or expected quality of life years after therapy, to determine when and when not to treat. Responses to these questions are apt to be linked to how "society" determines this *ex ante* macro-allocation of resources.

Given the vital importance of healthcare, one may expect citizens to want to take these decisions directly. In fact, responding to a growing interest in more direct involvement, some public authorities have tried to seize the opportunity to hand power back to the community, indirectly dealing with sensitive issues of distributional equity while boosting their legitimacy. But matters are not that simple. In 1988, for instance, following a complex process of asking citizens to rank healthcare priorities by expected benefits, the Oregon Medicaid Priority Setting Project released a list of interventions that would, and those that would no longer, be funded from the state's Medicaid budget.[4] Soon thereafter, the state's attention focused on the 10 years old Cody Howard, who had tried to raise $100,000 for a bone marrow transplant – no longer financed by Medicaid – but was $20,000 short when he died. Reacting to "public pressure", the government soon replaced initial formal cost-benefit justifications with references to the professional deliberations and judgment of an eleven member Health Service Commission. Put differently, when faced with the impact of their decision, citizens shifted the responsibility for it to the government, which passed it on to a committee.

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[1] Compare M. E. Porter, O. Teisber: Redefining Competition in Health Care, in: Harvard Business Review, June 2004, pp. 64-76, or G. Becker: New Drugs cut Costs and Medicare can help, in: Business Week, March 22, 2004, p. 32, with EU Commission: Budgetary Challenges posed by Ageing Populations, EU Economic Policy Committee, Brussels 2001, and R. Jackson, N. Hoew: The Aging Vulnerability Index, The Center for Strategic and International Studies, Washington DC, March 2003.

[2] D. A. Barr: Where do we go from here?, in: Introduction to US Health Policy: The Organization, Financing and Delivery of Healthcare in America, San Francisco 2002, Benjamin Cummings, pp. 223-37.

[3] D. Callahan: Old age and new policy, in: Journal of the American Medical Association, Vol. 261, No. 6, 1989, pp. 905-6.

[4] See also C. J. Rettern: Rationing Care in the Community: Engaging Citizens in Healthcare Decision Making, in: Journal of Health Politics, Policy & Law, Vol. 24, No. 6, 1999, pp.1363-1389. Similar priority setting initiatives have since been undertaken in the Canadian provinces of Nova Scotia and Saskatchewan and, under the label of citizen healthcare commission, are currently spreading across US states.

In an alternative process of *ex ante* resource allocation, the New Zealand parliament in 1993 rejected a vote on a defined core list of treatment in favour of guidelines and criteria to decide the state funding of treatment case-by-case. Although deciding on criteria – such as age – is obviously contentious,[5] the actual rationing decision was delegated, moving it from the abstract to the concrete, adding emotional involvement and informational complexity and requiring governance mechanisms to balance unavoidable discretion. Still, similar to the Oregon initiative, at least an attempt was made to democratically generate explicit *ex ante* rules to constrain resource allocation decisions.

By comparison, most OECD countries, in the final analysis, effectively remove prioritisation decisions from the public agenda and, with the partial exception of the UK, rely, explicitly or implicitly, on professional discretion and "bedside" rationing. In essence, healthcare providers are trusted to balance their concrete economic interest with a broad notion of healthcare efficacy, fill the regulatory vacuum and effectively define a nation's healthcare system and policy.[6] The problem is that the conjunction of implicit rationing criteria and healthcare reforms applying economic incentives to shape prioritisation decisions not only results in an awkward doctor-patient relationship, but in any given case may make reviewing the outcome difficult. While courts are unlikely to play a role in judging the quality of rationing decisions, they may be asked to pass judgment as to whether decision-making procedures are fair, transparent and concur with legal guidelines. Substantive rationing decisions would need to be reviewed by some board of medical examiners. But here the question is against which reference? While malpractice decisions are appraised against some generally accepted treatment standard, rationing decisions would need to be assessed in terms of a defined extent of treatment that a patient is entitled to receive. Are there any such inalienable patient rights with which to challenge rationing decisions?

Patient Rights

There are no inalienable patient rights! The World Health Organisation (WHO) identifies a range of conceptualisations of patient rights and implied differences in provider-patient relations. In its "paternalistic model", for example, "the best interest of the patient, as judged by the clinical experts, is valued above the provision of comprehensive medical information and decision-making power to the patient". By contrast, the "informative model", "sees the patient as a consumer who is in the best position to judge what is in her own interest, and thus views the doctors chiefly as a provider of information".[7] If the first notion captures the traditional doctor-patient relations, market-driven healthcare reforms require the latter. The question is to what extent patients have the legal standing to act on information and enforce their patient rights – and patient rights to what?

Patient rights may be formulated in three ways. As "legal rights" they pertain to well-defined areas and have no limitations related to resources. If violation occurs, patients can appeal to judicial authorities for compensation and sanctions. "Quasi-rights" are performance targets or framework conditions obliging healthcare providers subject to available resources at a given point in time. Non-legal policy documents, such as patient charters, formulate mere "moral commitments". Comparing national standards, patient rights in case of malpractice and injury are generally more widely recognised than any right to treatment. Legal regress in case of malpractice can hardly ever be directed against professionals but only against provider organisations. Here, judicial proceedings are not geared towards establishing guilt but instead aim to compensate the injured patient and to accumulate knowledge to pre-empt injuries in the future. "Legal rights" to treatment are even more limited and largely restricted to particularly vulnerable groups, such as the disabled. For anyone else, real economic limits abolish any pretense of inalienable rights to treatment.[8]

In Europe, the conflict between ambitions and resourc-

[5] Given that healthcare spending in general is heavily skewed towards acute care for the sickest, particularly the elderly, rationing decisions may be linked to age. In the normative search for an efficient decision rule, some may reject age-based rationing *per se* as it is held to violate principles of debt and gratitude that society is seen to owe to the elderly for their past considerations given to the younger. Conversely, others might view age-based rationing to follow the most clear-cut *per se* standard available. Others again may consider age-based rationing of no use in guiding any rule of reason decision chiefly because "chronological age is not necessarily an indicator of the severity of illness or the recuperative ability of individual patients, nor is it an absolute predictor of the efficacy of treatment." Cf. N. C. O'Malley: Age-based rationing of healthcare: a descriptive study of professional attitudes", Health Care Management Review, Vol. 16, Winter 1991, pp. 82-92; and D. Callahan, op. cit. Ethical and moral reasons aside, positive accounts would identify cases of age-based rationing or assess the likelihood of a democratic introduction of wholesale age-based rationing as a function the country's demographic profile. Cf. C. M. Clarke: Rationing scarce life-sustaining resources on the basis of age, in: Journal of Advanced Nursing, Vol. 35, No. 5, 2001, p. 799. Clearly, any of these perspectives unavoidably points to the second crucial question: how does "society" determine the *ex ante* macro allocation of resources?

[6] Even if it were to be assumed that physicians operate with societal interest in mind, recent research on how medical professionals actually evaluate specific treatment needs and benefits presents a less sanguine impression. Left to their own devices, physicians have developed their own set of rules of thumb "to think beyond the individual patient" when, for example, "choosing lower cost, slightly less effective but still good enough" treatment options. Ash and Ubel report examples of rationing norms actually used by physicians around the world that should trigger review. Cf. A. D. Ash, P. A. Ubel in: Rationing by any other name, in: New England Journal of Medicine, Vol. 336, No. 23, 1997, pp. 1668-1671.

[7] See http://www.who.int/genomics/public/patientrights/en/print.html.

es is clearly evident. Nordic countries, at the forefront of treatment contracts and care guarantees, do not offer any legal right to treatment. Although patient rights are enshrined in some Eastern European constitutions, their application and enforcement is limited to rare cases of "ministerial regulation." In the UK, the NHS is committed to providing a comprehensive service but recognises that resource limits cause the global allocation of funds, which unavoidably results in some services not being provided. Rationing decisions are open to judicial review only if the authority's decision is "unreasonable"; the government does not need to prove that rationing is required for financial reasons. The UK Patient's Charter mentions a limited number of patient rights related to access, quality assurance and complaint management. But so far the Charter itself has not conferred legally enforceable patient rights and does not provide for any external monitoring and enforcement mechanisms.[9] Similarly in Germany, patient rights so far have no explicit legal standing. Even though German courts have tackled patients' rights to information, deficits remain with regard to patients' right to inspect their medical records and, especially in cases of chronic diseases, to be clearly informed about their condition, treatment and prognosis. To the extent that civil law has established individual rights in some of these cases, they may be restricted by the social security system. Collectively, patients as patient organisations do not participate in developing guidelines. The 2003/4 healthcare reform brought a new documentation describing patient rights and duties, identifying the need for clearly defined service quality, the stage-wise documentation of treatment successes, and, on occasion, the reversal of the burden of proof relative to providers and the pharmaceutical industry. But policy perspectives have no legal effect; a "right to treatment" cannot be found anywhere in the reform documents.

The US model of decentralised healthcare governance requires patients to be given proper legal standing. Recognising this, the Clinton Administration's Consumer Bill of Rights and Responsibilities, issued in March 1998, was to strengthen the patient's role and confidence in the healthcare system. Since then, its underlying principles have spawned a plethora of divergent Patients' Bills of Rights offered by states, providers, health plans and patient groups.[10] But operational standards and enforcement mechanisms are often ill-defined and not every state that endorses a Patient Bill of Rights also adopts the necessary complementary legislation and administrative guidance.[11] Yet, even more important, deficient substantive standards not only heighten enforcement complexity and the risk of abuse but may also effectively void the opportunity of direct enforcement. As a result, patient rights in the state of New Jersey, for instance, originally envisioned as privately enforceable by patients against providers through a civil liability, were ultimately limited to enforcement exclusively by the State Department of Health and Senior Services.[12] Recently proposed specialised healthcare courts, if adopted, may help to address procedural concerns but cannot mitigate the lack of substantive direction.[13] Similarly, the renewed debate surrounding the US Patient Protection Act and the Supreme Court's intent to open up patient-doctor relationships for review, may broaden liability issues and thereby may have an impact on employers' insurance costs and trial lawyers' fees. But even these do not establish a patient's rights to treatment.

Hence in each case, the benefits given to one patient must be balanced by the ability to provide for all the members of society; hence robust prioritisation is needed. Yet, while in none of these countries governments operate an explicit and detailed system of priorities, in each of them ill-defined and legally loaded concepts such as patient rights create high expectations which, given resource limits, cannot but disappoint.

To advance from the current state of affairs, there is a need to engage in an open dialogue about resource constraints, opportunity costs and the extent of social solidarity that any individual can rely on. Only then can policy-making and implementation be separated, rules be technically efficient and enforcement be broadly shared, i.e. the provision of healthcare be effectively governed.

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[8] Cf. M. Silver: Patients' Rights in England and the United States, in: Journal of Medical Ethics, Vol. 23, No. 4, 1997, pp. 213-221; T. Fong, J. Tieman: Politics front and center, in: Modern Healthcare, January 12, 2004, Vol. 34, No. 2, pp. 26-29.

[9] Cf. J. Halford: Patients' rights, public law and the Human Rights Act, in: Consumer Policy Review, Vol. 11, No. 4, July/August 2001, pp.118-125.

[10] Advisory Commission on Consumer Protection and Quality in the Healthcare Industry: Quality First, Washington DC 1998. Patient rights statutes typically address concerns about information disclosure, access to providers and services, participation in treatment decisions, respect and non-discrimination, health data, and complaints and appeals.

[11] Cf. M. Silver, op. cit.

[12] Even if the informational advantage of public medical professionals were to be admitted, it may be wished to question the transparency and contestability of the agency's deliberation. For a broader discussion see R. Boscheck: Institutional economics & healthcare governance, forthcoming.

[13] Attempts to lower malpractice costs have let to the introduction of a variety of reform proposals in 2003/4. One bill, introduced by Senator Michael Enzi (R. Wyo.) in July 2003, seeks to establish special healthcare courts to resolve claims. Another model would define classes of avoidable injuries and create administrative panels to resolve these claims. Still, although the bills have made it into the Senate health and education committee, some observers believe that "the odds that these are being seriously addressed aren't very strong".

[14] Cf. T. Fong, J. Tieman, op.cit.