

Rationing of Health Care

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Abstract

Rationing refers to the allocation of a scarce supply relative to need and demand. In market-based economies, price typically establishes access to valued commodities except when ethical values, norms, and technical limitations make it impossible to allocate simply on the basis of price. Commonly recognized prototypes include allocation of scarce resources such as gasoline during war or currently in transplantation where the number of available organs is insufficient to respond to need and there are long waiting lists.

Medical care, even in countries that still depend on a marketplace model such as the United States, is an expensive service substantially funded by government. The availability and amount of services depend on government financing and its willingness to redistribute income through taxation. As the potentialities and costs of medical care continue to escalate beyond economic growth throughout the world, rationing is increasingly applied in distributing medical entitlement and resources. Such rationing is evident at every level of organization from defining the scope of health coverage to the allocation of care at the point of service.

Rationing can usefully be conceptualized as explicit (as in planned and defined allocations) to implicit when the norms are unclear and managers and clinicians use their discretion in allocation. This review examines the range of rationing approaches and dilemmas and how members of the public construe various rationing processes and their understanding. It examines the many levels of rationing decisions, many that are unrecognized, and how they are related to equity and social disparities of various kinds.

INTRODUCTION

Rationing in its most narrow sense refers to the allocation of a scarce supply, which makes it impossible to satisfy all wants or needs as occurred in the distribution of many basic commodities during World War II. The topic deals with how these commodities come to be distributed and the rules established for doing so in terms of efficiency and equity. In the case of many commodities, resources, and services, it theoretically remains possible to increase the supply if a source of public or private finance is able and willing to assume the cost but this commonly is not economically or politically feasible, making it inevitable that significant needs and wants remain unsatisfied.

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In health care, the most narrowly defined instances of rationing occur in the transplantation of the kidney, heart, lung, liver, and pancreas where the supply falls significantly short of need and many people die because of the scarcity. However, even in such extreme instances, supply could at least theoretically be extended if policymakers were to overcome cultural, normative, ideological, and ethical barriers in allowing a market for the sale of organs or partial organs, garnering organs from persons executed around the world, and other such socially restricted options.

While some analysts would restrict the medical concept of rationing to what have been characterized as “tragic choices” as in decisions about organ allocation (Calabresi & Bobbitt, 1978), more generally rationing refers to the allocation and distribution of services or commodities to defined populations that are arbitrarily limited because of budget decisions, unwillingness to increase taxes, limitations of facilities, personnel, and technologies and their maldistribution, and related economic and social contingencies.

The American health care system, and its market system and market ideologies, offers special challenges even while government pays for at least half of the health care provided. To the extent that health care is seen as a market, no different than the market for food, housing, clothes, or any other commodity, issues of allocation beyond insufficient supply are seen by some as no more than an issue of supply and demand and the capacities and willingness of individuals to purchase wanted health goods at the prevailing prices. However, governments throughout the world, including the United States, pay for the majority of health care through direct service provision (as in the Veterans Administration, the Indian Health Service or Military Medicine), sponsorship of care (as in the Federal Employees Health Benefits Program or comparable state programs or federal community health centers), or mandated insurance (Affordable Care Act, ACA), and provide many different subsidies for care to communities, hospitals, health systems, and special populations. Thus decisions by government, or its private and public intermediaries, determine who gets what and the allocation rules and administrative strategies are important rationing influences. In all of the above systems and programs, eligibility for coverage and obtaining services when needed are governed by rationing decisions and strategies.

FOUNDATIONAL RESEARCH

In the United States, there are few issues as contentious in health policy as the notion that a needed or desired health service would be withheld, particularly among the insured population. Throughout the history of health policy, the suggestion that a proposed new policy or system modification would “ration” care in some way, often used as a war cry by opponents, was

powerful rhetoric undermining support for health care changes. The backlash against managed care in the late 1990s (Mechanic, 2004) and the continuing attacks on the Independent Payment Advisory Board (see Atlas, 2012; for a contrasting view, see Jost, 2010) a component of the ACA, are two of many examples of political action and public opinion against arrangements that were alleged to ration care. When Republican legislators blocked the confirmation of Obama nominee Donald Berwick as Administrator of the Center for Medicare and Medicaid Services (CMS), their most frequent complaint being that he supported rationing of care, an allegation he denied, but which they inferred from a speech he had given praising the English National Health Service (see Atlas, 2012).

With the continuing rapid development of medical science and new medical technologies, and the increasing knowledge and sophistication of the public, all medical systems face increases in health care costs, and the displacement of other important public priorities, requiring strategies to constrain cost growth. Many are struggling to identify how best to achieve this while meeting the basic needs and demands of their populations. The United States is an outlier, spending approximately twice as much for health care as other developed nations and some 18% of its Gross National Product. Nevertheless, the United States stands alone in its failure to achieve universal coverage and the large gaps in access among varying subgroups in the population. Given the structure of American government and its politics, the United States has particular difficulty in constraining health care costs (Mechanic, 2006).

The ACA moves substantially in the direction of universal and more comprehensive coverage, but the United States also faces a significant challenge of restraining health care growth, especially in public programs in light of a large federal deficit, strong political ideologies, powerful industry and professional interests, and a demanding population. There is little agreement on how to contain costs successfully although the ACA includes, through incentives and demonstrations, a wide range of financial and organizational reforms allegedly able to achieve this while maintaining and even enhancing access and quality of care.

Health care rationing in its broader sense is ubiquitous, but the public generally only perceives some types of distribution as rationed. The concepts of explicit and implicit rationing help elucidate these perceptions (Mechanic, 1979). To the extent that patients live in a market system, they take for granted that their economic resources may limit access to specialists or the most expensive practitioners, that the less costly insurance they acquire may not cover many important services, that long waiting times in the facilities they use may be inevitable, and that medical encounters will be short and amenities few. To the average person, this is just the way things are.

Patients experience care as rationed, not when it is embodied in familiar patterns of care, but when it is “in their face” and when denial of care is explicit. The extraordinary backlash in the managed care arrangements that followed the failure of the Clinton health reforms was due to many factors (Mechanic, 2004), but not least among them explicit denial of care when the patient’s physician recommended it by an administrative authority such as a utilization reviewer. Patients were particularly unhappy that they had to seek their health plan’s permission for procedures they or their doctors thought essential. The same decision-making made by physicians in their everyday care would ordinarily arouse little opposition. This is now complicated by the Internet and media coverage of medical treatments, direct-to-consumer advertising, and increased awareness that one’s doctors may be compromised by conflicts of interest and administrative controls. However, to the extent that allocation decisions are embedded in patterns of care (that is, they are implicit), they typically are less problematic. The evidence reveals great variations in such decisions, particularly under clinical uncertainty, such as medications chosen, decisions for inpatient admission, surgical interventions, frequency of consultations, length of encounters, length of treated episodes, and waiting times among others (Aday, 2001; Wennberg, 2010).

Explicit rationing is most dramatic and controversial at the point of service, but explicit rationing typically occurs at administrative and managerial levels far from the point of clinical care. Health care can include potentially a large range of services and health insurance design establishes what will be covered. There is substantial variation among countries (Payer, 1996), and among health insurance programs in the United States, in what is covered from treatment in spas for rehabilitation to various forms of psychosocial care. Only with the passage of the ACA did mental health and substance abuse become essential services required in all insurance programs in the United States, and many types of care continue to be excluded commonly such as long-term care that is not rehabilitative, dentistry, and many other services used by large proportions of the population. Some types of coverage in public programs are controversial less for financial reasons than for political or religious reasons such as contraception and most persistently abortion services. Explicit determinations ration not only who can be covered (e.g., nonlegal immigrants in public programs) and what is covered (such as *in vitro* fertilization, substance abuse services, specialized cancer medications, or psychoanalysis), but also by the cost-sharing specifications that make some services more readily available and affordable. Some health systems such as the English National Health Service do not explicitly define the services covered or excluded nor do guarantee coverage for the population beyond what the allocated budget allows. In this instance, rationing is

determined by the established budgetary ceiling with much decision-making about care allocation implicit.

What people get under such conditions depend on how the budget is allocated among varying geographic areas and decisions about funding hospitals, clinics, health centers, and other facilities and their accessibility to the population. Rationing also results from the decisions made on how funding is allocated within medical organizations such as to specialty versus primary care, hospital versus ambulatory capacity, and the trade-offs made in funding particular services or types of specialty care. These also constitute explicit rationing decisions but usually do not approach the level of passion seen at the point of service when what is believed to be a life-saving intervention is unavailable or denied.

TRAGIC CHOICES

Calabresi and Bobbitt (1978) introduced the concept of “tragic choices” in the allocation of limited opportunities to obtain a life-saving therapy as in the transplantation of organs where needs far exceed the numbers of organs available and where many die waiting. In these dramatic situations of life and death, advanced countries have developed explicit systems of allocation that designate who in the queue has precedence, but many competing values are operative and there is no right decision. A classic study in 1984 on renal dialysis and other significant treatments in the United States and Britain found that treatment rates were significantly lower in the United Kingdom with very large disparities by age compared to the United States (Aaron & Schwartz, 1984). Such issues became salient first with the development of the artificial kidney and the establishment of the first renal dialysis unit at the University of Washington Medical School in the early 1960s. The capability to provide hemodialysis was small and only a few of the large number of persons who could benefit could be given access. In theory, a fair process would select by lottery from among those who met comparable medical qualifications, but lotteries are unpopular in these life and death situations and not accepted by the public. In contrast, a community committee was established to select recipients (Alexander, 1962) and the socially biased selection criteria used resulted in media attention, dissatisfaction, and public debate. Over time technological advances and public financing made dialysis for end-stage renal disease universal.

Organ transplantation has posed similar challenges. The US Congress enacted legislation in 1984 establishing the Organ Procurement and Transplantation Network (OPTN) to be administered nationally by a private nonprofit organization, United Network for Organ Sharing (UNOS). UNOS

developed computer algorithms in conjunction with procurement organizations at the local level and transplant centers throughout the nation, to direct access to an available organ among patients on various waiting lists. After considering such factors as tissue match, blood type, time waiting, and medical urgency, a number of normative and pragmatic issues come into play. The United States is divided into some 58 donor service areas each having an organ procurement organization covering from 3 to 10 million population (Leichtman, McCullough, & Wolfe, 2011). Organs are first offered to local transplant centers both because organs can spoil quickly in transport and because it is believed that serving the local area reinforces motivation to aggressively obtain donations, a form of geographic favoritism that some take exception to (University of Missouri Center for Health Ethics, 2011).

There are in fact a variety of nonmedical values that become relevant in the distribution of organs including the availability of health insurance to cover transplant services in many instances, the age of recipients where persons aged 75 or older usually are not considered and preference is often advocated for the young who are likely to have a greater number of potential quality-adjusted life years remaining. Other considerations that are sometimes operative are "worthiness" as reflected in previous damaging life styles such as substance abuse, a criminal record, developmental disabilities, noncitizenship, and legal status (Caplan, 2008). Some of these exclusions may be treated as medical issues based on assumptions of capacity to adhere to medical regimen, although these judgments are not necessarily consistent with evidence (see, e.g., Walkup, Sambamoorthi, & Crystal, 2001). Other rules facilitate favoritism such as allowing patients to have multiple transplant center enrollments, an expensive option because of repeated workups, primarily available to the affluent. An area of particular tension involves trade-offs between efficiency and equity, where the former emphasis is on assuring the largest number of life years saved for the supply of organs (Caplan, 2008; University of Missouri Center for Health Ethics, 2011).

Kidney transplantation has received the most sustained examination with waiting lists approaching 100,000 and kidney availability for <20% of those waiting. Moreover, given the wide range of donors with kidneys varying in quality and the complexity of the distribution system, the number of wasted organs has been increasing because of inefficient distribution (Sack, 2012). As John Friedewald, chair of the OPTN/UNOS Kidney Transplantation Committee has noted, "We can get thousands of extra life years out of the current supply of organs. But in each instance, we have made concessions in the name of equity ... we are trying to keep those really long lived organs for those who stand to benefit from them a long time. And by doing that, we can realize all those extra life years lived" (Friedewald, 2012).

The system for allocating kidneys from deceased donors has been fine-tuned in an iterative fashion over the years; however in December 2014, UNOS instituted significant changes to respond to a range of problems from inefficiencies in allocation to alleged gaming by transplant centers. The detailed changes are explained in reports and videos available on the OPTN website (Organ Procurement and Transplantation Network, 2014). These proposals are complex but essentially would divide the donor kidneys on the basis of a Kidney Donor Profile Index (KDPI), a clinical formula estimating the length of time the transplanted kidney is likely to function into two groups, the top 20% and the remaining 80%. Similarly, transplant candidates would be classified by an estimated posttransplant survival score (EPTS) clinically estimating duration of survival after transplantation. They too would be divided into the top 20% and the remaining 80%, with the best 20% of kidneys allocated to the 20% of recipients with the best survival prospects. The remaining 80% of kidneys would go to those on the local waiting list and if not appropriate medically would then be allocated first to other candidates in the region and then if not accepted to national candidates (Hippen, Thistlethwaite, & Ross, 2011; Leichtman *et al.*, 2011). Concerns about these recommendations include the unreliability of the KDPI and EPTS and the likelihood of clinician preference influencing these scores as medical judgment plays a significant part, and worry that live donors might be deterred, a concern particularly in the case of children who are most likely to attract live donorship but who could fare well under these new allocation criteria (Hippen *et al.*, 2011). While OPTN/UNOS is an impressively thoughtful approach, it cannot resolve the inherent conflict between efficiency and equity and in this sense decisions remain “tragic choices.”

FURTHER RESEARCH AND ANALYSIS

RATIONING INHERENT IN SYSTEMS OF CARE

Explicit rationing decisions are made at every level of decision-making. Depending on the role of government, expenditures for training of personnel, the construction and placement of facilities, and other important infrastructure such as information technology are planned and budgeted. In more private systems such as in the United States, such decisions derive from advocates and private or nonprofit actors influenced by the availability of governmental grants and financial and other incentives. Such mundane appearing policy decisions as definitions of essential health services to be covered, eligible treatments, permissible reimbursable providers, and administrative rules on conditions of service importantly establish who will be treated and how. These explicit decisions are compounded at every

level of administration and service. Managers at every medical facility must decide how to allocate their budgets and personnel. Hospital administrators must decide the resources devoted to departments such as emergency care, trauma care, burn units, behavioral services, and much more. They also usually must design the scheduling of work, the intensity of services, time allocated per encounter, the size of allowable queues and acceptable waiting times, the number and availability of surgical suites, and the like. Such operational decisions as the intensity of nursing service on different service units are significantly associated with important outcomes such as mortality (Aiken, Clarke, Sloane, Sochalski, & Silber, 2002; Needleman *et al.*, 2011). In a competitive market, hospitals may narrow their activities to services most remunerative (such as specialty hospitals), locate in suburban areas with few persons in poverty, or avoid functions that often operate at a financial loss such as emergency care, burn units, and mental health services.

Much of the rationing that occurs in health systems arise from these managerial decisions. Klein, Day, and Redmayne (1996), for example, have elucidated a range of rationing strategies that would not necessarily be seen as rationing by those affected. Among these strategies are denial, as when particular services are refused when not covered by a particular insurance arrangement; rationing by selection as when patients are chosen by the likelihood of success, willingness to pay more, or personal influence; rationing by deflection, such as referral motivated to get rid of bothersome or difficult patients; rationing by deterrence, as when various barriers are placed on access to services such as long waiting times, unresponsive phone systems, unpleasant and uncomfortable surroundings, and discourteous staff; rationing by dilution, as when encounter time is reduced or unnecessary repeated visits are required to complete the service; and rationing by termination as when clients seeking further help are told that no more can be done for them.

Much of the emotion surrounding rationing is evident when rationing occurs at the point of clinical care and when some service believed to be valuable is withheld. Many countries have had commissions and professional work groups to devise appropriate rationing rules but generally their products are too abstract and removed from the realities of care to be useful at the point of service (Sabik & Lie, 2008). Many medical ethicists seek explicit and transparent principles for such decisions (Daniels, 2008; Daniels & Sabin, 2002), but it can be argued that the great variability of patients, life circumstances, cultural differences, personal preferences, and the trajectory of illness itself make clinical discretion (implicit rationing) better suited to realistic contingencies at the point of service (Mechanic, 1995, 1997).

Perhaps the most explicit effort to establish a rationing approach was the Oregon Health Plan (OHP), designed to increase the number of enrollees

under its Medicaid program within a highly constrained budget, by devising a system to establish a hierarchy from the most basic and necessary care to less effective and less useful interventions (U.S. Congress, Office of Technology Assessment, 1992). After a number of advisory groups and public meetings, health professionals prioritized some 700 treatment condition/pairs by efficacy and other community values using various types of data. After the initial ranking, there were some obvious aberrations, for example, tooth capping had higher priority than surgery for ectopic pregnancy or appendectomy. Following much criticism, the rankings were readjusted by clinicians on the basis of professional experience. Initially, it was established that the budget was only sufficient to fund the highest 588 treatment/condition pairs, but it was expected that each year the service line would be adjusted depending on the budget.

The OHP effort received enormous attention around the world as well as in the United States. Implemented in 1994, the approach was to extend Medicaid coverage to an additional 320,000 enrollees. But contrary to much of the public discussion, the ability to do this came from enhanced state funding due to an upturn in the economy and the growing dependence on managed care. Moreover, not only did the list not ration care to any appreciable extent but in fact provided a more generous set of benefits than were available in the prior Medicaid program. There were loopholes as well that allowed physicians to provide services below the cutting point if patients had conditions needing treatment for treatment/pairs above the line (Leichter, 1999). Finally, as most patients were capitated within HMOs, physicians had discretion to provide whatever care they deemed necessary whether above or below the line. An interesting analysis by Jacobs, Marmor, and Oberlander (1999) saw OHP as more a political than rationing strategy to increase investments in health by bringing greater awareness of need to the public and the legislature.

As the years have gone by, it is clear that the key driving influence on what care is and is not provided is the state economic environment and funding for the Medicaid program. Oregon has faced some very difficult budgetary years requiring cutbacks in coverage and increased co-payments in their Medicaid program, leading to significant disenrollment among the poor.

TENSIONS BETWEEN EQUITY AND RESCUE

In the early debates over the treatment/condition pairs in Oregon, a major criticism of the initial list was the failure to acknowledge the rule of rescue that gives high priority to the saving of identifiable lives when such possibilities are evident (Hadorn, 1991). For example, tooth capping was given greater priority than surgery for ectopic pregnancy or appendectomy, which could

save lives. Public health practitioners and cost-effectiveness analysts are typically attuned to interventions that save or enhance statistical lives whether through prevention or careful planning of treatment, but the public, and often policy makers as well, respond to the poignancy of identified individual cases, allowing individual campaigns and disease advocates to skillfully use the media to encourage disproportionate resources to their cause (Daniels, 2012; Largent & Pearson, 2012). Major national health policies have been made, such as the initially unique eligibility of coverage for persons with end-stage renal disease treatment within Medicare, in part by staging individual patients and treatments before the key congressional committee (Rettig, 1991). Infant mortality rates and case fatality rates often appear to be less persuasive than presentation of an attractive patient whose survival requires a particular type of treatment. Many advocacy groups have developed impressive expertise in mobilizing emotional commitment to their cause in ways that appear to violate norms of equity and cost-effectiveness.

KEY ISSUES FOR RESEARCH

Over the years there have been allegations that these inclinations to think in terms of known individuals in contrast to aggregate disease burden result in a discordance between health care investment and the true burden of disease. Health research is also rationed with a majority of meritorious projects as judged by peers remaining unfunded. Observers point to the impressive success of advocacy for specific diseases such as HIV/AIDS (Gould, 2009), breast cancer (Lerner, 2001), and end-stage renal disease (Rettig, 1991), relative, for example, to other cancers, behavioral health, and most orphan diseases (Largent & Pearson, 2012). Discussion has focused on funding patterns of the National Institutes of Health (NIH), the largest health funding agency in the United States, for which there are data amenable to research, but even these data and their underlying classifications are elusive. Researchers have reported a range of conclusions about the discordance between disease burden and funding patterns (Sampat, Buterbaugh, & Perl, 2013). Using a new NIH data system, the Research, Condition, and Disease Categorization System introduced in 2008, Sampat *et al.* (2013) examined in a variety of ways the association between burden as measured by mortality and by hospitalization and NIH funding. Contrary to popular stereotype and anecdote, they found a reasonable correspondence between these measures. They estimate, for example, that deaths account for 54% of funding variation with similar estimates for hospitalization. This, of course, leaves a great deal of variation that requires explanation. These data are only a yearly cross-section and require more extended longitudinal analysis as new patterns of funding evolve. As NIH funding grows more slowly and is even more constrained, the debate about allocation will become more contentious.

Research in access to care and expenditure patterns document vast disparities by geography, urban and rural living, and residence as well as by race, ethnicity, gender, socioeconomic status, and immigrant status. Such disparities are large and persistent (Aday, 2001; Sampson, 2012). Such disparities and their consequences result from a multiplicity of biopsychosocial determinants and not directly by rationing. However, the same determinants of many of these disparities, such as access to information, resources, and influential social networks (Link & Phelan, 2010), also illuminate the extent of exposure to rationing and its effects. Nevertheless, these two large research areas and literatures are almost completely parallel, with little mutual awareness and almost no linkage. Yet, many of the major social determinants of health are linked to the burdens of rationing, where access to limited resources are affected by many of the same social determinants of social status, power and influence, information, and the availability of social networks. There is need, both theoretically and empirically, to blend these important endeavors to understand how social determinants shape where, when, and how rationing magnifies social inequalities.

There remain too few microstudies on how rationing policies are devised and implemented at different levels of the health care system from the explicit managerial decisions made by legislatures, administrators, and insurance executives to the provision of services at the clinical level. However, there are many relevant studies in varying disciplines and subareas of research that have never been brought together in a meaningful way or tied usefully to larger theoretical concerns although there have been some early commendable attempts (Elster, 1992; Klein *et al.*, 1996).

Rationing, however conceptualized and whatever we call it, will have increasing importance in health care in modern nations as technological possibilities outpace economic growth. Already, health expenditures are squeezing other important social priorities in many advanced countries, some with greater importance to health than the provision of health services. Establishing how to reign in health care costs is now one of the most important challenges of social policy and one where social and behavioral science have much to contribute.

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David Mechanic is the René Dubos University Professor of Behavioral Sciences and served as Director of the Institute for Health, Health Care Policy, and Aging Research at Rutgers University (1985–2013). He is the author of more than 400 publications, including *The Truth About Health Care: Why Reform is Not Working in America*; *Inescapable Decisions: The Imperatives of Health Reform*, and *Mental Health and Social Policy: Beyond Managed Care (sixth edition)*. Dr. Mechanic is a member of the National Academy of Sciences, the American Academy of Arts and Sciences, and the Institute of Medicine, and has received numerous awards, including the Rhoda and Bernard Sarnat International Prize in Mental Health from the Institute of Medicine, the Distinguished Career Award for the Practice of Sociology and the Lifetime Contributions Award in Mental Health from the American Sociological Association, the Rema Lapouse Award and the First Carl Taube Award for Distinguished Contributions to Mental Health Services Research from the American Public Health Association, and the Baxter Health Services Research Prize. Dr. Mechanic received his doctorate in sociology from Stanford University.

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