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1. Introduction

In many European countries where reforms of the welfare system are underway, reference is often made to the need to ‘rationalise’ the provision of health care. This term is generally used to refer to the need to organise healthcare effectively by reducing waste, containing costs, and ensuring that budgets are adhered to. Actions taken to achieve this are varied: some relate to the provision of services (for example, concentrating the provision of goods and services, redistributing health care workers); others require redefinition of the level of service provision (for example, avoiding hospital admission for conditions that can be treated in the clinic, or in day care); others rely on the application of the tools provided by evidence based medicine and evidence based healthcare to define the most effective medical care and interventions (for example, eliminating those procedures whose effectiveness is not supported by firm scientific evidence). All this is aimed at making healthcare provision more efficient and effective. Nevertheless, despite the efforts being made in this direction, it is becoming evident that rationalisation of healthcare provision is not sufficient in itself. The ageing population, the development of new and expensive technologies, the emergence of new diseases such as AIDS, Bovine Spongiform Encephalopathy (BSE), Severe Acute Respiratory Syndrome (SARS), and above all the rising expectations of healthcare users, are all leading to an unsustainable tension between demand and healthcare resources available.

Because it is not possible to provide everything to everyone, even by putting unacceptable pressure on present finances and by threatening provision for future generations, and since it is arguably socially unacceptable to leave the provision of healthcare to the free market, it is inevitable that certain choices be made. This implies a process of ‘rationing’, rather than ‘rationalisation’, that can be defined as ‘the distribution of resources between programmes and persons in competition’. In the process of rationing, a series of crucial questions must be posed: What treatments or healthcare services should be provided to citizens? How should these services be distributed between members of a society amidst budgetary constraints? Who decides? How? On the basis of which criteria? The problem of rationing (also referred to as ‘priority setting’, or ‘resource allocation’) in healthcare is therefore a problem of the moral legitimacy of such choices; this chapter illustrates this. As challenges of rationing are not expected to change in the foreseeable future, at least not in principle, we will address future and present rationing challenges in health care similarly.
2. From implicit to explicit rationing

Traditionally, the many resource allocation decisions in healthcare were made in a non-explicit manner. Healthcare budgets were allocated to local authorities on a historical basis and doctors were given the task of deciding priorities for the provision of services. Today, increasingly, the choices made by politicians and professional healthcare managers must consider general and specific criteria in planning within budgetary constraints, and they are subject to scrutiny from a general public that is increasingly determined to see proper provision of healthcare in return for their taxes. But it is doctors that are seeing the greatest changes. The old pact that implicitly gave them the task of distributing healthcare resources according to their professional judgement is gone. In the medical world there is now an explicit requirement to account for the treatment choices made, and there are mechanisms for checking disparities in the provision of diagnostic and therapeutic services. These choices were once seen as strictly a matter of professional autonomy. A further change that is indicating a move to a more explicit form of rationing is the change in the once paternalistic doctor-patient relationship. A better educated population with easy access to healthcare information, that is increasingly aware of the need to become involved in decisions that concern their own body and health, and their associated rights to healthcare, is pushing to question doctors’ decision making and to demand explanations of choices made to include or exclude certain conditions from healthcare provision. There are many cases of explicit rationing that are emerging in different European countries: one of the most widely discussed of these was the case of Child B in the United Kingdom, who was denied experimental therapy for leukaemia on the basis that it was prohibitively expensive and of unproven efficacy (Ham, 1999).

In general, there is some agreement that rationing should be more open and explicit, thus increasing accountability and the credibility of decision making. Despite this, a number of arguments have been posed against this, particularly that it may lead to instability in the health system and/or may cause harm to patients and the public. Others suggest that rationing is about decision making and should be considered a political process that is experimental and incremental.

3. Levels of rationing: macro, meso and micro

Healthcare rationing is a pervasive process that takes place at all levels and assumes various forms. Choices concern priorities, so that the rationing taking place at different levels of the public service through a hierarchy from high to low often constrains spending at the lower level. There are at least five levels at which choices are made:

- the level of funding to be allocated to health services
- the distribution of the budget between geographical area and services
- the allocation of resources to particular forms of treatment
- the choice of which patients should receive access to treatment
- decisions on how much to spend on individual patients

For convenience it is common to refer to three levels. The first (‘macro’) is the national or regional level, where the healthcare budget is decided. At this stage, decisions are made regarding increases in contributions, reductions in spending, or financing of particular programmes. Macro-decisions at a national level represent the key constraint within which
further divisions of funds between regions and local health providers are made according to
different functions and local authorities make decisions about local priorities. Such choices
may involve the priorities attached to, for example, treatment services versus preventative
medicine; particular patient groups, for example those with renal failure versus drug
addicts; or certain hospital services, for example cancer services, versus other services such
as respiratory care.

The third (‘micro’) level is the care level, where healthcare professionals make decisions
about who, how, when, where and how to care for patients. This is a question of
professional prerogative that can be limited by constraints from above, but never
eliminated.

4. Decision makers and problems in reaching consensus: Who decides?

In societies where health services are funded and supplied principally via the state, cost
increases and budgetary constraints impose difficult choices that influence the services that
can be provided, the patients served and the circumstances of healthcare. The notion that
public opinion can influence the decision making process has gained momentum. Taking
note of public opinion obliges doctors, managers and politicians to take account of the
concerns of the population, supports the formulation of objectives according to need, and
favours social cohesion as well as civil identity. Many claim that without the agreement of
the public, choices about rationing should never be effected, as they lack legitimacy. It is
important to remember that public opinion about what services should be provided
frequently differs from the opinions of doctors and healthcare managers. It is also important
to note that in some jurisdictions, healthcare professionals other than doctors/physicians
have a strong say in this matter.

Considering the tendency of healthcare providers to be sometimes unresponsive to the
needs of society and inward looking, this development of public involvement is to be
considered a positive step. In a democratic society it is no longer acceptable to make
decisions in the name of and on behalf of others without those others being informed and
consulted. It is a matter of what we now call ‘citizen rights’. Nevertheless, involving the
public in decision making is a complex process, both in principle and in relation to the
instruments that are used to gather public opinion. It is worth considering these limitations
in order to mitigate their effects (Mossialos & King 1999):

- The public, in general, is not in possession of enough information to make decisions.
  Unless certain information is supplied regarding the effectiveness, risks, costs, and
  quality of life implications of interventions, along with the options for alternative
  treatments, decision makers cannot fully understand the problem.
- There is a lack of familiarity with the debate on rationing, which would permit the
  public to be capable of assessing the questions presented.
- The effect of bias in public opinion caused by emotional responses generated by a
  media that prefers sensationalist reporting to accurate presentation of facts should not
  be underestimated, as shown by the Di Bella case in Italy (Benelli 2003).
- It is important to encourage the public to think in terms of public interest as a whole, for
  the common good over and above the good of individuals.
- Even public representation, when it exists, can present its own problems. The inclusion or exclusion of certain groups or individuals can influence the range of attitudes and values expressed. One approach is to involve service users, another is to solicit general public opinion, or the opinion of institutional representatives. In the US state of Oregon, for example, groups of disabled persons rejected the first list of proposed funded treatments; they argued that the quality of life of disabled persons was undervalued by the Commission addressing their matter.

- It is also necessary to consider the level at which choices are made (Litvaa et al. 2002). At the system and program levels, informants generally tend to favour consultation, without taking responsibility for decisions, but with the guarantee that their contribution would be heard and that decisions taken following consultation would be explained. At the patient level, it may be that the public should participate only by setting criteria for deciding between potential beneficiaries of treatment, leaving the final say to the doctors and the patients involved (and other healthcare professionals and family involved).

- There are many methods that can be used to solicit public opinion. These include surveys, in-depth interviews, public meetings, community forums, focus groups and citizens’ juries. This list is not exhaustive, but reflects a range of options available. Pros and cons in terms of time, costs, depth and breadth of analysis, discussion and deliberations should be taken into account.

- Regardless of the method used, the value of public participation in priority setting is largely dependent on the importance placed, by decision-makers, on the results of public consultation. The participation of the public in setting priorities is key for legitimacy. It is an educational process that has to be encouraged and sustained. Public debate should be based on relevant information and accurate communication, be open and transparent with all stakeholders, and should make use of appropriate tools.

5. Methods of rationing

Methods of rationing that can be applied are many. In general they are classified as follows:

- Selection: Using this method, recipients of care are selected on the basis of clinical benefit they will obtain, or the amount of time required to treat them.

- Denial: This method involves the exclusion of certain patient populations because they are deemed unworthy, or because their needs are not seen as sufficiently important.

- Deflection: This involves referring patients to other institutions. It is a form of rationing when a patient’s needs can be met by other health or social services.

- Deterrence: This involves deterring patients from accessing healthcare by the imposition of complex logistical/administrative requirements, such as inconvenient opening times, incomprehensible paperwork, and unhelpful staff. This type of rationing tends to disadvantage less educated and more vulnerable people.

- Delay: This method includes the use of waiting lists. It is the most recognised form of implicit rationing in healthcare, and discourages patients from accessing health services.

- Dilution: In this situation access to services is not denied, but the provision of services is reduced, such as the frequency of home visits.
- **Interruption**: This is the premature termination of a service or a treatment based on a maximum time limit for a given treatment, such as premature discharge from hospital or case closure.

Overall, these mechanisms of rationing are used by various decision makers, although only the first (selection) is formally endorsed. Often rationing is not deliberate or conscious, but is a means for professionals to cope with budgetary or other pressures. An alternative is the development of guidelines as a medium/long term solution.

### 6. Technical and distributive approaches to rationing

To make choices or establish priorities, certain criteria are required that reflect the most prevalent values in society. All countries that have embarked on this have stated the values on which they have based their choices. There are, in general, diverse principles that can guide a society’s choices. These can be classified into technical criteria or distributive criteria. The first refer to the ‘technical’ qualities that services must possess in order to be included, such as efficiency, efficacy, and appropriateness. The others criteria are ‘distributive’ in nature, in that they help establish an order of priorities in the choice between different patient groups, such as relative benefit, and the rule of rescue.

#### 7. Technical criteria

These are a prerequisite for any selection of priorities. For example, it is well established and accepted that healthcare interventions should be effective, efficient and appropriate. Such considerations can help in making choices, in as much as they help exclude those interventions that do not meet these criteria, but they are not enough in themselves to establish how many and which interventions to provide, and to whom.

- **Effectiveness**
  
  The principle of effectiveness affirms that priority must be given only to those interventions that produce positive medical results. It is a principle that is intuitive and attractive in itself. The difficulties arise when one has to apply it and face up to the implications of this principle. According to some studies, the majority of surgical and medical procedures in use today are not based on scientific evidence of their effectiveness (85% according to the US Office of Technology Assessment). The scientific method for evaluating the effectiveness of healthcare treatments is based on the use of clinical research, and has as its gold standard the randomised controlled trial, the most rigorous assessment instrument, (hence real life circumstances) although it addressed efficacy rather than effectiveness. Despite the recent development of evidence based medicine and evidence based health care approaches and more refined instruments such as meta analysis, the criterion of effectiveness is not without its limitations. Above all, the collection and analysis of data about interventions is often expensive and may lead to ambiguous conclusions. Sometimes clinical research is not conducted with the required rigour, and frequently a treatment that may not be of general effectiveness may be appropriate in particular circumstances. To eliminate all procedures not demonstrated to be effective would therefore be unwise: even those treatments that are not scientifically well corroborated may sometimes be helpful.

- **Efficiency**
Efficiency is an economic concept. There are at least three types of efficiency that have been identified: technical, productive, and allocative.

**Technical efficiency** compares the resources required for a healthcare intervention (input) with the health benefits obtained (output). The relation must be as high as possible: maximum output compared with input, or minimal input compared with output. An example of technical efficiency is that of using 10mg of alendronate rather than 20mg of it in the treatment of osteoporosis since studies showed that the smaller dose achieved the same clinical results (assuming use of the smaller dose is less costly than use of the larger dose).

**Productive efficiency** is related to the possibility of choosing between two or more alternative treatments in relation to costs and results. Consider, for example, a policy of changing from maternal age screening to biochemical screening for Down's syndrome. The concept of productive efficiency refers to the maximisation of health outcome for a given cost, or the minimisation of cost for a given outcome. If the sum of the costs of the new biochemical screening program is smaller than or the same as the maternal age programme and outcomes are equal or better, then the biochemical program is productively efficient in relation to the maternal age program. In healthcare, productive efficiency enables assessment of the relative value for money of interventions with directly comparable outcomes.

**Allocative efficiency** refers to the destination of resources, which society makes available to various alternative uses, and defines as optimal the allocation that improves the health situation of an individual without compromising that of another.

The promise of the principle of efficiency, in its three forms, as a guide for defining choices, is attractive from an ethical point of view because it promises to deliver a greater volume of healthcare services at the same cost, and to make choices less painful. But problems emerge when applying this principle, in deciding the optimal allocation of scarce resources within a society. Economic theory in general has led to the development of various methods of evaluating the costs and benefits associated with different healthcare interventions, in particular analysis of cost/efficacy, cost/utility and cost/benefit. Criticisms of this approach lie not so much in the evaluation of costs, as in the notion of benefit and the consequences on health and above all, in distribution. In the cost/efficacy analysis, the results of a healthcare intervention are measured using indicators specific to the intervention or the disease treated (for example, reduction in infection rates, or rates of five year survival) and therefore do not allow a comparison between different illnesses, but only amongst alternative treatments for the same disorder (for example, medication compared to a surgical alternative). In cost/utility analysis this limitation has been overcome, to a certain extent, by the use of complex formulae such as QALYs (quality-adjusted life years) and DALYs (disability-adjusted life years), which tend to better reflect not only the cost of an intervention, but the quantity and quality of years of life productive/independent and functioning gained. This allows a comparison between different interventions for different illnesses and allows the creation of a 'league table' of interventions, based on these criteria. Evaluating cost/benefit can also include a monetary evaluation of the health gain, even an evaluation of the economic value of the extra years gained.

The limitations of these techniques are that from a technical point of view they are expensive, complex and difficult to carry out, and from an ethical point of view they mask...
serious value judgements beneath their seeming neutrality. The fact that scarce resources may be used to favour certain social groups to the exclusion of others solely on the basis of economic criteria causes much ethical and social concern.

- Appropriateness

According to traditional classifications of treatments, an appropriate treatment is one where the expected benefits exceed the expected negative effects (risks) associated with the treatment. One can distinguish between clinical and organisational appropriateness.

Clinical appropriateness – a treatment that is not effective cannot be appropriate, but a treatment that has been scientifically corroborated may still be inappropriate if carried out on a patient whose condition does not indicate its use in their particular circumstances. For some years the question of the appropriate use of interventions has been the subject of health service research, addressing the variation of the use of services. In the United States it is estimated that certain medical procedures (including coronary angiography, endoscopy, coronary artery by-pass surgery, and hysterectomy) have a rate of inappropriate use that ranges from 15-30%.

Organisational appropriateness refers to the type of service provision (inpatient ward, day unit, clinic) appropriate to the intervention offered in terms of patient safety and the most economic use of resources. With the introduction of such payment methods as diagnostic related groups (DRGs), the assessment of organisational appropriateness includes a review (known as a ‘utilisation review’) of clinical paperwork to evaluate the medical necessity of the treatment provided, the means of providing that treatment, and its duration. In this way the intervention and the appropriate timescale for such an intervention can be evaluated, and inappropriately long care identified.

8. Distributive criteria

Distributive criteria are a set of principles that establish an order of priority in the allocation of healthcare resources. They do not address the question of what must be guaranteed to individuals and society at large, but attempt to establish who (which individual, which social group) can have access to such resources.

- Need

In almost all methods of resource rationing there is an underlying principle of equality or justice, in which resources must be allocated according to need. A key element of justice requires that individuals with the same needs should receive the same treatment and that greater need takes priority over lesser need. The principle of equality requires that those with the greatest needs should have the greatest claim on resources. But how does one evaluate which need is greater than another? By whose evaluation: the doctor or the patient? Needs may be evaluated in terms of the consequences or results of interventions. A just society would have the moral obligation to provide for the needs of each citizen for treatment, but not for mere desires. Doctor and patient preferences may not coincide when, for example, decisions about quality versus quantity of life have to be made. Even if the concept of need is crucial, it remains ill defined and elastic. To what extent a society can satisfy needs is closely related to the resources available. Science can help in classifying needs on the basis of their consequences, independently of consideration of costs. The relation between needs and resources is, however, a political choice.

- Merit/demerit

According to the notion of merit, priority must go to those who deserve special consideration. For example, older people may deserve more attention as they have
worked and paid their taxes for longer than anyone. Or children, because they have not yet had the chance to realise their human potential. Demerit is when judgments are made about lifestyle in relation to certain risk factors that may justify the restriction of the provision of health services. For example, heavy smokers, drug users and alcoholics may be deemed unworthy of receiving certain healthcare interventions unless they change their high-risk behaviour. The notion of merit/demerit is controversial if not unacceptable, as it contradicts the enlightenment tenet of the brotherhood (or more generally, siblinghood) of humanity.

- **Risk**
  The concept of risk is similar to that of need and refers to the deterioration of a situation that could occur in the absence of an action or intervention. While the concept of need measures the deficit in well-being of an individual, that of risk evaluates the consequences of a non-intervention. The service providers possess the necessary information as to the relative grades of risk.

- **Benefit**
  The communitarian sense of the principle of benefit is based on the discussion of collective good and the use of common resources. It is not the individual characteristics of need or risk that count have, but the final result for the community as a whole. Priority must be given to those who can gain the maximum benefit from an intervention (the ‘capacity to benefit’).
  The underlying principle is that scarce resources must be used in such a way as to maximise the benefit not to the individual, but to the collective whole. According to this principle, it is immoral not to consider the costs associated with intervention, as this would mean ignoring sacrifices imposed on others.

- **The rule of rescue**
  The duty to intervene when a life is in imminent danger cannot be avoided. According to this principle priority must be given to people in an emergency situation, or whose life is in danger. In healthcare, as in other sectors, the application of this principle is considered a fundamental indicator of our degree of civilisation. In fact, more importance is attached to the act of assisting than to the outcome of the intervention; this creates a practical difficulty, because it offers no assistance as to when to cease such interventions if the patient does not die. To apply the rule of rescue in all cases of need would lead to an unsustainable expensive system.

**9. Theories of justice in healthcare**

The technical criteria and particularly the distributive criteria that we have so far considered represent attempts to find some shared rational bases with which to deal with the problem of resource allocation in the health sphere. Apart from their apparent neutrality, they require a more or less explicit assumption of values. This in turn requires the consideration of theories of distributive justice, three in particular: *individual liberty*, *utilitarianism* and *egalitarianism*. These theories have profoundly different visions of the world, but are all inspired by two considerations that to a certain extent bind them together:

- Justice, while relevant to the individual conscience, is not restricted to the discretion of the individual, but represents the necessities of human coexistence
- Justice Relates to at least one of the following concepts: equality, liberty, responsibility, equity.
We will now examine different justice positions in more detail, both from a general point of view and in relation to the healthcare sphere.

**The theory of individual liberty**

This philosophical approach attaches the utmost importance to individual liberty rights. As a consequence, the state is required to support individual autonomy, both through rights that promote the notion and through promotion of a market economy. The market is left the task of redistributing resources in order to guarantee a level of dignified life for all, supporting individual expectations. The state becomes a discreet bystander in society where individual liberties take precedence, affording the fullest possible autonomy. For these reasons, in a ‘pure’ liberal state, there is no ‘formal imperative’ to support social solidarity. By definition the state is not obliged to tackle inequalities or to take on the task of supplying social services such as healthcare or education. In the healthcare sphere the results are as follows:

- There is no automatic ‘right’ to health for subjects
- The state is not morally obliged to provide any mechanism for the protection of health
- Health care is provided by means of a private contract between patient and healthcare provider; the patient pays for the service and the doctor/patient relationship reflects this
- The quality and amount of healthcare received is dependent on the ability of the patient to pay.

**Utilitarian theory**

The difficulties in the individual liberty theory lead to recourse to utilitarianism (or, more generally, consequentialism), where individual liberty rights are subordinated to the requirements to maximise utility, that is the state of ‘maximum happiness and minimal misery’, or ‘the greatest happiness to the greatest number’. By definition, each action is judged on the basis of the amount of utility it generates: the objective is the best possible outcome for the largest amount of people for the minimum cost in terms of loss of utility. Utilitarianism thus inverts the relationship between individual and society, favouring the second. The state, in pursuing the goal of social utility, will favour the good of many over the individual.

The provision of a public healthcare system is in keeping with the theory as a whole, bearing in mind that the objective is the promotion of utility in terms of best possible health status for the maximum number of people. From a societal perspective, treating many patients who suffer from various conditions is viewed as equivalent to saving a few whose lives are in danger.

**The theory of egalitarianism**

The egalitarian model includes a multiplicity of positions, sometimes philosophically and politically far removed from each other. It brings together forms of socialism, social contract theory, and communitarianism. Egalitarianism attaches maximum importance to the equality of fundamental rights (to life, liberty, work, culture, and more) and to the conditions that support and protect these rights. Collective and societal needs take precedence over individual need in their theory, where upon public bodies have a preeminent role in their duty to protect and support the needy. This is the antithesis of individual libertarianism, as here a cooperative society is obliged to tackle inequality in all its forms.
'Social and economic inequality must satisfy two conditions: firstly, they must be attached to offices and positions open to all under conditions of fair equality of opportunity; secondly, such inequalities are justified only if they benefit the worst off' (Rawls 1999)

Egalitarian healthcare is based on the ‘right to health’ – protection and promotion of physical and mental integrity, healthcare and quality of life and of the environment are seen as positive rights. The state must take on the protection and promotion of these rights, through provision of universally accessible healthcare on the principle of solidarity.

10. The conflicts and limits of philosophical approaches

Theories of justice and their implications for the organisation of healthcare and the problems of rationing lend themselves to a series of considerations that illustrate both the strengths and weaknesses of such approaches.

Theories of individual liberty have the advantage of guaranteeing maximum individual freedom, but the price paid is high, particularly for those unable to participate fully in the marketplace and those whose individual autonomy is weakened (the poor, the elderly, the disabled, and others). Not only that, but the market imperative, far from promoting the well-being of many, rewards selfishness and highlights economic inequalities. Furthermore, freedom without responsibility is incomplete, the material and moral life ruled by laws of supply and demand, with the only aim being the attainment of individual freedom.

Utilitarianism has the advantage of subordinating individual advantages to the well being of the many, the key objective being to maximise collective utility. The theory is not without its criticisms, however. One of these is that in maximising utility to the collective whole, there is potential to ignore the needs of the individual. There are also difficulties in defining utility, given that this is a subjective term (as wanted in quality of life assessments). The values involved, the burdens of expensive treatment and the clinical benefit derived for the patient are incommensurable (not capable of being compared with each other) unless there is a similar treatment alternative to use as comparator. Where there is no alternative, the application of a utilitarian evaluation often creates more problems than it resolves.

Egalitarianism seeks maximum social justice and protection of rights, but this theory also incurs criticisms. First, what is the foundation of this equality? Based on the social mechanism we want to refer to, social rights may be embedded in a more or less solid foundation. In the case of the social contract, rights are normally attributed to members of society or, by the same vein, are drawn from them. Yet social rights could also be attributed, regardless of a social agreement, as fundamental human entitlements that cannot be questioned, for example by the majority rule. Secondly, there is a risk that social dynamics could prevail over the individual, forcing the latter to accept priorities and objectives that are opposed to his or her own rights.

To conclude this part, when referring to rationing in health care, it can be argued that in pluralistic societies there are continuous tensions and confrontations about what distributive justice is about and how it can be guaranteed to citizens. An agreement based on the philosophical approaches outlined above is likely to be unachievable, thus it is necessary to explore other solutions to the problem of rationing of health care resources.
11. The ethico-procedural approach

Normative approaches are important as they help identify fundamental values that are at the core of political decision making, but they are not enough in themselves, as we saw that different theories lead to different conclusions and there is no consensus on which is the correct approach to take. Added to that is the fact that they are too abstract to be applied as such to the reality of the world of healthcare institutions. Empirical approaches are sometimes helpful, because they help identify what has been done and what could be done, but not what should be done. In the absence of a broad consensus on the acceptability of various guiding principles for the allocation of resources, the problem of ‘fair’ distribution becomes a question of ‘procedural justice’. An ethico-procedural approach requires a decision making process that allows agreement on what is legitimate and fair in terms of rationing. Rather than concentrating on principles and values that should underpin decision making, the ethico-procedural approach asks how such decisions are made. It involves a shifting of perspective from content to process. The rationale on which the ethico-procedural approach is based is as follows: irrespective of the financing or provision of health services, legitimate authority is conferred by the influence of the democratic process on the system. A well known ethico-procedural approach is ‘accountability for reasonableness’ (Daniel & Sabin 2002). The conditions essential to the application of this approach are as follows:

1. **Publicity condition**: decisions regarding both direct and indirect limits to care and their rationales must be publicly accessible.
2. **Relevance condition**: the rationales must rest on evidence, reasons, and principles that all fair minded parties (managers, clinicians, patients, and consumers in general) can agree are relevant to deciding how to meet the diverse needs of a covered population under necessary resource constraints.
3. **Appeals condition**: there is a mechanism for challenge and dispute resolution regarding limit setting decisions, including the opportunity for revising decisions in light of further evidence or arguments.
4. **Enforcement condition**: there is either voluntary or public regulation of the process to ensure that the first three conditions are met.

The advantages of this approach are many. For instance, there is an educational aspect. All parties to the decision can appreciate the value of debate and deliberation in achieving a fair decision under resource constraints. Furthermore, ‘accountability for reasonableness’ occupies a middle ground between implicit rationing and explicit rationing. In a similar fashion to the implicit approach, the principles on which the decision is made do not have to be disclosed in advance; in contrast, as in the explicit approach, there is an appeal to greater transparency in disclosing the reasons for decisions on rationing resources.

12. International experiences

At the international level, there are three basic strategies for rationing that have emerged. The first (and until now the only example of its kind) is that employed by Oregon (USA), which tackled two issues together: which treatments, and how much treatment, should the state provide to its citizens whilst acting within its budgetary restraints? It is the most explicit and radical form of rationing to date. A second strategy is that of the Netherlands and Sweden, which defined a set of principles on which to base a healthcare package of
available treatments for eligible citizens (the Netherlands), or to define priorities in the supply of healthcare (Sweden). Neither country has managed to produce a list of available treatments. A third strategy is that adopted by New Zealand and Great Britain, who are not so much concerned with general principles as with putting into place a continual process of drawing up guidelines and advice on appropriate treatment, supporting their view that rationing should take place at the local and individual (micro) level.

Oregon
The US state of Oregon was the first to explicitly and fundamentally address problems of rationing in healthcare. Following the death from leukaemia of a child who was denied a transplant, the authorities set up a commission in 1989, the Health Services Commission, to make recommendations on how the government funded Medicaid program could be extended to include a section of the population who were not covered, and how to set priorities within the Medicaid program itself. Having unsuccessfully tried an exclusively technical approach (cost effectiveness analysis), they turned to a method that paired disease with treatments and ordered these according to the gravity of the disease. Adjustments were made to the list, according to what the Commission viewed as ‘reasonable’ and taking into account the results of a public consultation. The ‘Oregon Plan’ was put into practice in 1994, financing 565 treatments of the 696 listed. This list has since been amended and changes were made to the originally identified priorities. The abandonment of the technical approach, debated furiously by the medical profession and the public alike, has become a symbol and a learning opportunity for many countries faced with difficult choices in rationing.

The Netherlands
The Dutch government set up a Government Committee on Choices in Healthcare in 1990, with the mandate remit of examining the problem of choices in healthcare and identifying criteria for drawing up a basic package of healthcare treatments that should be offered to all citizens with the necessary state or private health insurance. In their report, delivered in 1991, the Committee adopted a broad approach, with a method for evaluating the necessity and availability of treatments, using four criteria/filters:

- Necessity
- Efficacy
- Efficiency
- Individual responsibility

The report also dealt with issues such as technological developments, waiting lists, the appropriateness of treatment, and public involvement in priority setting. The Committee, however, did not chose to produce a list of treatments for inclusion in the basic package, but limited itself to applying the principles to a few controversial cases (in-vitro fertilisation, homeopathic medicine, dental care for adults, sports injury services, care of the elderly).

Sweden
The Swedish Parliamentary Priorities Commission was set up in 1992 to ‘discuss the role of health services in its social context and to outline the fundamental ethical principles that should guide the necessary prioritisation of resources’. An interim report entitled ‘No Easy Choices’ was published in 1993 and circulated for comment. The Commission
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identified two types of approaches to the problem of priority setting: a clinical approach based on patient need, and a politico-administrative approach where scarce resources needed to be considered. An interesting feature of the Swedish deliberations was the development of an ethical platform based on certain principles to guide choices about priorities:
- The human dignity principle
- The principle of need and solidarity
- The cost/efficiency principle

The final report did not contain a detailed list of services to be included or excluded, but it did group treatments into five classes of descending priority. This approach is a method for assisting in establishing priorities and helping those responsible to make decisions.

New Zealand

In 1992 a National Advisory Committee on Core Health Services was set up in New Zealand to ‘make explicit which services everyone should have access to, in acceptable terms and without unreasonable waiting times’. The practical difficulties in drawing up a definitive list led the Committee to identify as essential those services already provided, because these were deemed to be so as the ‘result of many years of reasonable good sense, decisions founded on principle’. The Committee to developed guidelines for services of general application, those with high costs, or those that are delivered in high volume. The guidelines are shared at conferences, and efforts to involve the public in the debate are notable.

Great Britain

In Great Britain there has been no national committee set up to address the problem of priority setting in healthcare. The task is delegated at a local level, and local authorities must determine an annual plan of services they wish to provide. Some have been more explicit in recent years about which services they will provide, albeit thus far restricting access to marginal treatments such as tattoo removal. At a national level there is an agency that evaluates treatments and develops guidelines – the National Institute for Health and Clinical Excellence – and another that looks at service performance – the Health Care Commission.

Developing countries

Developing countries who have limited resources more than developed countries, are obliged to make difficult choices in terms of healthcare provision and who to provide it to. A specific example is the provision of antiretroviral treatment for AIDS sufferers in Africa. Scarce resources, even when accounting for international help, do not permit universal access to these drugs: choices have to be made. Governments can make such choices on the basis of financial, socio-economic or medical criteria. As an alternative, or in conjunction, they may be allocated on the basis of less formal, unfair criteria such as individual preferences of decision makers, or political considerations (Rosen 2005). Developing countries are advised by the World Bank to direct resources to public health programs on the basis of economic and cost efficiency considerations, using tools such as the Disability Adjusted Life Years tool (World Bank 1993). In any case, the same considerations need to be taken into account: who decides? On the basis of which criteria? On what values are decisions based? How democratic is the decision making process?
12. Conclusion

International experiences serve to highlight yet again just how difficult the issue of rationing in healthcare is. Every country we have considered has found its own way to set priorities. There is no consensus on principles, or on the methodologies used to make choices. General principles, when they have to be applied in a practical way at a local or individual level, have to be interpreted in light of circumstances and there is an ever-present ambiguity in this application. It is not possible to predict all the situations in which the rules will have to be applied, so a certain level of discretion and interpretation is required. All this confirms that there are no easy solutions at hand (Holm 1998).

Coulter and Ham (2001) summarized international experience with health care priority setting, and concluded:

‘there is a need to strengthen institutional processes in which decisions are taken; priority setting processes must be transparent and accountable; clinical guidelines are increasingly being used as a priority setting tool, but fair processes are needed for guidelines, just as for priority setting more generally; the politics of rationing favours muddling through and the evasion of responsibility, but this is unsustainable in an era of increasing public awareness about policy making; priority setting policy making is an exercise in policy learning; and “accountability for reasonableness” is a leading ethical framework for priority setting in institutions’.

Accordingly, a strategy for improving priority setting in health care entails improving priority setting processes using guidance such as that provided by the “accountability for reasonableness” approach. Without analysis and debate about public policy, people and institutions can make arbitrary decisions about access to treatment, and implicit rationing can foster both inequity and inefficiency.

13. References


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Bioethics in the 21st Century
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Bioethics is primarily an applied ethics of health related issues. It is considered an important guide for health care and its discourses and practices. Health related technology, such as information technology, is changing rapidly. Bioethics should arguably address such change as well as continue to address more established areas of health care and emerging areas of social concern such as climate change and its relation to health. This book illustrates the range of bioethics in the 21st century. The book is intentionally not comprehensive but rather illustrative of established, emerging and speculative bioethics, such as ethics of mental health care, ethics of nano-technology in health care, and ethics of cryogenics, respectively. Hopefully the book will motivate readers to reflect on health care as a work in progress that requires continuous ethical deliberation and guidance.

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