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Guest editorial Why age-based rationing is not necessarily evil[1]

Confronted with a rapidly ageing population in need of medical care, and the drive for technological innovations in health care (e.g. diagnostic devices, therapy options and medicines), the need for rationing health care is unavoidable. For this reason, the National School of Public Health (ENSP in Lisbon) organised a multidisciplinary conference: 'Health care rationing in Europe: The past, present and future'. Speakers with different backgrounds from European countries addressed the controversial 'R-word'. Emerging rationing questions discussed were: who is responsible for rationing (the market, governments, bureaucrats, physicians or others); how does it function (explicit or implicit); what are relevant and acceptable selection criteria; to what extent is current rationing just and what can be done to make it more just; and, how will health care rationing affect equal access to health care?

Health care rationing is generally defined as setting limits to the basket of care that will result in the denial of, or delay in specific medical interventions; exclusion of necessary health care for other than medical – read financial – reasons. When alternatives to containing the costs of health care have failed, or appeared inadequate (efficiency measures, co-payments, etc.), more drastic cost saving measures such as rationing health care become a reality.

Nowadays, most health care systems are familiar with some kind of rationing, either explicitly or implicitly. Ideally, choices in health care are made explicitly, based on transparent, democratic and participatory decision-making procedures, valuing verifiable reasons or criteria known in advance. Except for the National Institute for Health and Care Excellence (NICE) – responsible for the appraisal of new technologies based on clinical and economic evaluations – such a deliberate and explicit process is unknown in most countries.

More common is implicit rationing decided by clinicians at the bedside. Neither the decision, nor the basis for that decision is clear. It happens in secrecy, 'behind the scenes', and lacks public scrutiny.[2] As a result, implicit rationing has been criticised since physicians fail to inform patients about the real reason for the denial of a necessary treatment, primarily to prevent distress or being put in an uncomfortable position. Nowadays, implicit rationing has been generally rejected,[3] but persists. An illustration is the situation in Russia as described by *Vlassov* et al. where leading physicians, acting as heads of de-

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2 E.g., S. Huster and others, 'Implizite Rationierung als Rechtsproblem', 25 *MedR* (2007):703-706; V. Vlassov and others, 'An idea alien to both worlds: why health care rationing is not acceptable in the USA and Russia', *JMLE*, 3: 2020.

3 E.g. G. Oei, 'Explicit versus implicit rationing: Let's be honest', 7 *American J Bioethics* (2016):68-70; F. Breyer, 'Implizite versus Explizite Rationierung von Gesundheitsleistungen', *Bundesgesetzblatt* 55 (2012):652-659.

partments, deny costly interventions not covered by insurance, although here the reason is given as 'controlling proper use', rather than rationing.[4]

Rationing comes in a variety of forms. At the macro level, NHS England and the Clinical Commissioning Groups (CCGs) – succeeding the commissioners' role on the Primary Care Trusts (PCTs) – have a mandate to decide which treatments are available and which are restricted because of limited resources.[5] As mentioned, these decisions of both NHS England and the CCGs are guided by NICE appraisal guidelines. In exceptional cases, by submitting an individual funding request, patients will be granted a treatment or procedure not generally available in the NHS (*Sheppard*). This is somewhat different from NHS-like systems, such as Italy's *Servizio Sanitario National* (SSN) which is more regionally based, as described by *Santuari*.[6]

In social health insurance (SHI) systems, the 'package of care' decision-making has been institutionalised by federal or national bodies, with a wide range of regulatory powers. These decisions, 'listing or delisting' services on/from a benefit catalogue are based on evaluation of evidence-based reports. So far, these evaluation studies have focused primarily on the cost-effectiveness of new medicines. Initiatives at European level, such as establishing an EU-wide network for Health Technology Assessment (HTA) and the Commission's proposal of a Regulation on HTA might help to improve the evaluation process, while increasing transparency in the appraisal decision-making process.[7] But overall, an explicit rationing mechanism or cost-effectiveness threshold is absent in most SHI systems.[8]

Probably the most difficult question is, which selection criteria should be used? *Martani* and *Starke* argue that *personalresponsibility* could be a feasible rationing criterion. But a system of reward and punishment based on personal responsibility has encountered the problem of 'practical enforceability'. The authors claim to have overcome that hurdle by means of the digital monitoring of medication-taking behaviour ('datafying health and making patients transparent').[9] An interesting but also controversial and worrying consequence of digitalisation in health.

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4 Vlassov, op.cit.

5 M. Sheppard, 'Rationing in the English NHS and the Tension between Patient Choice and Solidarity', *JMLE*, 3: 2020)

6 A. Santuari, 'Health care rationing in Italy: right to health vs. budget constraints in a regional-based health system', *JMLE* 3:2020.

7 See the HTA Core Model of EUnetHTA (www.EUnetHTA.eu) and the Proposal for a Regulation on health technology assessment and amending Directive 2011/24/EU, 31 January 2018, COM(2018)51 final.

8 It was suggested to apply a bandwidth with a median value of €40,000 per added life-year (QALY), CPB Document no. 152, 10 (in Dutch), see: www.zorginstituutnederland.nl.

9 A. Martani and G. Starke, 'Personal responsibility for health: the impact of digitalisation', *JMLE* 3: 2020

Apart from the clinical and cost-effectiveness thresholds, could age be considered as an acceptable criterion for rationing health care, or is that ageist and thus discriminatory? On other occasions, health ethicists have argued that certain forms of age-based rationing can be accepted with the 'fair innings' argument.[10] Elaborated by Fleck, age-based rationing does not generally advocate the withholding of all medical treatment from the elderly, but only limited to high-cost life-extending care, taking into account relevant circumstances such as, type of disease, survival prospects, and degree of effectiveness or benefits (subtle age rationing).[11] Also from a human rights perspective, I have argued that subtle age rationing is not necessarily discriminatory.[12] Taking into account the General Comment 20, which clarifies the understanding of non-discrimination in socio-economic rights, some forms of differential treatment may be permissible,[13] but only when complying with the Committee on Economic, Social and Cultural Rights' conditions.

Such a controversial measure will be compatible with the Convention rights, assuming that the aim and effects of age-based rationing 'promote general welfare' (sustainability), while respecting the elderly's health needs, except for life-sustaining treatment. Secondly, defining a maximum age for age-based rationing is considered an objective standard, to be defined by state parties, allowing (groups of) individuals the right to participate actively in the decision-making process over the selection of such a criterion ('democratic deliberation').[14] This approach then requires access to and disclosure of all relevant information, a transparent and participatory decision-making process, regulated by law and the mechanisms for legal redress when rights have been violated. In this way, such a fair and accountable procedure combines both substantive and procedural principles, echoing the accountability for reasonableness standards advocated by Daniels and Sabin.[15]

Although the fair-innings argument in age-based rationing has certain weaknesses, it is the least worst of the selection criteria. Alternative criteria (gender, socio-economic status, religion, disability, cost-effectiveness thresholds,

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10 J. Harris, *The Value of Life. An Introduction to Medical Ethics* (London: Routledge 1991):91-94; elaborated by L. Fleck, *Just caring: Health Care Rationing and Democratic Deliberation* (New York: OUP, 2009).

11 Fleck, Ibid. ch.9.

12 'Access to new health technologies and age-based rationing', in: A. Taylor, S. Negri, *Legal, Ethical and SocialImplicationsof Ageing* (OUP in press).

13 CESCR, General Comment (GC) no. 20 'Non-discrimination in economic, social and cultural rights', E/C12/GC/20, 2 July 2009, para. 13.

14 Also argued by Fleck, op.cit., ch. 5.

15 AfR: this is the idea that the reasons or rationales for important limit-setting decisions should be publicly available. In addition, these reasons must be ones that 'fair-minded' people can agree are relevant to pursuing appropriate patient care under necessary resource restrictions (N. Daniels and J. Sabin, *Setting limits fairly: Can we learn to share medical resources?* ch. 4, ebook).

random lottery) appear arbitrary and are therefore rejected. When other cost-curbing measures have failed, then limited age-based rationing remains the least onerous, but most necessary, option to cope with an imminent public health threat.

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