TEACHING AND LEARNING ETHICS

Teaching medical students about fair distribution of healthcare resources

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Healthcare package decisions are complex. Different judgements about effectiveness, cost-effectiveness and disease burden influence the decision-making process. Moreover, different concepts of justice generate different ideas about fair distribution of healthcare resources. This paper presents a decision model that is used in medical school in order to familiarise medical students with the different concepts of justice and the ethical dimension of making concrete choices. The model is based on the four-stage decision model developed in the Netherlands by the Dunning Committee and the discussion that followed its presentation in 1991. Having to deal with 10 medical services, students working with the model learn to discern and integrate four different ideas of distributive justice that are integrated in a flow chart: libertarian, communitarian, egalitarian and utilitarian.

they study the decision model in advance in order to prepare themselves to work with it.

The students then meet in groups of 15 and are required to cooperate, using the flow chart in fig 1, in order to decide which services should be included in a basic package. At the end of the session, the students compare this selection with their own lists and evaluate what they have discovered about ethics in the process of deliberating, discussing and choosing.

THE DECISION MODEL

The decision procedure we developed is an adapted version of a four-stage decision model developed in the Netherlands by the Dunning Committee.¹ This model contains four criteria for deciding which healthcare services should form part of a collectively paid basic healthcare package. The first criterion is the necessity of a healthcare service, interpreted by the Dunning Committee as healthcare enabling an individual to participate in social and public life. The second is the effectiveness of the healthcare service or intervention. The third criterion is its cost-effectiveness, and the fourth is individual responsibility and payment.

The Dunning report elicited two basic criticisms.^{2,3} Both are incorporated into the revised model we designed. In the first place, there was much criticism of the fact that “necessary healthcare” was defined from a communitarian perspective. For many critics, this choice for one particular theory of justice was not acceptable in a mainly liberal and individual-oriented society. For this reason, we chose to make this underlying ethical choice visible to facilitate the discussion about ideas of justice in our model.

In the second place, there were questions about the notions of “health” and “disease” and the question of who defines them.⁴ Since these concepts directly concern the goals of medicine, again we chose to make room for discussion of this theme. Thus our model starts with the question of ill health.

STEP 1: JUDGEMENT OF DISEASE BURDEN Manifestations of ill health

When can a patient have access to a collectively paid healthcare service? When there is a manifestation of ill health. But who decides what counts as ill health? Three parties seem to be involved here, each with their own perspective: physicians, patients and society. Whether a physician will start treatment or not will depend on his or her (subjective) interpretation of the biological abnormality detected. The term *disease* is often

Choices in the distribution of healthcare resources take place in a political context that is hallmarked by cultural factors, economic interests and strategic deliberations, among many other influences. As for the fairness of the choices that are made, various ideas of justice and disease burden play a role. In this paper we describe our experiences with a model we developed for teaching medical students about the role and influence of these two concepts. The learning process begins with preparations at home and is rounded off by exploration of these elements in small working groups.

Students prepare for the working group in three steps. First, they consider a list of 10 healthcare services: bevacizumab for colon cancer, IVF, cochlear implants for deaf people, cataract operation, kidney dialysis for terminal patients, acupuncture for palliative purposes, aesthetic breast enlargement, extracorporeal membranous oxygenation for neonates, rivastigmine for Alzheimer patients and contraceptive pills. Each student individually makes a spontaneous and intuitive selection of services that should be included or excluded. Next, the students find data on disease burden, effectiveness, cost-effectiveness and total costs for the 10 medical services they have just selected. They need this information later during the working group. Since the students are in their third year, they have basic knowledge about most of the services and can find this information quickly in their books and on the internet. Third,

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Figure 1 Steps 1 to 5 in ethical decision-making about what services to include in a basic health package

used for conditions with objectively verifiable abnormal structural or functional biological changes.⁵

However, there may be individual complaints about health and well-being that make an individual consult a physician. For this individual experience of ill health, the notion “illness” is used.⁵ Illness may be due to objectively verifiable biological changes but is not necessarily so.

Disease and experienced illness and can be distinguished from behaviour. From a sociological perspective, behaviour and impact on the social environment are called “sickness”.⁶ In our model, we use this term in a somewhat different sense, referring to the dimension of socially adequate functioning emphasised by the Dunning report. *Sickness* is used in our model to indicate that there is an abnormality that obstructs normal social functioning.

Disease, illness and sickness as we define them indicate different ways of assessing ill health. In our view—and we acknowledge that this is a morally relevant choice—these perspectives are complementary. Together, they give a complete picture of an individual’s experience of ill health.

Disease burden

Assessment of a disease burden is complex, because different individual, professional and societal value judgements about

disease, suffering and abnormality play a role. Taking into account all these different judgements would lead to many different groups of disease burden. To keep the decision model workable, we simplify and quantify the disease burden by distinguishing only four degrees: a high (3 points), moderate (2 points) or light (1 point) disease burden, or no disease or disease burden at all (0 points). A disadvantage of this simple classification is that the groups are broad and the borderlines vague. But it helps separate the two extremes (a high disease burden and a low or absent disease burden) from a broad, intermediate group of diseases for which inclusion in a package can be determined in later phases of the decision-making process.

In order to determine a complete picture of the disease burden, the students have to quantify the disease burden according to the three perspectives of disease, illness and sickness that we have already discussed. Although all three perspectives are important, some persons will attach more importance to the disease perspective, and others, to the illness or the sickness perspective. In a modern society, these different perspectives are manifest in different political groups, favouring advantage for the largest group, according to individual needs, or for the worst-off. For students, these different preferences offer an opportunity for debate. To facilitate debate, students

working with our decision model are asked to give one of the three perspectives a weight factor of 2. After an exchange of views, a choice must be made. This choice will have implications for the outcome of the decision process. If no agreement can be reached, the perspective supported by the majority of students will be chosen—as also happens in political practice.

This political debate on the reasons why one of the perspectives is considered to be of primary importance has an ethical dimension. This dimension is made explicit by connecting the above perspectives with different conceptions of justice. Four conceptions of distributive justice seem relevant here, three of which can be linked with the perspectives of disease, illness and sickness.

Four concepts of distributive justice

In ethical theory, four different concepts of distributive justice can be recognised: the libertarian, communitarian, egalitarian and utilitarian models. They have all played an important role in the Dutch debate about the Dunning report. For medical students, they are briefly characterised as follows.⁷

In the libertarian concept, individuals themselves are responsible for their own health, their own well-being and the fulfilment of their life plan.⁸ Therefore, everyone pays for their own individually experienced healthcare needs, directly or indirectly through private healthcare insurance. There is no duty to contribute to the healthcare needs of others. The only task of the state is to make healthcare services available to meet all individual healthcare needs. However, an important problem is that when every individual determines what he or she needs, collective choices about the limitation of the total healthcare budget must be made.

In the communitarian concept, the criterion of justice is based, not on the individual's decision about what healthcare services are desired, but on what society considers to be necessary healthcare.⁹ This, in turn, is determined by the values and standards of a given society and can therefore lead to different outcomes. For the Dunning report, it meant that priority was given to healthcare services for people who could not function normally as members of society.

The starting point for the egalitarian concept is the equality of every individual.¹⁰ It aims at creating possibilities for individuals to become as much as possible equal to others, also with regard to health and well-being. According to the egalitarian concept, it is not the individually experienced healthcare need that is central, but an objectively determined healthcare need. Priority is given to patients with a great

disease burden, and an important element in this model is to determine the disease burden of a given condition. It is not important whether the condition is common or rare.

According to the utilitarian concept, justice means increasing the total health of the whole population. It is based on an economic motive: the available financial means should be used in such a way that the greatest possible health gain for the whole population is achieved. The health gain is measured in terms of years of life gained (usually with a correction for quality of life), and the more (average) health gain a specific medical intervention of service provides, the more priority it is given. The implication of this concept of justice is that ineffective or expensive treatments for rare conditions do not have priority. In contrast, crisis medicine or services improving the health of large groups of patients will be given priority.

In our decision model, each different notion of ill health is connected with a different model of distributive justice. The disease perspective can be linked with the objectifying perspective of ill health that assesses the effectiveness, cost-effectiveness and utility (in terms of expected health gain) of a specific treatment: a utilitarian concept of justice. The illness perspective can be connected with a libertarian concept of justice: emphasis is on patients' subjectively experienced need for healthcare, which arises when they are no longer able to give form to their own life according to their own views and ideas. The sickness perspective is associated with a communitarian concept of justice, for which obstruction of social functioning is the central criterion; it prioritises healthcare services that enable individuals to function as members of society and to contribute to it.

Total score

After a weight of 2 has been assigned to one of the three perspectives and after a condition has been categorized as imposing a high, moderate or low disease burden, we can give a total score for the condition (table 1). We classify the total scores for the disease burden of the condition into three categories: high (for total scores of 8–12), moderate (5–7) or low (0–4). This distribution can be explained as follows. The maximum score in the category high disease burden is 12 points (3+3+[2×3]). It seems reasonable to decide on 8 points for the lower limit of this category, because this limit implies that for two perspectives the maximum number of 3 points is given, and for one perspective, 2 points. If 1 point is given for this perspective, the limit can also be reached if the student group has given this perspective a weight factor of 2. The

Table 1 Assessing the disease burden of a disorder

Manifestation	Criterion	Ethical perspective	Weight factor of perspective	Disease burden (score)	Total score
Disease	Objectively verifiable abnormality	Utilitarian	1 or 2	High (3) Moderate (2) Low (1) None (0)	
Illness	Obstruction of individual functioning	Libertarian	1 or 2	High (3) Moderate (2) Low (1) None (0)	
Sickness	Obstruction of social functioning	Communitarian	1 or 2	High (3) Moderate (2) Low (1) None (0)	
Total score:					

maximum total score for the light disease burden category is 4 points ($1+1+[2\times 1]$) if 1 point is given for the three different perspectives (and one of the perspectives gets the weight factor 2). In such a situation, there is consensus. The category moderate disease burden (5–7 points) lies between these two extremes.

Determining the total score in one of the three disease burden categories is the first decisive step in the discussion—a step, moreover, that includes three concepts of distributive justice. These categories form the basis for the further stages of the selection process, in which three further criteria are applied: the effectiveness of therapies or medicines (step 2), their cost-effectiveness (step 3) and the total costs of a given therapy at population level (step 4). Each of these trade-offs can be corrected by egalitarian considerations.

STEP 2: EFFECTIVENESS

For the assessment of effectiveness, four categories are introduced: high, moderate, unknown and small. The first and last categories are not really problematic. Problems arise when the effectiveness of services or interventions is disputed or unknown—for example, because they have been included in the basic healthcare package in the past without any evaluation of their effectiveness. Besides, it is not clear in advance whether a given treatment will work for a specific patient. It seems fair and reasonable to try such a treatment when a patient has a high or moderate disease burden, especially when the trial period is restricted on the basis of medical criteria (see fig 1, step 2). On the other hand, therapies that are not very effective should not be included in the basic package.

Behind the criterion of effectiveness is a utilitarian concept of distributive justice: collectively financed healthcare services should lead to maximum health gain for a majority of the population. In actual practice, however, sometimes a correction from the egalitarian perspective may be appropriate here. There are medicines for conditions with a high disease burden whose effectiveness is doubtful, but for which there is no good alternative (for example, rivastigmine for Alzheimer disease).¹¹ In this case, non-utilitarian considerations (Alzheimer disease is a serious condition prohibiting social participation) seem to influence the decision to reimburse the drug. Another example is lung transplants.¹² From a utilitarian perspective, lung transplants should not be included in a collectively paid package, because they are intended for a very small group of patients. Lung transplants are reimbursed even though they achieve little health gain at the population level; the great disease burden is apparently the decisive factor. In these cases, compromises have been sought in the Netherlands by introducing strict medical criteria for the prescription of rivastigmine and lung transplants.

STEP 3: COST-EFFECTIVENESS

Cost-effectiveness is likewise motivated by utilitarian considerations. The concept, however, is much more complex and demands extensive economic analysis. There is another problem to this element: even though considerations of cost-effectiveness receive a great deal of attention nowadays, in practice they are often not decisive. One reason is that there is no agreement on what aspects should be included in cost-effectiveness calculations. Should they be restricted to the medical costs? Should societal costs (compensation for lost income and so forth) also be taken into account, and if yes, which costs exactly? Another reason for the complexity of this element is that cost-effectiveness is a relative notion. A drug, for example, is cost-effective when it is effective and when the effectiveness–cost ratio is favourable in comparison with another drug or treatment.

Because the aim of our model is restricted to discovering and experiencing the ethical dimension of fair distribution, we introduce cost-effectiveness here as a relative notion, ranging from cheap interventions with great impact on well-being (such as aspirin) to very expensive interventions with mixed health results and high risks of complications and comorbidity (such as lung transplants). Our range of cost-effectiveness is subdivided into four categories: high, moderate, unknown and negative (fig 1, step 3), but here, too, a correction from the egalitarian justice model can be appropriate in order not to disadvantage the patients with the poorest health status, especially when the cost-effectiveness is unknown or negative. It may be ethically appropriate to reconsider the use of a given service or intervention precisely because of a great disease burden.

STEP 4: TOTAL COSTS

A healthcare service can be a good candidate for the package with respect to disease burden, effectiveness and cost-effectiveness, but the total costs at population level can be so high that this leads to a disproportionate and unfair distribution of money for different healthcare services. Usually this criterion of total cost remains implicit. We have chosen to discuss it explicitly in our model, however, because it does play a role in discussions about, for example, lung transplants (where the total costs remain limited by the use of strict medical criteria and a limited supply of donor organs).¹² Other examples are the money that is spent on very expensive medicines for cancer treatments or on statins. In the Netherlands, a combination of the criterion of total cost with an egalitarian perspective was an important argument to limit the use of statins on the basis of medical criteria.¹³ In our decision model, we explicitly give these considerations of justice an appropriate place (fig 1, step 4): where total costs are high, further conditions can be introduced to limit use.

STEP 5: INDIVIDUAL PAYMENT

The first four phases of the decision model and the corrections from a justice perspective are in principle sufficient to decide whether a healthcare service can be included in a basic healthcare package. Yet it is important that students realise that the income effects of the excluded services can be considerable. These effects may be restricted if the service is included in a supplementary (private) insurance package, but they may be considerable for patients who have to pay for them out of pocket. This especially holds for the chronically ill and socially disadvantaged groups. These effects can be reduced when limits to private payment or co-payments are introduced, for example. For this reason, as a fifth step again we included the possibility for debate on an egalitarian correction.

DISCUSSION AND CONCLUSIONS

After having worked with the original Dunning model for some years, and having found that the working groups made the same criticisms reported in the literature, we have now been using the model described here for 3 years, in cohorts of approximately 320 medical and 110 biomedical sciences students each year. Students work for 2 hours with the model in small groups of 15 persons. During the first hour, one of the students leads the discussion. The second hour is supervised by one of the ethicists. Working with the model, which has been adjusted in small details every year, we have had the following experience.

First, students acknowledge that if it is used appropriately, the model helps to elucidate the moral dimension of distribution choices. Working with the different accounts of justice and seeing how different concepts of justice require a balanced

argumentation helps them to understand and articulate why it is so difficult to make fair healthcare package decisions. Second, the model is helpful because it makes them critically reflect on the necessity of including items that they had taken for granted, such as contraceptive pills, as being part of a just healthcare package. As a whole, students learn to understand the importance of the process of discussing choices, despite the information gaps that always play a role.

There also are some limitations to our approach. In the first place, we have excluded discussions on preventive medicine from our model. In the working groups, however, students often discover how curative and preventive medicine are interwoven (compare, for example, the effect of statins on cholesterol). A further limitation is that most of our students are inclined to be result oriented. If the model is not used as a framework for ethical discussion, but merely as a superficial formula to generate a plausible package, the learning process has failed. The model is just the basis: in our experience, a good working session requires both motivated students and good supervision by trained ethicists.

Last, because of its theoretical character, the model raises the question of actual practice among the students. This limitation, however, can also be formulated as a strength, as the model points beyond itself and encourages further research into the process of decisions regarding healthcare packages and the political power games that enter into this area of healthcare. Our model is intended to train future physicians and biomedical scientists in discerning and understanding the ethical dimension of this process. Once they have understood this dimension, we hope they will continue to take it seriously throughout their career. As teachers, we are open to learn from any criticisms that can help to find a better balance between doing justice to the complexity of the field, on the one hand, and educating students on the other.

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REFERENCES

- 1 **Government Committee on Choices in Health Care**. *Choices in health care*. Zoetermeer: Ministry of Welfare, Health and Cultural Affairs, 1991.
- 2 **Hoedemaekers R**, Oortwijn W. Problematic notions in Dutch health care package decisions. *Health Care Anal* 2003;11:287–94.
- 3 **van Willigenburg T**. Communitarian illusions: or why the Dutch proposal for setting priorities in health care must fail. *Health Care Anal* 1993;1:49–52.
- 4 **Hoedemaekers R**, Dekkers W. Key concepts in health care priority setting. *Health Care Anal* 2003;11:309–23.
- 5 **Boorse C**. On the distinction between disease and illness. In: Beauchamp T, Walters L, eds. *Contemporary issues in bioethics*. Belmont, CA: Wadsworth Publishing Company, 1977:64–73.
- 6 **Mackenbach JP**, Maas PJ van der. *Volksgezondheid en gezondheidszorg*. Maarssen: Elsevier Gezondheidszorg, 2004:261–2.
- 7 **Hoedemaekers R**, Dekkers W. Justice and solidarity in priority setting in health care. *Health Care Anal* 2003;11:325–43.
- 8 **Nozick R**. *Anarchy, state and utopia*. New York: Basic Books, 1974.
- 9 **Callahan D**. *Setting limits. medical goals in and ageing society*. New York: Simon & Schuster, 1987.
- 10 **Vathorst S**. *Your money or my life* [PhD thesis]. Amsterdam: Vrije Universiteit, 2001.
- 11 **Richard E**, Walstra G, Campen J van, et al. Rivastigmine bij de ziekte van Alzheimer; evaluatie van de eerste ervaringen en van gestructureerde effectmeting. *Ned Tijdschr Geneesk* 2002;146:24–7.
- 12 **Enckevort PJ van**. *Economic evaluation of lung transplantation*. Groningen: Regenboog, 2000.
- 13 **Gezondheidsraad (Health Council of the Netherlands)**. *Cholesterolverlagende therapie*. Den Haag: Gezondheidsraad, 2000:nr 2000/17.

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