

## CHAPTER 8

# The Uncomfortable Truths of Healthcare Prioritisation

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### Summary

A correct approach to healthcare prioritisation requires accepting certain uncomfortable ethical and political truths. This article sets out and analyses some of these truths. Specifically, these are: that health prioritisation (i) is inevitable; (ii) means the denial of available resources to patients who need them for some kind of health benefit; (iii) is an issue of social justice and not of mere equitable access to the health system; (iv) is an ethical issue, which is not resolved through mere clinical and/or economic reasoning and will not be resolved through applying a morally painless ethical criterion; and (v) demands a commitment to solidarity above individual freedom. This article analyses each of these uncomfortable truths and how they relate to the correct management of health prioritisation.

### Introduction

The greatest of the uncomfortable truths of prioritisation is that it is inevitable. It has several specific causes. The main one is, probably, the enormous technical progress made in healthcare brought about by advances in scientific knowledge; this has led to the appearance of ever more expensive new technologies. Nonetheless, there are other, no less relevant, factors. Among these are the progressive ageing of the population; the appearance of new diseases; the increase in the number of chronically ill patients; and a new concept of health as complete physical, mental and social well-being (as generously defined by the World Health Organisation [WHO]), and not merely as the absence of illness. The result is that we now have greater knowledge than resources to use this knowledge in the medical needs of all patients.

Therefore, the greatest challenge to equity is not knowing if all citizens have guaranteed access to healthcare, but choosing the criteria to provide such access when the demand for healthcare outstrips supply. For example, should those patients with a better

prognosis be given priority over those who are sicker? Should we take into account the individual's responsibility for their illness and discriminate access for this reason? How much of the budget should be assigned to the chronically ill, the terminally ill and in prevention? Should hospital costs be reduced in favour of socio-medical costs? What is the list of treatments, services and medicines that must be excluded from a free public health system? How can the conflicts between efficiency and equity be resolved? The answers to these questions force us to reinterpret the meaning of the right to healthcare, a right that has traditionally been linked to equal access for equal need. How can we make the right to healthcare compatible and, at the same time, ration limited medical resources?

At times prioritisation is, naturally, the consequence of morally debatable economic and health policies (e.g. ideologically motivated policies cutting health budgets); at other times, prioritisation is the result of the majority values of a society that prefers to use part of its wealth to cover other social assets, such as education, transport infrastructures, security or private consumption. As Ronald Dworkin reminds us, it would be a foolish society that mortgaged its entire wealth in health prevention (e.g. by contracting unlimited health insurance policies), thus ignoring the funding of other social assets that also contribute to the construction of a good life.

Nonetheless, while at times we may reduce the need to prioritise, it would be a delusion to believe that we can totally avoid health prioritisation and be utopian in current societies.

Another uncomfortable truth of prioritisation is that, in reality, it is not merely a prioritisation. Prioritisation is a euphemism referring to an uncomfortable truth in a wealthy, consumer society such as ours. When we prioritise, we ration limited resources, giving those resources to some patients but not to others while knowing that the resources denied would have been beneficial in some way to those who have not received them. This uncomfortable truth is the basis of four further truths that I will discuss below. The first is that healthcare prioritisation is an issue of social justice and not only of equitable access to the health system. The second is that healthcare prioritisation is an ethical issue that mere clinical and/or economic reasoning cannot resolve. The third is that prioritisation will not be resolved through applying a morally painless ethical criterion. The fourth is that prioritisation demands a commitment to solidarity above individual freedom. Each part of the text below is dedicated to one of these uncomfortable truths.

## **First Uncomfortable Truth: Health Prioritisation is an Issue of Social Justice and Not Only of Equitable Access to the Health System**

One of the uncomfortable truths of healthcare prioritisation arises with the appearance of social determinants of health. Current epidemiology sustains that the greatest inequalities in health are not mainly explained by biological factors or voluntary lifestyles; neither are they explained by unequal access to the health system, but by inequality related to social determinants of health. While the health system is, itself, a further determinant of health, it is not even the most important, as shown in the Black Report and the Whitehall Report of the 1980s. Numerous studies have corroborated this since then, and in 2008 the WHO's Commission of Social Determinants on

Health published a conclusive report with data on health inequity from around the world (CSDH. *Closing the gap in a generation: health equity through action on the social determinants of health. Final Report of the Commission on Social Determinants of Health*. Geneva: World Health Organization; 2008 [1]). The report reached two basic conclusions that would defeat health inequalities: improve daily living conditions, and tackle the inequitable distribution of power, money, and resources. In other words, if we wish to eliminate or reduce health inequalities, we must eliminate or reduce social and economic injustice. A fairer access to a quality health system is another measure in social justice, but it is neither the sole nor the most important one in reducing health inequalities. Therefore, the most pressing and basic health prioritisation is that which prioritises improvements in the standard of living of the poorest while reducing social and economic inequality. The best health policy is that of greater social justice.

What is the above affirmation based on? Health inequalities are, above all, due to social factors related to differences in status, and material inequalities. This is the conclusion drawn when incorporating social determinants of health to the epidemiological analyses; the conclusion leads to at least two effects on equity, when this is taken to be the elimination of unjust differences in health [2]. Or, in more operational terms, as the absence of systemic disparities in health between groups with different levels of advantages/disadvantages linked to gender, wealth, power, ethnic origin, age, etc. The first effect is that the relation between the social determinants of health and equity become very close; the second is that their impact should redefine the aims of healthcare equity.

Regarding the first point, the concern of equity for inequalities of health between individuals and social groups is also at the heart of social epidemiology. Both areas of knowledge are committed to the explanation of the causes of illness and their social distribution. Hence, the moral concern for social inequalities in health and the hypothesis those social determinants of health responsible for these patterns of inequality create a close correspondence, a symmetry of interests, between equity in health and epidemiological research into such determinants.

Regarding the second effect, social determinants of health should contribute to the redefinition and widening of policies that are traditionally associated with equity in health. Traditional explanations of inequality tend to focus on biomedical factors, including healthcare attention, which are those that healthcare professionals best master, leaving aside social factors of health, which the professionals find far harder to detect, control and change. Perhaps this is one of the reasons why social determinants of health have not normally received the attention they deserve. Nonetheless, access to quality healthcare has a limited explanatory capacity to deal with inequality in health. The proof is that this still exists in countries that have high-quality free, universal healthcare. In Great Britain, for example, and despite the existence of the National Health Service, life expectancy in a wealthy neighbourhood of Glasgow can be almost 30 years greater than in a poor one [3]. In a Spanish city like Barcelona, the difference between the wealthy neighbourhood of Pedralbes and the poor one of Torre Baró is 11 years [4]. Indeed, over the past century, in countries with universal access to healthcare, this accounts for just 20% of the increase in life expectancy. The remainder has been mainly due to improvements in quality of life, above all in hygiene. Universal access to high-quality healthcare is a requirement that is necessary but insufficient to mitigate the great differences in health.

The argument that lies behind the idea of equity based on access to healthcare services is based on social justice: the equitable, universal access to the healthcare system is needed to ensure the health of the population, itself one of the requisites of equal opportunities. However, the evidence of social determinants of health undermines such an argument [5]. While it is still true that equity in access to the high-quality healthcare system is a requirement of social justice, real equity in health is not only, or even principally, achieved through universal access to high-quality healthcare services; above all, it is achieved through a fair redistribution of social determinants of health. As well as the material resources of subsistence, the determinants mentioned include psycho-social factors, such as control over and autonomy of one's work and life, social support (mainly through the social networks of family, friends and neighbours), and the absence of anxiety and stress leading from a lack or shortage of social recognition [6]. These factors explain how societies with greater social inequality are also those with greater inequality in health. This does not mean that social inequality directly causes inequality in health, since the causes may well be found in associated factors. Furthermore, it should be borne in mind that the causation does not automatically result from the correlation [7].

Consequently, the best strategy to reduce inequalities in health, by which we mean increase justice or equity in the health of the population, is achieved when exposure to an illness is the same regardless of class, and not only when equal access to high-quality medical treatment is achieved. This is due to the fact that, while access to the healthcare system is fair, social determinants of health show that individuals may access the system already being ill for *socially unjust* reasons that are not only related to exposure to toxic external agents (the explanation offered by classical epidemiology), but rather to the impact of the unequal social structure in the appearance and development of illnesses (the explanation given by modern social epidemiology). If social determinants of health are not fairly distributed among the population, the power of equity in access to the healthcare system is limited to not further increasing this existing unfairness, but it can neither eliminate nor even reduce such unfairness. The result is that, while access to the healthcare system is through health needs and not, for example, through an individual's ability to pay, those that suffer most from social inequalities are guaranteed neither equity in health nor equality of opportunities.

Another consequence of the impact of social determinants of health in equity affects the redefinition of bioethical priorities. The origin of bioethics is closely linked to the vindication of patient autonomy. The horror produced by the discovery of Nazi experimental medical atrocities and legal cases in the USA in the 1960s regarding demands for patient autonomy led to a rethinking of the fundamentals of medical ethics and the birth of modern bioethics as an academic subject. Bioethics is now taught in all advanced medical faculties and forms part of the essential, high-quality training of healthcare professionals.

Nonetheless, with the arrival of evidence provided by social determinants of health, bioethics should reorient its aims. The autonomist bias still dominant in bioethics should be compensated in favour of greater research into social justice and equality of opportunities in health. Justice should take over from autonomy in bioethical priorities. This is for two reasons. First, if we bear in mind the magnitude of the facts, the greatest current challenges of bioethics are not a greater vindication of respect for patient autonomy, but the urgency and need to address questions of fairness locally, nationally, internationally and globally.

Respect for patient autonomy, whether in clinical or experimental medicine, is increasingly well covered in the legislation of democratic countries and, while the old, excessively paternalist attitudes of some professionals do not match legislative advances, the path is well marked. This does not mean that the conflict between autonomy and welfare can always be easily resolved. There are particularly complex issues and cases such as euthanasia, the difficulty of knowing when a patient is truly able or competent to decide, or specific issues of confidentiality. There is no easy answer to these questions from the standpoint of public ethics, meaning that they require special, continuous attention. However, the most important step in the vindication of autonomy was taken some time ago: the recognition of its unquestionable value in all fields of medicine, from the legislative to medical merit.

Nonetheless, the principle of fairness is still far from being respected. Despite the declarations of the WHO in favour of the right to health, this is far from respected in almost the whole world. Inequalities in health are huge. For example, the life expectancy at birth of a Japanese or French person is above 80, which is double that of someone from Swaziland. It should be added that such inequalities are greatest in women and children. A sub-Saharan woman is 100 times more likely to die in childbirth than one from an industrialised nation, and an Angolan child is 73 times more likely to die before the age of five than a Norwegian child [8]. Over 11 million children die each year from treatable illnesses, such as diarrhoea or malaria. Tuberculosis alone kills almost 2 million people in poor countries [9]. It goes without saying that, with such data, questions of justice are, and should be, a bioethical priority henceforth.

The second reason that justifies the priority of justice in future bioethics is found in the evidence taken from the intervention of social determinants of health. These show that their distribution is enormously unfair, that the social factors that determine the appearance of illness are not equally spread, neither do they follow a fair distribution pattern. In a classical epidemiological or biological model, differences in health are explained by factors that are not susceptible to fairness or unfairness. Ultimately, the biological nature of each individual does not follow moral patterns. Nonetheless, on proving that health and illness are closely related to social determinants of health, the distribution among the population of which is clearly unequal, with those people and groups most affected not directly responsible for this, the problems of justice are evident.

This does not mean that it is easy to identify those responsible for the injustice in the unequal distribution of social determinants of health or the right policies to resolve or significantly reduce such injustice. However, this is a further reason to suggest that bioethics, along with epidemiology and other scientific disciplines greatly affected by the arrival of said determinants, such as the economy of health, should include the study of justice among its priorities for the 21st century. If, despite being a science, epidemiology has an ethical base and moral purpose, (e.g. reducing health inequality among the population), bioethics, with its concern for social justice in relation to health, needs the knowledge provided by epidemiology. In other words, if we demand sound epidemiology, whether social or of another kind, and if we want to understand what social justice consists of, we must place moral and scientific concerns for human health at the heart of the theory and practice of social justice. As Michael Marmot and Sridhar Venkatapuram say, 'epidemiology as a field is inescapably linked to the moral concern for the health of people, and no conception of social justice can be considered complete if it does not account for the

social bases of impairments and mortality' [10]. Without a rationale that combines ethics and science, and justice and inequality in health, it will be impossible to build a general theory of justice in health that takes into account all the causes, degrees and consequences of illness and the kind of social response that should be offered.

## **Second Uncomfortable Truth: Healthcare Prioritisation is an Ethical Issue That is Not Resolved Through Mere Clinical and/or Economic Reasoning**

It is often argued that there are insufficient funds to pay for all the healthcare the population needs. And this is true. This justification has been used in many countries over recent years to make cutbacks in public healthcare budgets that lead to an increase in waiting lists and problems obtaining dependency benefits for the most vulnerable patients, as well as other socio-sanitary and preventative measures. The result is that the population's health suffers and worsens. Although we already have data regarding the effects on health of cutbacks [11], the worst effects will doubtlessly be produced in the medium- and long term. This is not only because health problems that are not now being corrected in time will become more acute in the future, but also because those people most affected by health cutbacks are also those worst affected by the economic crisis, the working- and middle classes. Quality of health depends on the quality of the healthcare system, but above all, on the quality of life in general and the level of social and economic inequalities, and the social determinants of health, as seen above. Therefore, should social and economic inequalities increase – as is happening in the current economic crisis (in Europe, at least) – and should the problems of access to the best possible quality public health system also increase, unfair inequalities in health will also increase. Inequalities in health are unfair when they are unnecessary and socially avoidable [12].

Although there are a number of causes of inequalities in health, ethics cannot be ignored in their analysis; in other words, without taking into account the moral value we place on health and equity. To justify this idea, three concepts that are frequently found in times of economic crisis in healthcare need to be analysed. Authorities often say that 'we should be more efficient' and 'the system should be more sustainable'; that is, the health system needs to be 'rationalised'. This normally means adding greater rationality and less passion, greater management and less policy, greater economy and less ideology. Such expressions (efficiency, rationalisation, sustainability) seem to contain an aura of moral and ideological neutrality, of a technical or pragmatic solution to the problem, as if maintaining equity is only guaranteed through general solvency.

There is no doubt that, in principle, it is better, morally better even, to be efficient than inefficient. Neither is there doubt that it is preferable to maintain, or sustain, something good – such as public healthcare – over time than enjoy it in the present and lose it in the future. What happens is that, in practice, efficiency and sustainability are not morally innocuous ideas from the viewpoint of justice, as they often benefit some while discriminating against others with no sound ethical justification.

The communicator usually expresses their intentions through the language they choose. For example, the limitation of a basic asset, such as healthcare attention, leads to the need for its rationing. We can substitute rationing for rationalization (which means



applying reason or reasoning to the understanding of a fact or the solution to a problem), or for prioritisation (for example A preceding B, without us knowing yet the moral value or importance that the order has for us). However, the word that best describes the limited access to a basic social resource is neither rationalisation nor prioritisation, but rationing. This word carries with it historical overtones of times of shortage and misery (wartime, for example) that are avoided when we turn it into a euphemism for rationalisation or prioritisation. However, reality is stubborn, and modifying or renaming it does not make it vanish.

Something similar happens with the words 'efficiency' and 'sustainability'. A priori, nobody sensible could be against increasing the efficiency and sustainability of the health system. The problem arises when they are applied, including painful ethical, and at times unjust, compromises. These are not always obvious and should be unmasked.

For example, efficiency indicates that we should not prioritise expensive medical treatment of low effectiveness. If we prioritise more effective treatments at a lower financial cost, we optimise the amount of healthcare we can offer, not only because it is cheaper, but also because we free resources to cover other needs. However, efficiency does not tell us how many resources to invest, the importance we place on the aim of the investment or what to do with 'inefficient' patients. This last point is especially compromising, since it leads to a moral problem that lies at the very heart of efficiency. Let us imagine that there is an expensive, not very effective (but not totally ineffective) treatment for a minority or rare disease. Few patients, very expensive treatment, low effectiveness; in other words, all the ingredients needed to place its funding by the public health system at the end of the list of priorities. The problem is that the treatment to be eliminated for its inefficiency is perhaps the only one that can improve the lives of specific patients. If we eliminate it, we cannot say that efficiency is forcing us to discriminate against these patients. Efficiency is the main reason we give to justify the cutback or priority, but the final decision, the end reason, is ethical, along the lines of 'the health of all is equally important, but the health of those who can gain most health with the same resources is morally more important'. Therefore, the health of some people is more important than that of others. The paradox is apparently avoided when we add the following argument, 'the health of all is equally important *in that we do not wish to discriminate against anyone for reasons unrelated to health*, but, precisely because we are only guided by health, we favour those who are able to generate greater health with the same resources, and we discriminate against those who cannot, even though these patients do not deserve to be discriminated against'. However, we must not forget that when we benefit and discriminate against some patients over others, these are moral and not merely technical choices. Efficiency may be a good reason to justify a specific prioritisation, but it does not release the person who uses it from moral responsibility as another decision could, strictly speaking, have been made. We are not morally obliged to be efficient in the same way a doctor is morally obliged not to harm a patient or a judge is to follow the law. Once could, for example, choose – and it would not be a morally reprehensible choice – to prioritise the patient with a rare, serious disease – the only treatment for which is expensive and not very effective – and not treat less sick patients who are better converters of health resources. That is, a more inefficient decision could be made that is fairer for morally more important reasons unrelated to efficiency.

A balance needs to be struck between efficiency and equity, and between these and people's rights. Not schooling a child who lives isolated in the mountains may be efficient, but it denies them their right to education. Making a healthy person give (and not donate) their kidney to a patient to save their life is also efficient from a health point of view, but it violates the right to personal integrity and individual freedom. On the other hand, it should be stated that rights are neither sacred nor limitless, and should be considered in arguments about efficiency. Does a dying 90-year-old have the right to demand all possible (and expensive) available resources to lengthen their life by a few weeks if the same resources can be used to improve the health of many? This is a debate that a mature society should urgently have; however, this debate should start by recognizing that its conclusions should be ethically (and, perhaps, politically) justifiable, but not from clinical and/or economic rationality that, in this context, are mere instrumental rationalities.

Let us now address the question of sustainability. Sustainability consists of creating the conditions under which the health system can continue to function with the same quality and equity in the future. To achieve this, austerity is generally recommended in the present use of available resources. Excessive current spending (even through great borrowing) may lead to the bankruptcy of the system, thus depriving us of its benefits in the future. Any family easily grasps the meaning of sustainability, and knows that it is connected to prudent savings and thinking about tomorrow.

What, though, do we want to be sustainable? The answer would seem to be clear: the high-quality and equitable healthcare system we have enjoyed until now. So, how can we achieve sustainability without harming current quality or equity? If, for example, we eliminate some healthcare services, we can maintain the quality of those that remain, but it is hard to maintain equity. If we maintain equity through cutting, if not eliminating, some services, maintaining the same quality as now, with less staff, fewer ambulances, more obsolete medical technology, fewer hospital beds, etc., is highly complex. If this is the case, then we should be honest and admit that the sustainability of the healthcare system discriminates against today's patients in favour of those of tomorrow. This painful exchange would not necessarily be unfair were those future patients, for example, responsible for the precarious situation of the healthcare system or, even should this not be so, they democratically accept the sacrifice of their personal interests in favour of those of future generations. Nonetheless, currently, neither of the two conditions is given. In any event, this is not the place to discuss this important political issue.

On the other hand, leaving aside intergenerational equity, the intragenerational equity of the healthcare system is maintained if the rationing of health resources affects all patients equally, or if, at least, any discrimination is proportional to their responsibility for worsening the system. This is not happening where there are cutbacks in healthcare. If we leave aside, for the time being, the responsibility for the economic crisis, those patients discriminated against by limiting public healthcare service resources are those with insufficient purchasing power to access private healthcare of the same quality. The consequence is that the sacrifice made in favour of sustainability is not equitable and is, therefore, unfair. We need to be aware of the contradiction involved in sacrificing current equity in health in favour of producing – if not merely sustaining – future equity. If the health of the current population is to be sacrificed for sustainability, equity calls for the sacrifice to be the same for all, independently of their economic state. And if we accept inequality in access to healthcare services, those who suffer from worse access should be



fairly compensated. Whatever the case, all roads of healthcare equity lead to a reduction of unfair inequalities in healthcare; that is, a reduction of social and economic inequalities in the population. If there is an economic crisis and sacrifices have to be made, if future generations have to be protected, all citizens should be committed to this – the greater sacrifice being demanded of those less affected by the crisis: the richest. The opposite is inequitable and, unless we can accept such a contradiction, it cannot be justified by the need to make the system sustainable.

### **Third Uncomfortable Truth: Healthcare Prioritisation Will Not Be Resolved Through Applying a Morally Painless Ethical Criterion**

Equity is not an unequivocal concept. Formally, it means that we should treat equal as equal and unequal as unequal. But, who are the equal and, above all, the unequal in the healthcare system? Citizens are equal, and as such, they should have equal access to healthcare services. As is obvious, this is the limit to strict equality. Nobody imagines that each citizen has an equal share of medical resources regardless of their illness. Access to resources should be unequal depending on a morally relevant criterion of inequality. This criterion has traditionally been either medical need or the patient's ability to pay. The first means that illness is the only requisite necessary to receive treatment, with the other conditions such as sex, ethnic origin, religion, social class, geographical origin, personal financial situation, etc., being irrelevant. The second means that treatment is given to the person able to pay the medical institution or doctor's fee. The first criterion is the basis of the public healthcare system, while the second leads to the private system. In some countries both systems coexist, although not fully. For example, in countries with highly established public healthcare systems, such as Great Britain, France or Spain, patients such as undocumented immigrants or unemployed young people are sometimes denied access to numerous health resources. The private system is often closely linked to the public system through fiscal advantages or the private management of some public services.

We will look at the moral justification for the private health system and its relation to prioritisation later. Regarding the public system, ethical problems are not restricted to the above-mentioned discriminations. At the very heart of medical need are at least two morally exclusive alternatives; these become more evident as the need to ration or prioritise between patients becomes greater.

The priority between patients occurs when people have unequal access to limited resources. It would be ideal for access to be equal; that is, that everybody who needs healthcare attention obtains it independently of other considerations. The problem here is that this is simply not possible. A shortage of resources means that we cannot all have equal access to the resources we need; while scientific and technological progress makes this inevitable to a degree, it is also avoidable, as has been mentioned. While it may seem to be a contradiction, the question is the following: what kind of inequality best respects the principle of equality among people to healthcare access? What is the legitimate inequality to access scarce healthcare resources? The tradition in the field of public healthcare is that those with the same medical needs are equal, so providing equal treatment means prioritizing those with the greatest needs.

That said, invoking the concept of medical need as something that can be defined solely in medical terms does not resolve the problem of prioritisation among patients. This is partly so because the meaning of health and illness is often social, which leads to numerous discrepancies as to what medical need really is. Two cases in point are a change of sex and artificial insemination. It is also true that there are epistemological problems on determining who needs what. For example, medical specialists do not always agree as to the treatment a patient needs. However, above all, the conception of medical need is not a merely technical question as there are at least two diverging philosophical interpretations of what medical need is.

The classical view of medical need is linked to the severity of a patient's illness – the most ill patient being the one who deserves greater attention. Nonetheless, this interpretation does have its detractors. They argue that it makes no ethical sense to dedicate resources to gravely ill patients with no, or very remote, chances of recovery if those resources are denied to less ill patients but whose state of health may greatly improve due to them. Those who argue thus believe that the real need of healthcare attention increases with the benefit that this attention can provide. They say that if the aim of healthcare institutions is to offer health to citizens, the greater the health they can provide, the better they fulfil their task. Need does not then depend on how ill the patient is, but on the benefits expected from the treatment. Those who defend this argument generally measure healthcare benefits through a formula that combines years of life gained and the quality of life over these years, or QALY (quality adjusted life years).

Nevertheless, this second interpretation of medical need leaves some ethical questions unanswered. For example, while there is no clear justification, it is taken as given that, since a person generally prefers to live longer than not, it is preferable that a person lives more years than that 'another' person lives fewer. Among other things, this means that young people have total priority over old people. Therefore, resources dedicated to paediatric medicine are of much greater value than those dedicated to geriatrics. Taken to an extreme, this means that there would be justification in investing all resources in saving the life of a new-born baby (who, in our society can expect to live until 80) even if this meant letting 79 old people die who would only gain a year of extra life each through using the same resources. In philosophical terms, this utilitarian approach falls into the fallacy of the absence of moral separability or 'separateness' of persons; that is, it assumes that the moral value of people is interchangeable, the health that some gain compensates for that which others lose while the result is a positive total.

Moreover, the utilitarian criterion ends up prioritising, paradoxically, the healthiest patients who access the healthcare system as they generally have greater possibilities of recovery through the available resources. It seems that the system functions under the motto 'the sicker you are when you need medical care, the later we will treat you'. The criterion of maximization of health that hides behind this interpretation of medical need is clearly related to the utilitarian theory of justice, a theory that has received numerous philosophical criticisms.

But the ethical dilemmas of prioritisation are not limited to the definition of medical need. Alternative criteria exist to prioritise patients that are not ethically negligible. We could, for example, prioritise those citizens who have made, or are expected to make, a greater social contribution, or those who have greater social obligations (e.g. taking care of dependent relatives), or those who have known how to take greater responsibility for

their own health, or the poorest who have no access to private healthcare. Whatever the case, it is clear that equality and equity (in this case in healthcare) are not unequivocal concepts, but include distinct meanings, each of which has its own weight in an open ethical discussion that is committed to the principle of equality [13].

All these criteria are merely orientative regarding the rationing of healthcare services and treatments. In countries that have put into practice an explicit prioritisation (and we should not forget that one is always tacitly prioritising), even with wide social debate regarding the soundness of the criteria, it has been impossible to reach sufficient consensus regarding fair prioritisation. The more detailed the list of resulting criteria, the greater the disagreements that arise. We are yet to have a socially successful criterion and combination of criteria. This failure is explained, among other reasons, by the refusal of the population to generally accept that what is scientifically possible may not be economically *within the reach of all*, and much less so if it concerns an asset as basic as medical care.

Prioritisation exists, even though it is not openly talked about and is often invisibly and arbitrarily carried out by the decision maker (the politician, manager or doctor); this person may not even be aware that they are prioritising through ethical criteria or even differently to their colleagues. But when it is openly mentioned, or when rationing criteria are made public, almost nobody wants to accept it. A certain moral infantilism is imposed; life and health are held to be priceless, but few are willing to mention the economic cost of such a statement, and much less accept the social and political cost of rationing. We expect the State to cover all healthcare needs with money that, as taxpayers, we are not always willing to give (and that our governments cannot limitlessly borrow on the international financial market), since, at the moment of truth, we show we have other priorities, such as building more roads, bailing out banks or enjoying greater private consumption. Each and every one of us is responsible for healthcare prioritisation, even if we look the other way when it is mentioned.

Nonetheless, the difficulties in facing up to healthcare rationing do not depend solely on this moral naivety. There are other causes. One of them is the characteristic of tragic choice that healthcare prioritisation sometimes shows. In a tragic choice of this kind, any decision as to the distribution of limited resources substantially affects the life of people. An often quoted example of tragic choice happened in 1841 with the survivors of a ship that sank between Liverpool and Philadelphia. One of the lifeboats was occupied by more people than it could hold. The survivors knew that, unless the weight was soon reduced, all would drown in the icy waters of the north Atlantic. In an attempt to avoid the certain death of all, 14 people were thrown into the sea. The criteria used to choose were 'not to separate husband and wife and not throw any women overboard'. The lifeboat bore the weight of the lucky ones, who were finally rescued. The most surprising aspect of the story is that one of the survivors, a member of the sunken ship's crew, who was responsible for carrying out the chosen prioritisation criteria, was tried and found guilty of murder [14]. The surprising part is that he was the only person who was brave enough to take responsibility for his actions and carry out the moral decision that had been made.

The tragic choice above consists of the fact that all possible choices are morally detestable. There were basically three alternatives: (i) wait for the death of all those in the boat, which would happen, for example, on following the Kantian rule that nobody should be sacrificed to the benefit of another, or the Christian mandate that only God has power over life or death; (ii) save a specific number of people thanks to a random criterion of choice,

such as tossing a coin, and; (iii) save as many people as possible using a non-random criterion of choice, which requires stronger moral commitment as in, for example, the case itself, or that which would have probably saved most lives: prioritise the thinnest.

This example highlights the fact that bioethics and rationing often have to grapple with tragic choices. An example of this is the separation of Siamese twins that will lead to the certain death of one of them; in the choice of patients who are to receive an organ transplant; in the tolerable waiting list for highly dangerous diseases, etc. The particularity of a tragic choice lies in the fact that, in extreme situations, no individual deserves the grave but inevitable discrimination that the final choice leads to.

A possible alternative to avoid this type of decision consists of the abdication of moral responsibility, for example through the use of random choice systems, such as the lottery, or the 'first come, first served' criterion that is so common in healthcare. From a theological standpoint, one can defend that in random procedures only God makes the moral choice. However, from a secular standpoint, one can reply that abandoning the moral choice to the lottery or, simply, to fate, is a way of running away from the ultimate commitment to human responsibility. If we leave someone to die when we could do something to save their life, even if we leave them to die in order to save an equally valuable other life or lives, we must assume the moral responsibility of this choice.

When faced with the inevitable contexts of tragic choices, two further uncomfortable questions arise; (i) who should choose, and how, the ethical criteria of rationing? and; (ii) to what degree should citizens be informed that they are being denied resources that are to be used in treating other patients?

Let us address the first question. Who decides, and how, what is fair in healthcare prioritisation? Who decides that it is fairer to treat a seriously ill patient who has a good prognosis instead of treating one with a poor prognosis? Who decides that it is better to dedicate part of the healthcare budget to preventative campaigns that may save many lives than to use the same resources to treat a patient with a rare disease – the treatment for which is very expensive and who has little, but not non-existent, likelihood of recovery? The decision maker can legitimize difficult choices in a number of ways. One is that they have been democratically elected to make this kind of decision. The legitimacy here is not provided by the results, but rather the procedure used to designate them. Procedural legitimacy can be improved through a group of democratically selected experts that deliberatively takes morally complex decisions by examining the medical and economic evidence. Daniels and Sabin [15] sustain that this type of procedural legitimacy incorporate various conditions: (i) that citizens should know who the experts are, and their presence should be both technically and politically justified; (ii) the experts must publically answer for the decisions they take and the criteria they use, and citizens should deem such decisions reasonable; (iii) that these decisions are based on criteria that are under constant review as new facts, evidence or discoveries come to light; and (iv) that the experts must ensure that the above requisites are respected at all times.

As there may be a greater conflict of values or reasonable disagreements than in procedural justice, legitimacy is placed on the procedure and not the result. However, this system is not free from problems. One of these is that it is not immune to the tyranny of experts; that is, that the ethical values of the experts prevail over those of the general population. Another is that, in valuing what should be prioritised, experts impose their values indirectly when giving priority to some evidence over other. There is no question

that a fair decision-making process is better than one that is arbitrary and/or lacking in transparency, and that it is also better to leave the making of difficult decisions to the decision maker. Deliberation and accountability should be two essential conditions in taking any morally complex decision in healthcare prioritisation. However, we must accept that no method of choice avoids the most uncomfortable truth of all: that healthcare prioritisation demands that some patients will not receive an existing treatment that could help them.

Let us now look at the second, thorny point. Should ethical criteria of prioritisation be explained so that patients and the general population know why a certain patient will not receive the medical attention they require, or is it more convenient to keep the prioritisation criteria used hidden or implicit? There are reasons in favour of and against both attitudes. Let us first examine the latter.

First, we already know that there are different ethical prioritisation criteria and that we cannot always affirm that any one of them – or any specific combination – is clearly better than the others. There are no criteria universally valid for all cases. We have seen that, in some cases, even seriousness or order of arrival may not be morally recommendable criteria. Should there be no clearly superior criteria, and should the population know this, permanent controversy may further complicate the consensus necessary to apply ethical prioritisation criteria. This argument calls for the doctors and politicians responsible to be the ones to decide, without consulting or informing patients and population, in order to avoid the proliferation of arguments, controversies and confusion that would only complicate things even further.

Linked to this argument, another one arises which sustains that an explicit prioritisation or rationing would produce enormous 'disutility', caused by the fact that both patients and population would know that they do not receive certain treatments or they would receive them too late due to economic reasons tied to the limiting of resources or, whatever the case, for reasons unconnected with medicine itself ('too expensive', 'too old', 'too irresponsible with their health', 'less ineffective', 'too little social value', etc.). This knowledge of the truth would produce anxiety, indignation and frustration, both in healthcare professionals, who would become rationers instead of good Samaritans, and in patients, who would know that they were being denied resources they needed for reasons unconnected with medical need. It can also be argued that there is something inhumane in explicitly informing a patient that, while there is a cure for their illness, it is very expensive and the healthcare system is not going fund it or provide further doctors and services. It would, thus, be better for patients to believe that if they do not receive treatment, or are at the bottom of the waiting list, it is basically due to clinical reasons, even though this is not the whole truth.

Third, it can be argued that explicit prioritisation has numerous administrative and political costs. It complicates the professional lives of doctors and nurses who are forced to examine moral questions far removed from strictly clinical practice. It also complicates the lives of healthcare managers, who have to publically set ethical limits and receive constant criticism by society and those patients most discriminated against. It complicates the lives of politicians, who have to be *burnt* telling people that they will not be treated for economic or other, but not clinical, reasons. Furthermore, there are too many unique cases for the general population to understand that what is morally good for one person is not so for another. Mistrust of the system may become generalised, thus increasing not only

administrative costs but also the loss of the healthcare system's social legitimacy. Therefore, it would be preferable for patients to believe that the reasons they are not correctly or quickly treated are always clinical, even though this is untrue.

Nonetheless, there are also reasons that support explicit, open and transparent ethical prioritisation. First, and despite there being numerous criteria for access to a waiting list, those that are related to seriousness or defined by *need* have certain moral advantages. Need may be determined by the grave condition of the patient, their ability to benefit from available treatment or the social needs linked to the care of their dependent relatives; however, whatever the case, need is a morally superior criterion to social merit, age, personal responsibility for health, nepotism, sympathy or ability to pay. It is true that, among the criteria of need, unanimity does not always exist as to the best combination, and criteria not associated with need should not just be discounted, as some of them may and should play a specific role in prioritisation; nonetheless, there is doubt that need-related criteria provide extra moral legitimacy to healthcare prioritisation, bearing in mind that the kind of asset to be distributed fairly is health [16].

Answering the suspicion that social disutility would result from making the ethical criteria of healthcare prioritisation explicit, one could argue that a lie is not the best producer of social utility. The more mature a society is, the less it accepts lies, whether they be white or paternalist lies. Moreover, the right to be informed is morally superior to the disenchantment or frustration that comes with knowledge of an uncomfortable truth.

Making the ethical criteria of healthcare prioritisation explicit would doubtlessly lead to administrative, political and professional costs. Nonetheless, the rights of patients and the general population to know the truth are greater than the inconveniences caused to the system and its professionals. Secretiveness, arbitrariness, and the lack of transparency in such a delicate question may also lead to abuses. Overall, the arguments in favour of making the ethical criteria of healthcare prioritisation explicit, including waiting lists and the denial of treatment are superior to those against it. Whether society is mature enough to understand and support this is another question. However, banking on social immaturity is never a sound democratic policy.

## **Fourth Uncomfortable Truth: Prioritisation Demands a Commitment to Solidarity Above Individual Freedom**

The main challenge the current healthcare system faces is not so much the production of morally explicit and committed criteria of healthcare equity, but the struggle against the risk of reducing public responsibility for health. Policies of cutbacks are usually accompanied by privatisation measures and, in a wide sense, an abandonment of public responsibility for patients' health and demands that they assume the costs of their healthcare. A range of political, economic and social interests lie behind such policies, but this text will emphasise the neoliberal argument that supports it.

According to this argument, which Robert Nozick [17], among others, has explained well, it is not fair (as it violates individual freedom) for some people to be forced to pay (under the coercion of law, police and justice) for the healthcare attention of others if they have not caused their loss of health. The State has to allow free generosity, for example, by promoting benevolence (or charity), but it can in no way oblige citizens to pay the



healthcare costs (or educational, professional training, pension or social security costs, to sum up – the welfare state) of others through coercive measures, such as taxes. For those who defend this general argument, nobody is responsible for the accidental loss of health of third parties. Let us imagine, for example, that a child develops a grave genetic disease that requires expensive treatment. The neoliberal thesis sustains that, although the child suffers from a disease, it has no special moral reason to request compensation in the form of healthcare. Nobody should help the patient beyond the dictates of their own conscience or wishes. Any aid the patient may receive is due to the feeling of charity or personal commitment to others, but there is no demand for justice. According to Nozick, justice is reduced to the process by which we legitimately appropriate things. Physical misfortune is a mere trick of fate and justice is no reason for it to be socially compensated. Therefore, a citizen has no right to healthcare unless they have purchased it through the market. Any attempt to redistribute resources to treat those whose health is worse is essentially unjust. Applying this criterion means that there is no justification for either the public health system or the guarantee of justice-based healthcare attention criteria. In the minimal State designed by neoliberals, which limits protection and guarantees to the right to private property, there is no place for the universal protection of health [18].

Many objections to this neoliberal position can be made from the standpoint of justice. The main one is that, in the name of the inviolable nature of individual freedom, the health of millions of people depends, in the best of cases, on the charity of the richest, both nationally and internationally. Furthermore, since it supports the arguments of those who defend social responsibility in healthcare matters, placing the emphasis of justice on individual responsibility may paradoxically go against the neoliberal aim to protect private property. Social epidemiology reminds us that unequal social structure (a product of society and not of chance or need) is the main cause of inequalities in the population's health [19]. Therefore, the responsibility for the damage caused would force society *to take charge* of the healthcare necessary to remedy it. Moreover, many medical discoveries and technological innovations have been made using public funding. Why, then, deny the population the beneficial consequences of research that their taxes have contributed to?

On approaching the concept of responsibility for health, three further arguments should be highlighted. The first argument affirms that health is a requisite of equality of opportunities and not merely the result of free use of equal opportunities. It is true that individuals may use their social and life opportunities to place their health at risk, and that they should take responsibility for doing so, but it is also true that health is a condition of almost all social opportunities. Without good health, the quality of life is very poor, severely limiting one's personal projects. Therefore, health cannot only be treated as a reward or punishment for the free actions of individuals, but, above all, as a condition of freedom.

The second argument sustains that healthcare attention cannot be treated as just another commodity, comparable to mere consumer goods, such as a telephone or a watch. Health is a necessity and not only a preference. While it is true that, at times, it is a socially and culturally shaped need, health is not a simple social preference subject to a liberal market's laws of supply and demand; for example, the need to cut one's hair is not morally comparable to the need to regain lost health. In the second case, the need is much closer to an urgency [20], and a society that does not attend to the necessary moral urgencies of its population treats them with neither respect nor dignity. Health itself has a moral value that other consumer goods lack [21]. Why then, should some people bear the costs of the

health protection of others they have not harmed in any way? Let us return to the example of the child with a serious genetic disease whose parents cannot afford the treatment the child needs. Why, despite everything, do we have the duty of justice, and not charity, to attend them? The answer is that the health of people is a good in itself.

According to this argument, health has a special moral importance since limiting it impedes the enjoyment of equality of opportunities, but this should not lead us to think that its value is merely instrumental. Health has a value in and of itself. This is a normative judgment, but it has an empirical base. The person who loses their health does not only think about the loss of a valuable resource with which to achieve important life goals. They also experience harm in itself, the deterioration of their body and the pain of the illness. These internal effects are health-based; they define the loss of health itself. It is the attribution we place on the moral importance of this loss that finally gives value to the need to recuperate health. Therefore, the value of health not only depends on the external effects that can be produced, such as greater personal freedom, gaining employment and wealth, greater social opportunities, etc. Such effects make health even more important, but its final value is intrinsic. To put it another way, someone's health could be undermined if this results in an increase in their wealth or freedom. For example, the State could coercively worsen the health of its citizens in exchange for a better-paid job that leads to greater social opportunities or economic advantages to the community. If we believe that health should not be the price of these positive consequences, it is because we believe that the value of health does not solely depend on them. The thesis that health is good in itself and not just in its use is not an example of metaphysical essentialism, neither does it require any justification apart from health itself (e.g. by sustaining that health is good in itself because God has so wished). Health is good in itself because its value does not depend on what we can achieve through it or its consequences. Health is a good in itself as is freedom. Freedom and health are necessary conditions for achieving other ends, but the enjoyment of freedom and health is independent of these other ends.

This does not mean that a person cannot freely compromise their health through deciding for themselves what best serves their own idea of health. Health is an objective good, but it is also subjective. Just as there is no single way in which to exercise personal freedom, there is no single definition of good and bad health. Someone may, for example, believe that their personal freedom means that moderate alcohol intake and smoking marijuana with friends from time to time, or taking part in a hazardous sport, is all part of what makes them happy, of what forms a healthy life overall. This person must be aware that there is a probability that certain lifestyles can negatively affect their quality of life in other important senses. Even so, the last word on the right way to maintain this global concept of good health must go to the person affected and with all available information.

However, the freedom to decide what one's own health consists of is not a reason for it not to be protected by everyone. Health protection is still a social responsibility under socially agreed terms as to the basic conditions of good health (and bearing in mind the possible limiting of resources) as part of what it means to protect the existence of people, always with the option that the exercise of individual freedom and autonomy may mean that such protection is totally or partly refused.

Conversely, the idea that health and freedom have an intrinsic value may clash with the duty to protect them. This happens, for example, when the principle of justice is at stake. Let us imagine that somebody refuses to have a medical procedure for religious

reasons (e.g. a blood transfusion). The doctor, following their duty of medical beneficence, offers them an alternative, or second best, treatment at a much higher cost. Should we all fund this second treatment? Probably yes. People should not be punished for exercising their freedom to the detriment of their own health. Let us now suppose that the refusal of the most effective medical treatment is due to personal choice that is unconnected with religion (e.g. a woman who refuses a mastectomy, a procedure considered effective against her breast cancer, for esthetical reasons or of personal identity). Let us imagine that the second treatment entails greater expense in medicine to prevent possible future relapses. Should we make this woman pay the difference between the two treatments? No. Personal freedom must count when accepting or rejecting a medical proposal, but it should not mean that the person exercising it is socially or medically punished. In both cases, individual responsibility for one's health does not free society from offering the best possible treatment that the individual will accept, and restrictions to second best treatments must follow reasons of ethical prioritisation unconnected to individual responsibility.

Therefore, if health is a good in itself, we should not care who is responsible for the illness when determining *what we owe* patients. And not just this. If health is a good in itself and we know that a fairer redistribution of wealth improves the health of the poorest without harming that of the richest, *ceteris paribus*, then we should make this redistribution. This is a classic argument in favour of progressive taxation.

We have the moral obligation to protect our own health and that of others. If greater health protection can be achieved through incentivising individual responsibility, it should be taken into account, but never at the cost of not attending to the sick or leaving people unprotected against illness. This does not mean that we should place the good of health before individual freedom to do with one's health what one believes convenient. Society owes people their health protection, even against unwise behaviour, not its imposition. Neither does this mean that individuals lack moral responsibility for their health, but this has to be differentiated in the name of fairness from what we owe each other. We could, for example, morally reproach someone for the foolhardiness of climbing a mountain without being sufficiently prepared, or ingesting excessive amounts of saturated fats, without this breaking our even more basic obligation to help people should such actions result in an accident or illness.

However, the main argument against the social exemption of responsibility for the health of *all* patients is deeply-rooted in the principle of solidarity. If we eliminate the concept of justice from solidarity (which has nothing to do with beneficence and charity) from the above example of the child with a serious congenital disease, the child is at grave risk of being unattended. Neither utilitarianism nor neoliberalism feels the obligation to help the child. The former, because the treatment may prove inefficiently cost effective. The latter, because those people prepared to care for the child might lack the economic resources to do so. Without the duty of solidarity, the child is abandoned to their fate and, consequently, society cannot say that it treats all its members with equal respect and dignity.

Solidarity, understood as the will of citizens to jointly face the avoidable risks of existence (poverty, illness and unemployment being the most important), should be considered part of social justice if we believe there is a duty to attend to the child that goes beyond individual will; in other words, if attending to the child is a unique obligation. Solidarity has been a mechanism by which social inequalities have been compensated and a founding principle of the welfare state since the second half of the 20<sup>th</sup> century. However,

its continuity is threatened on multiple fronts: the economic crisis affecting us over recent years; the growing trend towards an individualism that is indifferent to the needs and suffering of others, which includes the belief that individuals are those most responsible for their own fate; the preponderance of neoliberal ideology, which prioritises the right to private property over any other right; or the progressive deregulation of markets. This new scenario may well require a transformation of solidarity [22] if we wish to preserve the will to collectively share (between young and old, sick and healthy, rich and poor) the above-mentioned risks. Whatever the case, as long as its demise is not confirmed, its absence leads us to a distancing and final abandonment of what makes a society good or just.

The crisis of solidarity our liberal societies are experiencing is now going through a new, disheartening episode: the contractual interpretation of solidarity that says that people must behave according to a 'logical counterbalance' [23] in order to deserve the resources that may prove beneficial through solidarity. Solidarity then is no longer an unconditional right, a collective assurance unconditionally guaranteed by the State in the form of rights. It becomes a reward given only to those who deserve it, those who use their individual responsibility to look after themselves according to the parameters of health authorities, and those who, through their voluntary behaviour, prove to those financing the solidarity that their trust is not being abused. In this scenario, responsibility for the policy of solidarity is no longer public, but is ultimately moved to the recipient. Individual merit substitutes their rights as a citizen. In the classical conception of solidarity, the aid the sick citizen needs is also a way of aiding the community, of communal self-help, which strengthens the community. Social protection is constructed on a building of rights. Nonetheless, in the liberal or compassionate conception of solidarity, aid to the needy individual is a personal merit, a privilege that must be won through their own responsibility.

## Conclusion

Healthcare prioritisation or, better said, rationing, must accept certain uncomfortable truths. The first and fundamental one is that rationing is not always avoidable, so we are forced to face this. In order to do so, what we must do first is recognise that healthcare prioritisation or rationing is an ethical issue that cannot be avoided. We must also accept that the ethics of healthcare rationing are linked to social justice and cannot only be limited to clinical ethics.

Unfortunately, we do not have an ethical criterion or a combination of ethical criteria that serve as a magic wand to ease our conscience after each prioritisation, even though there are procedures that are fairer than others to determine how to achieve them. In general terms, the ethical criteria of prioritisation linked to need are fairer than those that place the emphasis on personal merit and responsibility for one's own health. This does not mean that they play no role in prioritisation. What it does mean is that its importance is secondary or peripheral.

Prioritisation means that some patients are not receiving the healthcare they need, and no ethical criteria of prioritisation can evade the resulting moral dissatisfaction. The ethics of prioritisation consist of the final decision being the most reasonable from the standpoints of social values and the information available, but the ethical conflict within society and the moral dissatisfaction of any sensitive decider will always be inevitable.

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