

*Issues on Luck Egalitarianism, Responsibility, and Intercultural Healthcare Policies*

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**Abstract:** This article analyzes the criteria for the distribution of healthcare services through different justice theories such as utilitarianism and liberalism, pointing out the problems that arise when providing services to a culturally diverse population. The international epidemiological setting is a favorable one for discussing personal responsibility and luck egalitarianism; however, some provisions have to be made so that healthcare institutions do not treat ethnic, cultural, religious, and linguistic minorities unfairly. The article concludes by proposing that accommodations and culturally sensible attention should be provided when possible, without affecting the equal opportunity of others to access these services.

**Keywords:** luck egalitarianism; justice; healthcare; interculturalism; responsibility

Good health seems to be, for everyone, a basic requirement for attaining a satisfying life, and therefore there are several goods that must be well distributed to reach that goal. The 30-year increase in life expectancy reached over the past 250 years is mostly due to an improvement in nutrition, sanitation, and housing conditions. Out of the 30 years gained, probably only 5 are due to healthcare services per se.<sup>1</sup> However, these services also have to be well distributed in order for a society to be considered fair. Our growing and aging population faces an increasingly complex epidemiological situation that healthcare systems need to address in order to be able to provide satisfying services. The matter becomes even more pressing in developing countries where poverty and limited access to doctors, clinics, and other healthcare services have a negative effect on the quality of life of its population. In this article, I deal with the criteria for the distribution of healthcare services in this setting. This subject is addressed through a revision of the justice theories associated with liberalism: utilitarianism, liberalism, and luck egalitarianism.

A vast amount of literature has focused on health and the fair distribution of the resources dedicated to healthcare. However, there seem to be problems in each of the criteria exposed when dealing with specific problems. Utilitarianism faces problems in that it fails to take care of those who suffer diseases and need very expensive treatments. Liberalism solves some of these deficiencies by focusing on health rights; it can also face troubles when dealing with illnesses of pandemic proportions such as diabetes and hypertension. These diseases do not require expensive treatments, but they require scores of resources due to their wide prevalence in the population. This epidemiological setting is a favorable one for

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discussing personal responsibility and luck egalitarianism, where several strategies are sought in order for individuals to look after of their own health and keep the healthcare systems viable both clinically and financially.

Special attention is paid to the problems and dilemmas that arise for healthcare personnel and ethical committees in the face of cultural diversity. Both liberalism and luck egalitarianism have problems when attending to cultural, linguistic, and religious minorities and respecting their forms of life. The kinds of lives that individuals from different cultures lead and the type of responsibilities that are demanded from individuals will require that the attention offered be culturally sensitive.

### **Efficiency and Scarce Resources**

As stated previously, there are many pressing matters to tend to when dealing with healthcare; therefore, healthcare services—that is to say, hospitals, drugs, and healthcare personnel—will always be working to allocate scarce resources and will often make these decisions without much time to ponder different options. Healthcare needs will always be greater than the accessible resources, even in developed countries that invest large amounts in these matters, because we can always live a little longer or take better care of those who are ill.<sup>2</sup>

In this setting, utilitarian criteria almost become common sense. These criteria would recommend allocating resources to help as many people as possible. Utilitarianism is a consequentialist approach to ethics that evaluates different courses of action according to their outcome in terms of the aggregate well-being they produce. In terms of healthcare, utilitarianism would approve those actions or rules that promote a better health or quality of life for as many people as possible. Measuring such outcomes has proven to be a difficult task, because there are different aspects of what can be considered positive effects on health. It is not easy to determine what good health is; it is not only about living longer lives but also about the quality of life, and on this matter the opinion of patients, policymakers, or medical experts may sometimes vary. Different approaches have been taken into account when calculating this well-being. The quality-adjusted life year (QALY) and other instruments aim at combining both perspectives to measure the healthcare outcomes and then allocate these resources efficiently.<sup>3</sup> But the utilitarian calculus would recommend treating common and cheap diseases, leaving behind those who are ill and need complicated and expensive treatments. For example, those who suffer orphan diseases (ODs), such as Gaucher's disease, are in a very difficult position. These diseases are rare, and due to the fact that many of them are caused by genetic disorders, their treatments are expensive. Because ODs affect fewer than 5 out of every 10,000 inhabitants,<sup>4</sup> the pharmaceutical industry is not very interested in developing biomedical research for these diseases, because it would not be very profitable. As a consequence, treatments for these diseases are not always available, or they are very expensive and inaccessible to most of those who need them.<sup>5</sup>

Even though these measurements of well-being try to bring in the perspective of the patients, the utilitarian calculus does not account for our society's great cultural diversity and different forms of life, which require a plural approach to establish what services are important in healthcare.<sup>6</sup> A value monism tends to operate whenever measuring health and patient well-being, and the perspective of the expert takes precedence over that of the affected.

These would be, no doubt, setbacks to a utilitarian approach to the distribution of healthcare. However, these setbacks do not suggest that efficiency and utilitarianism should be discarded altogether, because if, with the same resources, a hospital can satisfactorily treat more rather than fewer patients, then the correct option is evident.

### Liberalism, Health, and Life Plans

Liberalism has significantly transformed the way in which healthcare services are provided, as well as the doctor-patient relationship. Because it is one's own life and life plans that are at stake when visiting a doctor, the traditional model of paternalism and beneficence on the part of medical personnel has moved toward the introduction of ethical principles such as autonomy in the doctor-patient relationship.<sup>7</sup> The goods that should be distributed equally are not the treatments and the services themselves but rather the capability of each and every individual to develop his own life plans. Because healthcare services are core to our development of life plans, access to these services must be guaranteed.

What this means is that the best way to offer these services in liberal institutions is to consider healthcare not according to the Rawlsian *difference principle*, which regulates differences in primary goods, but, rather, as part of the *principle of equity of opportunity* to develop one's own life plans, to have access to jobs and offices.<sup>8</sup> This interpretation of the principles of justice is justified if we consider health and healthcare services not as goods that can be acquired in different degrees but as a requirement of our liberty, and as a necessary entitlement in order to carry out a life plan. Thus provision of healthcare has preeminence, and it cannot be considered in relation to a more urgent principle, as would be the case if healthcare were dependent on the difference principle.<sup>9</sup> This move allows for its distribution to be egalitarian, and it supports the idea of universal care. Nevertheless, it does not tell us to what degree access to healthcare enables our life plans, because in this matter the individual, social, and cultural perspectives would be determinant.

The problems that have been found in the utilitarian criteria for distribution are solved in liberalism, because what is distributed is not well-being but rights. If rights are assigned behind a veil of ignorance, it is not necessary to abandon those whose treatments are onerous, because it would be possible for everyone to conceive that a just society gives health rights to those whose capabilities are impaired, for everyone could be in that situation. Besides, this approach does not say what a healthy individual must look like; rather, it considers the life plans and choices of each individual and procures the capabilities needed to develop such plans. However, it is important to prevent the leveling down of expectations of those who are worse off, as Nussbaum warns in the case of Indian women: they tend to live fewer years than men, and often they are not the least troubled by it.<sup>10</sup> Most liberal theories on this subject establish a minimum quantity and quality of healthcare to enable the individuals' functioning.

In the cases in which basic social services have been provided, there has been an increase in life expectancy, but one of the great problems that has to be faced in distributing healthcare services is that an aging population requires greater resources and somewhat different healthcare services. A large proportion of the population of developed and developing countries are growing old, and severe problems will arise if well-designed services are not provided for this growing

segment of the population. But how to provide treatment to the elderly is also a pressing matter, because treatment at the later stages of life becomes much more expensive, and its effects on life expectancy and quality are less clear.<sup>11,12</sup>

In connection to this previous issue, in the developing world infectious diseases are no longer the main cause of death; chronic degenerative diseases have taken this place. Diabetes, hypertension, and other related heart diseases are noncurable and have become some of the main causes of death in these countries; their treatment will become central to the fairness discussion.<sup>13,14</sup> These illnesses were traditionally related to old age; nowadays, they are an increasing problem in every age group. As a result, many private insurers do not cover chronic diseases (or do it at a ridiculous price), and public healthcare plans have problems dealing with these afflictions because of the pandemic dimensions of the situation. These are diseases that are perfectly treatable, and patients may have a good quality of life; but treatment requires the cooperation and participation of the patient in changing his life and eating habits. Often those involved have no interest in making such changes; by not participating and taking care of their health, patients will require treatment at much more acute stages of their illness, which will mean longer hospitalizations, more treatments, and a diminished quality of life. All of the above impose an important healthcare cost on others.

Serious questions can be raised in regard to the liberal criteria for the distribution of healthcare services, mainly the version presented by Sen's capabilities approach,<sup>15</sup> which privileges the liberty of the population to seek these services or favor some other functioning over those related to a good health.<sup>16</sup> The values that are central to leading a good life may be divergent in different cultures; for example, some cultures do not even consider a long life as a valuable end.<sup>17</sup> Liberalism accommodates these cases, allowing everyone the liberty to choose their own functioning, to pursue what they consider to be a good life. Such liberty may pose problems in tending to matters such as the responsibility shared by the institutions and the general population. A population that does not take care of its own health will often incur greater expenses, which could overload the capacity of the public healthcare sector and potentially block the capabilities of others.

## **Responsibility and Healthcare**

Luck egalitarianism introduces an element of responsibility into the allocation of resources and healthcare services; however, this proposal is deeply controversial and therefore needs to be revised. G. A. Cohen<sup>18</sup> explains that a person suffers from bad brute luck when his bad luck is not the result of a gamble or risk that he could have avoided, and that (luck) egalitarianism intends to block the influence of brute luck on distribution. Hence, unequal access to education based on unequal wealth would be unfair because a child would not have been able to control any of those circumstances; in contrast, unequal access to education due to differing efforts on the part of students would be tolerable, and there would be no claim for retribution.

Similarly, in the case of healthcare, differences in the quality or quantity of and access to these services would not be justified if they do not depend on options chosen by the individuals. A newborn has no control over the decisions made concerning his health, and therefore not to give him access to good healthcare services would be unfair. Someone born with a severe disability had no influence

on it and therefore suffers from brute bad luck and is justified to receive greater resources to have equal opportunity to develop his life plans. On the other hand, even though basic health needs have to be met to protect the individual's capabilities, some considerations of the responsibility of individuals toward their own health can be made, because some illnesses are caused not by brute bad luck but by the individual's own conduct, and such individuals need not be compensated in all situations.

There are some instances in clinical ethics—for example, transplantation ethics—in which responsibility is already well established. Because organs available for transplantation are such a scarce resource, responsibility is taken as a consideration in the allocation of organs. For example, a risky behavior such as heavy drinking may contribute to liver failure; if a transplantation committee has to choose between a patient who needs a liver because of an infection that was of no fault of hers and the aforementioned heavy drinker, it seems that responsibility is a factor that can ethically be taken in consideration.

However, as soon as scholars began to discuss these implications on healthcare, Elizabeth Anderson raised a strong objection concerning the "abandonment of the reckless."<sup>19</sup> How can a healthcare system be fair if it will abandon those who have been careless: drunk drivers, smokers, or anyone who could have avoided his affliction or disease? A fair healthcare system that is sensitive to the responsibility of the population cannot at the same time abandon the reckless in order to reach universal care.<sup>20</sup> First of all, there would be problems in determining which behaviors should be considered voluntarily risky and which ones should not. Exercising is required for a population that needs to stay healthy, but it is not equally easy (or hard) to jog for 30 minutes every day in a fancy residential area with parks and public lighting than in a poor neighborhood where crime rates are high.

In order to be able to provide healthcare services to a population with the current epidemiological configuration, there is a need to meet the basic healthcare needs of all the population, and these needs include not only doctors, hospitals, and drugs but also, and even more importantly, access to clean air and water, nutritious food, adequate and hygienic housing, garbage disposal, and sewers.<sup>21</sup> According to Segall, on these matters there cannot be consideration of the responsibility of the subjects, as such goods are essential for ensuring equal opportunity.<sup>22</sup>

Then again, in most of the chronic diseases that nowadays are killing the population there is a very strong component that depends on the decisions, lifestyle, and behavior of the patients;<sup>23</sup> and therefore it would be justified to make the imprudent patients bear at least some of the burden of their own treatment.<sup>24</sup> Whatever these responsibilities would look like, it is clear that the qualification of the fulfillment of these responsibilities should not fall on the physicians, because this would affect the needed trust in the patient-doctor relationship. This task would probably be carried out by policymakers and social workers.

Segall proposes that the element of responsibility of many of these high-risk behaviors can be dealt with through an *ex ante* taxation.<sup>25</sup> That is to say, cigarettes, alcohol, and high-fructose drinks could be highly taxed, and those funds could be redirected toward the treatment of illnesses related to their consumption. This would only take care of certain forms of behavior and would not take care of passive behaviors such as a sedentary life, to which *ex ante* taxation is difficult to apply, and which is a key factor in medical conditions such as obesity and its

connection to type II diabetes. Nonetheless, it is possible to issue tax returns to people who are exercising, losing weight, or quitting smoking. All of the above are *ex post* measures that would enable transfer of some responsibility to the general population and at the same time would prevent the overloading of healthcare systems.<sup>26</sup>

Although several problems arise in discussing fairness and the distribution of healthcare services, I would like to focus on two discussions between luck egalitarianism and a Rawlsian kind of liberalism. I first address the idea that desert is not relevant for justice; second, I examine how healthcare attention should be distributed in a culturally diverse population. The latter discussion will be traced along the lines of the Dworkin-Cohen discussion of expensive tastes,<sup>27</sup> and the problems that follow when asking communities to change their habits, for it may disrupt their identity. In order not to affect minority groups, the requested changes have to be sensitive to their form of life, their beliefs and values.<sup>28</sup>

### **Culturally Sensitive Healthcare**

It seems that responsibilities are harder on those who are worse off. When trying to get a population to become more active to avoid diabetes or high blood pressure, there would be problems in making everyone equally responsible for changing their habits. Jogging or exercising tend to be more difficult for those who live in poor neighborhoods. The efforts that a person is willing to make are related to natural talents, skills, and the opportunities open to her. Therefore, says Rawls, "the better endowed are more likely, other things being equal, to strive conscientiously, and there seems to be no way to discount for their greater good fortune. The idea of rewarding desert is impracticable."<sup>29</sup> Would we need to abandon the idea of including responsibility in order to reach a fair universal healthcare system?

Certainly not. On the contrary, the fact is that such a measure would enable a better setting to face the economic challenges of a universal healthcare system. Segall points out that those with better luck also seem to have greater responsibilities; a progressive system for assigning such responsibilities can be thought out.<sup>30</sup> Also, there would remain the obligation to compensate those who live in adverse environments and have difficulties taking care of their own health. However, both liberalism and egalitarianism have trouble accommodating culturally sensitive healthcare attention.

To what extent can medical attention be adapted to the beliefs, values, and lifestyles of the patients and still be fair to all? Are cultural factors being tended to or are preferences and desires being satisfied? One of the problems is that these preferences often can be expensive to satisfy. It is not difficult to justify basic needs, and specifically basic medical attention.<sup>31</sup> However, certain accommodations to cultural diversity seem to go a bit further than what we would call basic attention. The existence of translators and cultural facilitators at hospitals is not basic, and it comes at a higher cost. But proper attention to this population would not be possible without their help. A patient-doctor relationship would not be established if not for them, and the capabilities of individuals from minority groups would be affected.<sup>32</sup> Therefore, in this case it is also well justified to compensate and offer a broader set of services to minority patients, so that they might receive treatment that accommodates their beliefs, values, and lifestyles.

Here again we encounter the problem of what constitutes brute luck and what is a preference that one could change or avoid. It is obvious that, in a sense, it is not impossible to change one's own cultural affiliation; in this sense it is voluntary. However, in another sense, being born into a culture or language is not something that anyone controls. If considered in the former sense, cultural forms of life—and the accommodations they require—are a preference of some individuals, and the need for such accommodations can be considered an expensive taste<sup>33</sup> that needs no special consideration or compensation on the institution's behalf.<sup>34</sup> One permanent quarrel among ethics committees in hospitals everywhere concerns the bloodless treatment for Jehovah's Witnesses. To accommodate the religious beliefs of these patients, physicians must use more difficult and costly techniques to substitute for the use of transfusions.<sup>35</sup> Do healthcare systems need to compensate such patients for a preference that they have chosen?

Healthcare systems have a duty to accommodate these religious beliefs as long as doing so does not affect the equal opportunity of others to access these services. In the case of scheduled surgery, the techniques and equipment necessary to operate without need of blood can be made available, especially in places where there is a large community of Jehovah's Witnesses. Through good planning, it is possible to operate according to the values and beliefs of the Jehovah's Witnesses, without excluding others from equal opportunities for welfare. The bloodless surgery techniques have proven to be just as effective as traditional surgery in fields such as cardiology and have helped to avoid such ethical dilemmas.<sup>36</sup> Therefore a basic level of attention has to be offered to these patients and can reasonably be widened to take care of the special needs of specific minorities.

The more complicated cases in which the technique of a bloodless surgery cannot be applied, such as accidents and emergencies in which the patient has already lost a considerable amount of blood, have to be considered. Sometimes the ways around a transfusion require heroic measures and the use of extremely expensive drugs.<sup>37</sup> In such cases, physicians and healthcare professionals would have no obligation to carry out such procedures if doing so could mean a substantial blow to a hospital's finances, thus affecting the equal opportunity of others to access healthcare services. Even if these preferences can be considered objective—not manufactured—their legitimate claim cannot override others' right to equal opportunity and access. In such cases, it is important to offer the patient the opportunity to cover such costs privately, helping her as much as possible. This point may be controversial, mostly in the case of emergencies, because of the unlikelihood of these negotiations happening. These decisions would need to be the responsibility of hospital administrators and never of the physician, because this responsibility would affect the necessary trust between the patient and her physician.

It is the right of the competent patient not to receive a treatment (i.e., transfusion) that he does not wish to receive. But before we come to this point, we may engage in an intercultural dialogue in which trust in the patient-physician relationship is central.<sup>38</sup> Cultural competences prepare the healthcare personnel to deal with cultural diversity in their practice. The development of such competences allows the healthcare personnel to realize how everyone's points of view are value laden and heavily configure their priorities and preferred courses of action. Then it is possible that, on review of the disputing positions, an agreement may be reached that allows the patient to carry out his form of life. A strong and

sincere commitment on the physician's behalf to only use blood as a last resort has achieved, on occasion, the informed consent of a Jehovah's Witness patient to receive a transfusion if needed. This commitment must be sincere and shared by both parties; hence trust and proximity are essential to this intercultural dialogue.

### **Intercultural Dialogue and Patient-Centered Medicine**

Often, treatment for indigenous peoples and ethnic, linguistic, or religious minorities is paternalistic and discriminating. Attention is offered from the dominant medical perspective, which is focused only on the clinical evidence and not on the patient. Healthcare providers often discredit the values and beliefs of the patients. Such attention is far from being sensible to cultural, religious, and linguistic diversity. Indigenous, rural, and migrating populations are not fully considered in the dialogue that should take place between patient and physician in order to achieve a diagnostic and treatment that improves the opportunities and welfare of the patient, because such dialogue seems to be established exclusively from the physician's point of view.<sup>39</sup> A new perspective is proposed in which patients are considered as the center of the practice, and technical and scientific knowledge is put to the service of those who are ill, thus combining Hippocratic philanthropy with evidence-based medicine.<sup>40</sup>

A public institution that is trying to offer an equality of welfare, or opportunity of welfare, needs to take into consideration the cultural perspective in which medical attention is going to be offered. Scanlon argues that welfare is objective and therefore independent of preferences.<sup>41</sup> If a minority group has a very different standard on the urgency of the demands that arise from cultural diversity, the group must produce strong evidence that the consensus is genuine and unmanufactured. But if there is a genuine consensus, these preferences are not entirely voluntary and are objective, at least in the sense that they are formed by values that are accepted and govern the social life of a community.

The indigenous peoples in Latin America, for example, are at a severe social and economic disadvantage; thus they suffer from brute bad luck. They have limited access to medical attention and other important public services. Therefore it is justified to expend greater resources to allow them to take care of their health and develop their life plans; however, and in accordance with the prior argument, the kinds of policies to be developed and the attention needed do not seem to be extremely expensive.<sup>42</sup> First of all, an important increase in the access to these services is needed. Countries with large indigenous populations, like Peru, Bolivia, and Mexico, have made efforts to make these services available by developing intercultural hospitals, where options from biomedicine to traditional indigenous medicine are offered. Even though intercultural hospitals require different facilities and more personnel with specific training, the costs are not off the charts. They do not require expensive equipment or expensive drugs; on the contrary, traditional medicine does a lot with very limited resources. For example, many intercultural hospitals keep a garden to grow the medicinal plants needed.<sup>43</sup>

If intercultural policies can be provided for people with different cultural backgrounds, some thought has to be given to what kind of responsibility will be assigned to those who are diverse. If lifestyle changes are to be required in the conduct of a community, it is necessary that those changes be sensitive to the existing forms of life, beliefs, and values,<sup>44</sup> so that responsibility may be laid



out in terms that are coherent with the culture in which they are sought. It would be counterproductive in terms of the preservation of a culture to seek changes or assign responsibilities that would go against the culture's conceptions of life, health, and death.

This approach would be part of not being paternalistic toward minorities. In the case of indigenous groups who are protected by international treaties, states have an obligation to take them into consideration in the design of the public healthcare policies that concern them. Healthcare institutions should take into consideration this cultural component. If such policies are designed with the participation of these groups in mind, culturally sensitive responsibilities may be laid out. At the same time, individuals who do not take on these responsibilities would not be entitled to receive this special medical attention. Of course, diversity comes in many forms and fashions. The specific features of each of the cases and regions have to be thought out, but the present discussion has outlined a culturally sensitive attention that is fair in terms of luck egalitarianism.

## Notes

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40. See note 38, Altamirano-Bustamante et al. 2013.
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42. A large part of the population in developing countries uses medicinal plants to meet their primary health needs. Even though indigenous peoples in Latin America and their medical traditions can be very different at times, in general indigenous practices offer medical benefits. Several universities in Bolivia (Potosí and La Paz) have graduate courses on intercultural health in which the pharmacopeia of indigenous medicine is studied, validating through clinical trials some of the popular uses of these plants, in order to increase our knowledge of these plants and their benefits. In Mexico, several years ago the Institute for Social Security (IMSS) implemented a nationwide study on the use of medicinal plants. For example, guava leaves (*Psidium guajava* L.) were prescribed with great therapeutic success and at a very low cost to treat common diarrhea and other gastric diseases; such use and its results have recently been confirmed. The results of many of these trials have been positive and have attracted the attention of ethnobiologists and the pharmaceutical industry. See Aguilar A. El estudio etnobotánico de las plantas medicinales en México. In: Ríos M, Borgtoff H, eds. *Las plantas y el hombre*. Quito: Abya-Yala; 1991; and a more recent study in Costa Brandelli CL, Brandt Giordani R, Attilio De Carli G, Tasca T. Indigenous traditional medicine: In vitro anti-giardial activity of plants used in the treatment of diarrhea. *Parasitology Research* 2009;104(6):1345–49.
43. The structure of intercultural hospitals allows combined access to traditional healers and biomedical physicians. A patient who comes to an intercultural hospital may choose to see a traditional healer or a biomedical physician, and what is important in these cases are good reference mechanisms between the healers and physicians, that also allow further reference to second and third levels of attention. Intercultural hospitals seek to join the efforts of these different forms of medicine to help the patient. Of course, there are parts of the traditional indigenous medicine that have no clear clinical impact, such as the ritual part of this medicine, but it is still important in maintaining patient-centered care. The joint work of traditional healers and biomedical physicians ensures

that these practices are not harmful to the patient and, at the same time, that they are welcoming to indigenous minorities. See Duarte-Gómez B, Branchet-Márquez V, Campos-Navarro R, Nigenda G. Políticas nacionales de salud y decisiones locales en México: el caso del hospital Mixto de Cuetzalan, Puebla. *Salud Pública de México* 2004;46(5):388–398; Mathez-Stiefel SL, Vandebroek I, Rist S. Can Andean medicine coexist with biomedical healthcare? A comparison of two rural communities in Peru and Bolivia. *Journal of Ethnobiology and Ethnomedicine* 2012;8(26). Available at <http://www.ethnobiomed.com/content/8/1/26> (last accessed 16 Jan 2016).

44. See note 28, Campinha-Bacote 2002.