

EDITORIAL

TRANSPLANTS – BIOETHICS AND JUSTICE

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Bioethics, as a branch of philosophy that focuses on questions relative to health and human life, is closely tied to the idea of justice and equality. As such, in understanding the concept of equality in its original sense, that is, in associating it to the idea to treat “unequals” (*those who are unequal or different, in terms of conditions or circumstances*) *unequally (differentially), in proportion to their inequalities (differences)*, we see that the so-called “one-and-only waiting list” for transplants established in law no. 9.434/97, ends up not addressing the concept of equality and justice, bearing upon bioethics, even when considering the objective criteria of precedence established in regulation no. 9.434/98. Thus, the organizing of transplants on a one-and-only waiting list, with a few exceptions that are weakly applicable, without a case by case technical and grounded analysis, according to each particular necessity, ends up institutionalizing inequalities, condemning patients to happenstance and, consequently, departs from the *ratio legis*, which aims at seeking the greatest application of justice in regards to organ transplants. We conclude, therefore, that from an analysis of the legislation and of the principles of bioethics and justice, there is a need for the creation of a collegiate of medical experts, that, based on medical criteria and done in a well established manner, can analyze each case to be included on the waiting list, deferentially and according to the necessity; thus, precluding that people in special circumstances be treated equal to people in normal circumstances.

DESCRIPTORS: Bioethics. Ethics. Equality. Justice. Lei 9.434/97. One-and-one waiting list. Transplants. Regulation 3.407/98 .

In this paper we will analyze the transplant law and the regulation that was established in light of the principles of justice and equality that focus on bioethics, seeking especially to analyze the intrinsic parameters that apply to the so-called “one-and-only waiting list” for recipients of organs. Therefore, it seems of fundamental importance that the concepts be well delineated, in a natural interdisciplinary manner in dealing with the proposed theme, making it patent that we make manifest our inconformity to the epistemological rupture, where fragmented scientific knowledge leads to the abandonment of common sense in multidisciplinary knowledge that

honors and disciplines rationality. In order to “defragmentize” the scientific knowledge, considering here, the varied arguments necessary in examining the question aired, it behooves us that the interdisciplinary approach be fundamental in the formation of our thinking, although there does not exist neutral knowledge, or that is, there is always a certain amount of subjectivity in scientific studies; this being human nature.

BIOETHICS AND JUSTICE

To Segre¹, bioethics is *that part of ethics, a branch of philosophy, that*

focuses on questions relative to human life (and, hence, to health).

Likewise, in an in-depth study on the subject, Cohen² defines bioethics as *an ethical comprehension of the questions relative to health and human life*, and continues, citing thinkers of the “Kennedy Institute of Ethics”(EEUU), adducing that bioethics is based on three principles: autonomy, beneficence and non-malevolence and justice, with the concept of justice being understood as the collective welfare and not as contractual liberty, in which power is determined by the reciprocity, without subjection and subordination, unless the lord and master of all, by some mani-

fest declaration of his will, had distinguished one above the others and unequivocally bestowed upon him, by indicating clearly and evidently, the rights of a master and sovereign³, departing further from the Aristotelian concept of natural apportionment.

It is pointed out, however, that bioethics, as well as ethics, (of which it is a part) is closely related to the idea of justice, that understood as collective welfare, ends up bringing to the surface the necessity of discussion, regarding the principle of equality.

THE CONCEPT OF EQUALITY

It is said that, although it is not understood what equality is, it is much desired (Lucas⁴), to the point of becoming an obsession of political thinking. Rui Barbosa, in his *Oração aos Moços* (*Prayer to the Boys*), invoking the Aristotelian concept, stated that equality and inequality are both rights, according to the hypotheses; equality when it is a matter of a fundamental right, and inequalities, when they fall into a category of acquired rights. Rights are fundamental when they apply to man for being man, independently of any acquisitive act. They are the essence of the individual human being, as are the rights to life, liberty, security and property. Acquired rights are those that each man has, in virtue of the acquisitive act: to work, to inherit, to buy, to donate, to find something and others that the law may comprehend as creators of sources of rights. In light of acquired rights, all are equal. However, in either case, the treatment of the law is equal for all the citizens in the same conditions⁵ and complete, *the rule for equality does not consist in only apportioning unequally to unequals, to the proportion that they become unequal.*

We verify that many times (if not in the majority) equality is achieved

by way of unequal treatment, or, that is to say, *laws are created to guarantee inequality and not equality, giving the appearance of equality to an inequality in which it is affirmed*⁶.

Although it is known that equality does not receive uniform treatment in what is referred to as its conceptualization, when, on the one hand, it follows a liberal line of reasoning, which gives a major emphasis to liberty and then, on the other hand, a Marxist one, which emphasizes isonomy proper, the fact is that as much as our constitution tries to achieve, as a democratic ideal, material equality and not only formal equality – before the law –, human beings do have differences that should be respected, taking into consideration the notion of respecting inequalities. Ignacio Burgoa⁷ adduces under the epigraph “juridical idea of equality” that juridically, *equality is expressed such that various persons, undetermined in number, in a determined situation, have the possibility and capacity to be entitled qualitatively to the same rights and to contract the same obligations that emanate from that said condition. In other words, equality, from a juridical point of view, is manifested in the possibility and the capacity that several people, numerically undetermined, acquire the rights and contract the obligations derived from the certain and determined situation in which they are found.*

Moreover, it is not difficult to note that the concept of equality, respecting inequalities, is closely correlated to the previously mentioned principle of justice, guided by ethics and originating from the Latin proverb, *Suum cuique tribuere* – Give to each one what is his – where we add, respecting their inherent differences. Moreover it is necessary, as Costa points out, to remember that equality as a proposition, *represents a relative “ought-to-be”, to the extent that possible equality is*

that which is related to rights and their being put into effect and not to the characteristics or to the personality, since, as Bobbio⁸ well reminds us, one of the maxims most charged with emotive meaning is that which proclaims equality to all men, but frequently, attention is not given to the fact that that which confers an emotional charge to the enunciation – which when it is a descriptive proposition, is excessively generic and even false – is not the equality proclaimed, but the extension of equality to include all.

Hence, with the especially wise concepts having been established of bioethics, justice and equality that emanate from the law to guarantee inequality (for those in special circumstances) and not equality, it behooves us to analyze the transplant law, as pertains to the obligatoriness of obedience to the one-and-only waiting list, in such way as to verify if it is indeed adhering to the principle of justice of bioethics, modeled after the principle of equality.

THE TRANSPLANT LAW

With the intent of resolving the problems that arise with organ transplants in Brazil, in 1997, Law 9,434 was published (04/02/1997) and promulgated and later changed by Law 10.211, on March of 2001, which rescinded Law 8,489 of November of 1992 and Decree no. 879 of July 18, 1992, which is the law which provides that tissue, organs and parts of the body, live or post mortem, are made available on a free basis for the purpose of transplants and medical treatment. Following that, Law 9,434/97, promulgated Decree 2,268/97 and Regulation MS no. 3,407/98, which was the law that sought to regulate the so-called one-and-only waiting list.

Therefore, besides the provisions concerning the procedures to be

adopted for transplants of organs, specifically in the complementary provisions in its article 10, the Law 9,434/97 provides, *in verbis*:

Art. 10 The transplant or graft only will be done with the expressed consent of the recipient, so enrolled on the one-and-only waiting list, after counseling over its exceptional nature and the and risks of the procedure.

§ 2nd Enrollment on the one-and-only waiting list does not grant the intended recipient or his family the subjective right to exemption, if the transplant is not carried out due to alteration in the condition of the organs, tissue and parts to be destined to him, as a result of an accident or an incident during its transport.” (bold print is our addition).

With the purpose of making effective the abovementioned legal articles, Regulation no. 3,407/98 purports to regulate the one-and-only list system, formulating, initially, a one-and-only list system for each type of organ, body part or tissue (art.36) – divided as such into: kidneys, liver, lung, heart and cornea.

Likewise, patterned after art. 37, § 2nd, of the aforementioned Regulation:

“§ 2nd To the degree that the recipient needs **diverse organs, the criteria for distribution will be defined by the organ in greatest demand in the one-and-only waiting list system.**” (bold print ours).

Finally, to emphasize, Regulation no. 3,407/98 stipulates the objective criteria for indication of precedence of the patient in relation to the one-and-only list, when there are urgent clinical conditions (art.38), stipulating these conditions in its art. 40, according to each type of organ, i.e., *kidney – lack of access for carrying out a dialysis; liver— fulminant hepatitis and the necessity for re-transplant; lung – necessity for re-transplant; heart – necessity for re-transplant; cardiogenic shock; hospitalization in an intensive*

care unit with vasopressor medication; necessity of mechanical assistance in cardiac activity; cornea – graft failure; ulcer of the cornea with no response to treatment; descemetocoele; perforation of the eye ball and a recipient with less than 7 years of age with bilateral corneal opacity.

Thus, what is known as the transplant law, among others, was innovated, establishing the one-and-only waiting list, wherewith, the legislators certainly thought that isonomy and equality would be respected; whereby, with the creation of a one-and-only list, distortions and privileges would be avoided, treating all individuals equal who would need a transplant. A one-and-only list was to be created, wherein the order of enrollment was to be observed, and wherewith it would be guaranteed that the principle of justice, guided by bioethics, would be adhered to.

Moreover, with the regulating of urgent cases, that gave preference to recipients who were in objective situations, foreseen by the regulation, it was expected that problems with urgent cases would be resolved.

We cannot agree with this sophism, taken as an argument based on premises considered as being true, seeming to be a result of formal rules of reasoning, arriving, however, at an inadmissible conclusion.

Let us clarify this; in fact, the premise that the creation of the so-called one-and only-waiting list was based on certainly was the necessity for organization in what has to do with effecting transplants in Brazil; but, as it is, without the minimum of organization, certainly some people could be privileged at the detriment of others, even in situations where there is less serious risk to life. Establishing a one-and-only list, based on nothing more than the order of enrollment (a first come, first served basis), ends up violating rather than guaranteeing the

principle of equality, in that it ends up treating equally individuals who are in unequal situations, especially as pertains to life expectancy, in cases where there is the risk of death.

In effect as we pointed out before, laws are made in order to guarantee inequalities and, as such, guarantee, in essence, the observance of equality. Only in this way is it possible to speak, in principle, of justice in bioethics, since when the law purports to guarantee equality in unequal situations, it ends up institutionalizing inequality. The effect is just the opposite of what is expected.

It is what occurs, we contend, concerning the one-and-only list, based on the order of enrollment of the recipient, who has to wait his turn to have a transplant, even if this costs him his life.

It is not necessary to be an expert in order to see that the system created for organizing transplants results in institutionalizing inequalities, departing from the principle of justice, and it introduces a new factor, which is unacceptable in its being treated as normal – luck. Even in the more advanced countries, the number of donors is always less than the number of recipients, such that, whether it be greater or less, there will always be waiting. It is necessary, therefore, that there be a list organizer for this waiting. However, we contend that the needed organization of the list of recipients cannot be established with the luck of the recipients as the condition, since although, in principle, all the recipients are really in situations of extreme necessity, some can be in more urgent situations than others, in what can be as serious as risk of life and, even then, find themselves at the end of the list. The transplant law does not correct these distortions. The pretext for organizing transplants, ends up subjecting recipients to a factor that is too subjective – luck..

On the other hand, the criteria of §

2nd of art. 37 becomes teratological when it stipulates that the recipient who needs various organs, will be submitted to the criteria for distribution of the organ of greatest demand in the one-and-only list system. Now, this very patient, with multiple organ failure and consequently at the greatest risk of life, will have to be subjected to the list of the organ in the greatest demand, where, generally speaking, the wait is longer!

Furthermore, the aforementioned stipulation of objective criteria of preference does not resolve the problem. It very timorously defines relevant clinical criteria – *giving priority to cases of re-transplantation, in which the recipient is already enrolled on the one-and-only waiting list*, but it does not include, as it indeed could not do, all the clinical situations of risk of death to the patients.

It is not expected that the legal or infra-legal norm would be able to include all the possible cases or situations that could cause the death of a patient who is on the waiting list. On the other hand, this is not even the objective of the Law, which cannot be deterred by trying to deal with untold numbers of specific details, at the expense of excluding relevant situations. Nevertheless, it is expected that more comprehensive and just parameters be established, in which those situations of precedence also can be analyzed – that provide greater possibility of life to those enrolled on waiting lists, trying to obtain the very essence of bioethics.

Sometimes, the argument is that it would be impossible to know which recipient would need the transplant most urgently, without incurring the risk of an error, or even what subjective criteria of necessity could lead to distortions and favoring, since it is human nature to favor patients, besides there being the difficulty of verifying the validity of information. It is our

opinion that solutions can be found to these problems.

Initially, it should be pointed out that the physician, from the first day that he exercises his profession deals with risks and the possibility of making errors. Risk and the possibility of errors are inherent to the profession. *What differs from luck is the possibility of technical analysis and the requirement of a foundation to the diagnosis.* It is exactly on this point that we see the advantage of a one-and-only waiting list (divided up by the different organs), organized according to the impending necessity of the recipient and not merely according to his position of enrollment. A collegiate of physicians could be formed that analyzes each case with all the information about the patient, and it would be the duty of the group to establish, in an systemized and technical manner, the position of this patient on the waiting list, that would be valid for a determined time period, with the possibility of even re-positioning when necessary. It is evident that a series of subjective and supervening factors could lead to the death of a patient. However, it is our judgment that it is still better to have a group of *experts* do a case by case analysis for the purpose of positioning patients on the list, even if an error could occur, than to leave a potential recipient to the mercy of sheer luck or to timorous objective criteria that have proven not to exempt cases in which patients are in danger of dying. Worse than a wrong diagnosis that, incidentally, when made unintentionally, does not incur responsibility, is a lack of an ampler and more-encompassing diagnosis, made for the purpose of determining in which order organs are received – such a lack, which, in reality, exists at present. The fact that diagnoses depend on information that is essentially subjective and difficult to verify does not elide the duty of professionals in

the field to elaborate well-grounded concepts that comprehend the situation of the recipient at that moment, which could improve the chances of his life, since no professional can try to shield himself with the excuse of difficulties-such behavior has the potential of perpetuating situations that we see as being unjust.

It should be pointed out further, regarding the privilege or corruption factor, the fact of there being the presence of a collegiate body of experts, such as has been proposed here, would reduce these risks. Notwithstanding, it is our judgment that it would be possible to have a periodic changing of members of that collegiate, which would reduce further those risks.

The details of the entire process as to how all this would function can still be better studied, but it is our opinion that only with more serious and technical criteria, would it be possible to achieve the aims of the legislator of creating a one-and only waiting list, maintaining what exists by that name, today, but its nature should be changed, so that it is organized, taking into account the needs of each recipient.

CONCLUSIONS

i) Bioethics, as an ethical comprehension of questions relative to life and health, is intimately related to the idea of justice and equality.

ii) Equality is only achieved by treating unequally those who are unequal, in proportion to their inequalities; i.e., giving each individual what is rightfully theirs, respecting their inherent inequalities;

iii) Regulation 9,434/97 seeks to give equal treatment to those in need of transplants, not achieving, however, the principle of justice and equality;

iv) The one-and-only waiting list, based on the order of entry of the

enrollment violates the principle of equality, attributing equalitarian treatment in unequal situations;

v) The criteria established in art 37 § 2nd of the Regulation MS 3,407/98 becomes a teratology, when it stipulates, in the one-and-only list system, that the recipient who needs diverse organs be subjected to the criteria for distribution of the organ in greatest demand;

vi) The objective criteria of preference, established in Regulation MS 3,407/98, is insufficient and is not wide enough in scope, requiring a case-by-case evaluation of the risk of death to the recipient;

vii) The risk and the possibility of error in diagnosis, when there is a case-by-case analysis, for purposes of inclusion on the one-and-only waiting list, are inherent in the exercise of medicine, but what makes them different from the risk factor alone is exactly the possibility of having technical analysis and there being the requirement of a foundation to the determination;

viii) It is our judgment, thus, that there exist a one-and-only waiting list, divided up into organ categories and organized according to the imminent

necessity of each recipient, based on diagnoses by medical experts in the field, who are to compose a collegiate with periodic member replacement, whose result will be that it function in such manner that the position of each recipient on that list be determined by said collegiate, in a technical and established manner, seeking, hence, the principle of bioethics, as a corollary of justice.

FINAL CONSIDERATIONS

We know that the concepts of justice and equality are relative, and we are aware of the uncomfortable situation of an individual who, waiting for an organ, depends on the order of enrollment in order to receive it; since, we have no doubt that all lives have the same value. In considering this, it is our judgment that with jurisdiction within the technical criteria, it is possible to attempt to achieve equality more effectively, giving priority for transplants to those individuals most in need of them, without eliminating the carrying out of transplants on those who have conditions that enable

them to wait for longer periods of time. Life is an absolute concept, which cannot be compromised, especially with the argument that people on waiting lists die everywhere. We add to this argument that every day, every hour of the day, every minute of the day, deaths are registered for diverse causes, as it is human nature, and not only by reason of waiting lists, a motive for which we cannot passively accept unequal situations, when we seek to save the greatest possible number of lives, as Hippocrates taught.

Therefore, bioethics, with an ethical view of questions concerning human life and health and with the principle of justice (collective welfare) as a fulcrum, cannot be far removed from the discussion of such an important question (raised, in terms of the law) that, we contend, at the present time, ends up transgressing the Aristotelian concept of justice, which has been definitely incorporated in our ordering paradigms and that teaches us that true equality is only achieved by treating “unequals” (those who are unequal or different, in terms of conditions or circumstances) unequally (differentially), in proportion to their inequalities (differences).

RESUMO

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A bioética, como ramo da filosofia que enfoca as questões relativas a saúde e a vida humana, está intimamente ligada à idéia de justiça e igualdade. Desta forma, entendendo o conceito de igualdade em sua acepção original, ou seja, associando-o à idéia de *tratar desigualmente os desiguais na medida de suas desigualdades*, observamos que a denominada “lista única de espera” para transplantes, prevista na Lei

9.434/97, acaba por se afastar do conceito de igualdade e justiça, norteadores da bioética, mesmo considerando os critérios objetivos de precedência previstos na Portaria n.o 3.407/98. Assim, a organização dos transplantes em lista única de espera, com tímidas exceções para alguns casos, sem a análise técnica e fundamentada, caso por caso, quanto à necessidade preeminente, acaba institucionalizando desigualdades, relegando os pacientes à própria sorte e apartando-se, assim, da *ratio legis*, que visa buscar maior justiça no que tange ao transplante de órgãos. Concluimos, então, a partir da

análise da legislação e dos princípios da bioética e justiça, pela necessidade da criação de um colegiado de médicos *experts*, que baseados em critérios técnicos e de forma fundamentada, possam analisar cada caso para fins de inclusão na lista de espera, de acordo com a necessidade e preeminência, evitando-se, assim, que pessoas em situações desiguais sejam tratadas igualmente.

DESCRITORES: Bioética. Ética. Igualdade. Justiça. Lei 9.434/97. Lista única de espera. Transplantes. Portaria 3.407/98.

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