

Ethical perspectives about organ allocation for transplantation

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The ethical questions suggested by the allocation of organs for transplantation can be assembled around the notion of justice. It is a domain of health care in which there is a chronic lack of resources, but for patients whose life is at stake, sometimes at short term. It has similarities with the triage, imposed in some conditions of emergency medicine, at war or during civil catastrophes. The question will be approached from the points of view of the main stakeholders. (*Acta gastroenterol. belg.*, 2004, 67, 168-171).

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Introduction

Organ allocation is one of the most difficult tasks in organ transplantation. This results from the chronic imbalance between the number of organs available for transplantation and the number of patients waiting for a graft. In spite of all efforts to increase the number of organs available for transplantation, either by recurring to living donors or by increasing the number of organs harvested from deceased persons, in no country was it possible to eliminate such an imbalance. The consequences of this chronic unsatisfactory situation was the creation of permanent organ transplant waiting lists of patients and of rules governing the attribution of organs to patients on the waiting lists.

Organ allocation belongs to what is called local justice or distributive justice (1), which is a small section of justice, and guides also the allocation of low fare housing to poor people in a community, the selection for layoffs, the admission to selective colleges, the choice for military service or the allowance for immigration or children adoption.

The function of organ allocation is inserted between two important functions : that of the waiting list management and that of the evaluation of the results of transplantation, which is essential for understanding the consequences of organ allocation. The ethical aspects of organ allocation cannot be presented without mentioning those which are related to the waiting list management and to the analysis of the results of transplantation.

What is at stake in organ allocation is the duration of the stay on the waiting list, which conditions the life of a patient, either in its quality or in its duration. Every year, many patients die while on the waiting list for a heart, liver or lung, and their death can clearly be related to the fact that no graft was proposed to them during their registration time. What is at the root of allocation rules is also that two types of constraints exert their effect on the process leading from harvesting to trans-

plantation : biological factors, such as blood groups or histocompatibility reactions, and logistic factors, impacting on the quality of the graft. It is well known that breaking those constraints would lead to immediate failure of the graft and should therefore be avoided.

The concept of equality is at the center of organ allocation. There is not a single method and a single criterion to measure inequality. There is a quasi infinite number of such criteria which can be chosen according to what needs to be put in the forefront according to ethical values (2). The allocation of organs does not escape to this observation.

The ethical aspects of organ allocation can be seen from four perspectives, that is from the point of view of four stakeholders : the first concerned, the patient ; the doctor, that is the physician or surgeon in charge of a transplantation team, who is torn between care for one and care for several ; the organism in charge of allocation, which has to implement distributive justice ; the society which, invited to participate to donation, is sensitive to the question of justice.

The patient's perspective

The patient, stricken by a disease, is constrained to be registered on a waiting list. Often ill informed about the organization of the waiting list management and the organ allocation process, he could be seen as having no responsibility in organ allocation, apart from suffering of the process.

This is not true, if one considers that the patient has a responsibility in respecting the rules which have been devised for the management of the waiting list. For example, in France, it is not allowed to be registered in more than one transplantation center. If a patient breaks this rule by being registered in some centers in other countries, he is clearly acting unfairly compared to other patients registered in France. At the other end of the process, the care that the patients gives to his graft, through compliance to immunosuppressive treatment, is also a crucial factor. The nature of the disease and level of understanding can interfere with this ability and most

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patients cannot be accused of having interrupted their immunosuppressive treatments. In some cases, however, some negligence can be the reason of the failure of the graft, which can lead to retransplantation.

Apart from such responsibilities, the patient can also, isolately or within patients associations, have a view about the principles that should guide allocation rules. Patients should be invited to participate to the elaboration of allocation rules. It is known, for example, that kidney recipients pay much attention to kidney transplant waiting times and do not accept major differences on this indicator.

The doctor's perspective

A heavy burden weighs on the doctor. Meticulous updating of the waiting list and regular and honest reporting of the results of transplantation are important features. However, the role of the doctor and its immediate professional environment takes a prominent place in the allocation of organs, when organs are not attributed directly to a single patient identified through the allocation rules, but to the transplantation team which, then, has to identify a recipient among the patients which it takes in charge.

In such a two step procedure, fears are sometimes expressed that, in such a situation, the choice of the recipient might not be based upon medical or biological criteria, but exerted under the coercion of pressures, which might be of financial, political, ethnic, or religious nature. This risk, the reality of which is difficult to assess, is certainly low. A more important and realistic pressure, which can be exerted on the doctor, is that which arises from medical colleagues. If a physician sends a patient to a transplantation team and the patient dies before transplantation, the doctor could say the next time, "I sent you a patient, which died before transplantation. I wish to send you another patient. Do you think that you will be able to do this transplantation in time? Or should I send the patient to another transplantation team?" Such a pressure, which threatens the activity of the transplantation team and thus its existence, is a strong pressure. A pressure, which is difficult to resist to, is when the candidate for transplantation is closely related to the transplantation team, either because he is a member of this team or a close parent to one of the team members. It is most probable that, in such a rare case, the general rules will be respected, but the patient will be transplanted soon.

At the level of the transplantation team, in order to minimize the risks of pressures being exerted on them, doctors often elaborate local rules of allocation of organs. The definition of those rules and the process of organ allocation should be elaborated collectively within the team and made public within the department of transplantation and, if necessary, outside of it. In France, such local rules were brought to the knowledge of the *Etablissement français des Greffes*.

The perspective of the doctor is also an essential element of the process of elaboration of allocation rules at a larger scale. Sometimes, the difficulty for the doctor to separate what stems from commitment to a patient and from an institutional perspective becomes apparent. Allocation rules are in fact a powerful lever to influence the number of transplantations made by a team.

Recent conflicts in the United States of America between large and small centers in the field of liver transplantation, have exemplified the ethical dimension of this factor in the process of definition of allocation rules. If the financial health of a medical institution or the income of the surgeons is mathematically linked to the number of transplantations performed in the institution, and therefore to the allocation rules, it is clear that the doctor's or institutional perspective might be influenced by such considerations.

Usually, considering the allocation rules, the doctor is torn between two attitudes. The traditional attitude is to put, at the first rank, the patients which are in the most critical condition, for example those the life of which is endangered, most probably at short term. Another tendency, influenced by the observation of a constant lack of organs, is to consider that the good quality of the results of transplantation should be aimed first. This leads some transplantation teams to avoid, at least partially, the performance of transplantations with a high risk of failure. Such an attitude, leading to a rational use of a rare resource, can favor the implementation in the allocation rules of an indicator promoting transplantations with good results.

This is one reason why the quality of the evaluation process and the ability to evaluate the results of transplantation according to risk factors, that is to compare what is comparable, influence the way the doctors will see the comparison of the results of transplantation between centers and their acceptance to give a high degree of priority to patients for which transplantation is a high risk operation.

In some countries, the doctor's perspectives is also focused on the problematic registration of non-resident patients on the national waiting list. For the sake of the activity of the transplantation team and its international reputation, the perspective of the doctor can be to encourage or, at least, not to discourage the registration of a large number of non-resident patients on the waiting list. Considering that the perimeter of the obtention of the grafts is limited to the perimeter of a nation or a group of nations, such registrations, if numerous, can have a strong impact on the activity of the teams if the rules give some weight to the number of patients registered on the list of each center. This was the situation in France, particularly concerning liver transplantation, at the beginning of the nineties. The transplantation teams were then invited by the *Etablissement* to pay attention to the patient, but also to the public health aspects of transplantation. The percentage of non-resident patients registered on the national organ transplant waiting list

was brought from 25% to less than 5% within five years. Such an evolution made the health professional community more serene concerning the allocation of organs in France.

This underlines however that the allocation rules for organs within one country cannot be considered without paying attention to the question of the management of waiting lists, organization of transplantation and allocation rules in the neighbouring countries. On this matter, the guidelines recently produced by the Council of Europe on the management of organ transplant waiting lists are useful (3).

The perspective from the institution in charge of organ allocation

In France, the Etablissement français des Greffes, a national state agency, is in charge of this mission. It approaches organ allocation from several points of view.

The basic mission is to put into practice, day and night, all along the year, the application of the organ allocation rules.

It also has to promote organ donation. The way the rules of organ allocation are applied may have an impact on the promotion of organ donation. If the rules are not applied properly, if there are justified complaints from the doctors or from patients, if a doctor can act contrary to the rules without being identified and without reaction, trust from all the stakeholders in the way the rules are applied is likely to deteriorate rapidly, with its deleterious effect in terms of organ donation. As a compensation, if the increase of the number of organs to propose does not allow to escape from the rules, it relieves some part of their psychological weight.

All along the process which led to the application of the rules, the Etablissement had a sequence of tasks to implement :

1. to organize the elaboration of the rules. It meant that all the stakeholders had to be invited to contribute to this elaboration (doctors, patients, representatives of the State).
2. to clearly state, in the documents describing these rules, their underlying principles. For example, the balance had to be indicated between the advantage given to patients in a very difficult situation, because of emergency or a particular difficulty to have access to a graft, and the measures taken to use each organ as efficiently as possible, considering the technical constraints which apply to organ harvesting and transplantation.
3. to document everything from the general principles, to the rules themselves, which became a legal text in France (4), then to their modalities of application, so that any controversy might be clarified according to the existing rules. In order to avoid difficult controversies, it may be useful to implement the voice recording of all discussions with the doctors concerning

the application of the rules, as it is the case at U.K. transplant.

In France, it was also felt necessary to build a system allowing a margin of decision to the doctors, who know their patients better than anyone else, and leaving some room to the local allocation of organs, in order not to create a strong disincentive to organ procurement in some hospitals. The allocation system had also to be capable to operate at the frontiers defined by the rules. For example, if the rule says that the super urgent category will be accessible to a patient which needs retransplantation less than eight days after a first liver transplantation, the question becomes difficult when such a retransplantation should occur ten days after transplantation.

In order to face such difficulties, a group of independent experts was constituted in France in order to help the Etablissement français des Greffes to solve such difficulties. Such a group is constituted for each type of organ and permanently accessible. Within a few hours or minutes, they can propose a decision with regard to the position that the Etablissement français des Greffes should adopt about a potential waiver to the rules. In the critical and urgent situations, like for liver or thoracic organs, the decisions are transferred through telecopy. The experts are proposed by each transplant team and selected in each case so that, if the patient is in one area, the two independent experts will be specialists from other geographical areas.

The role of the Etablissement is finally to analyze the results of the allocation process, particularly for the priority categories, in order to integrate these results in the continuous improvement of the allocation process, which is regularly implemented, according to the evolution of science. However, care is taken to maintain the basic rules, reflecting the basic principles, as stable as possible. The legal text concerning allocation rules was modified, and slightly, only one time in eight years (5).

The society's perspective

Each member of the society is potentially invited to participate to transplantation by becoming a donor. Opposition to organ harvesting remains one of the main causes of the lack of organs. Thus, the role of the population and the health professionals in the process of organ harvesting and transplantation is crucial. The idea that organ allocation might be unfair is one of the motivations advanced by the people who declare their opposition to organ harvesting.

The point of view of the society is, well shown by the general expression that priority should be given to children, a group of the society which, in our times, is considered as eligible for more attention and care. Therefore, communication about allocation rules should include also information of the general public, upon the guiding principles of the rules and the way the organs are allocated.

In each country, enquiries about public opinion reveal the belief that there is an organ trafficking and that shortcuts are frequent. Trust in transplantation is fragile. Whether information campaigns are able to alter these rumors is uncertain. For these reasons, an extreme vigilance should be paid when a patient is registered on the waiting list, which carries a special risk concerning trust in the application of allocation rules. This is the case with prominent figures of the political world, media or sport. In such situations, the organ allocation system should be considered in a situation of pre-crisis. If the patient is transplanted rapidly, the suspicion of shortcut will be very difficult to eradicate. If the patient is transplanted late, pressure on the allocation process is likely to increase with time. All these elements, which relate to the view that the public has about the allocation of organs, should be taken into consideration.

Conclusion

Increasing the number of organs is limited and therefore, the ethical difficulties of organ allocation cannot be

solved easily. These difficulties require the elaboration of permanent rules and important precautions, considering the views of all the stakeholders.

Due to their persisting nature and their direct impact on the life of patients, organ allocation rules may constitute a model for those, who face the permanent uneasy task which consists in allocating rare resources to a large population, and who cannot multiply fishes and breads.

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