

*Gundolf Gubernatis*

## **Rationing in Medicine: A Presupposition for Humanity and Justice**

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### **Abstract:**

Limited resources are the permanent condition in health care. Rationing, according to H. Kliemt, is the distribution of limited resources below market prices to all people in need for these resources. Therefore, rationing is a basic component of every kind of human health care system. However, the crucial problem is how to find just and fair rules for this distribution under the premise, that every patient should have the same chance. The allocation of organs for transplant can serve as a paradigmatic example for studying rationing problems, as shortage of organs cannot be denied nor abolished. H. Kliemt compared the situation with the classic decathlon. The selection of factors and the combination and weighing of these factors for ‘winning a donor organ’ should strictly be related to individuals. Non-medical criteria should generally be accepted and authorized as far as they are relevant to the question of justice and fairness. In this paper the so-called ‘solidarity model’, an example of joint research with Hartmut Kliemt, is introduced as an allocation system with the power to enhance justice and fairness.

Munich 1994, Congress of the German Society of Surgery—the head of my surgical department, Prof. R. Pichlmayr asked me to join a special conference: A book was to be presented by a philosopher on organ allocation.

Curiously, I agreed at once and a few minutes later, I listened to Hartmut Kliemt presenting his idea on a club model: “Donor Organs for Members only”. The auditory did not agree. The reactions ranged from a lack of understanding to indignation posing a lot of arguments against such ideas. In short, the “unreal theoretical thoughts of an unworldly philosopher” were generally refused.

I remember being surprised. However, I realized that the idea was based on the fact of the actual and undeniable scarcity of organs, and the club model presented was an attempt to propose a solution ensuring a fair distribution of too few organs. Thus, my spontaneous comment was that although nobody liked the philosopher’s idea, Hartmut Kliemt was closer to reality than we all liked to admit. This was the beginning of a lasting and fruitful cooperation with Hartmut Kliemt and, last but not least, of an equally good and lasting friendship.

Moreover it was also the beginning of difficult discussions within the professional society of organ transplantation which have put Hartmut Kliemt and

myself at odds with the mainstream position of large parts of this society—a position in which we still remain.

Later, in July 94, the *Ärztliche Praxis* published Hartmut Kliemt's proposal together with three comments: F. W. Eigler's point of view was totally against the model ("Organspende nur auf Gegenseitigkeit nicht in die Praxis umzusetzen") based on ethical principles of the medical profession. R. Pichlmayr was also against the model ("Als Arzt kann ich doch keinem die Behandlung verweigern"), however, was more moderate respecting the idea of mutual help as a basis for organ donation. My statement ("Ein Transplantat ist keine Pille, die man sich bei Bedarf rezeptieren lässt") was in favour of starting the discussion about solidarity as a relevant factor for justice in organ allocation and of developing such models on the basis of the idea of the club model.

To my surprise Hartmut Kliemt continued working in the field of organ allocation. I considered this subject too specialized or respectively too unimportant for general studies, however, I learned from Hartmut Kliemt, that organ allocation can serve as a perfect paradigmatic example for studying rationing problems. In contrast to a financial shortage which can arguably be solved if the society is willing and strong enough, the shortage of organs can neither be denied nor solved and should be evident to all. Thus, organ allocation is the best example to develop and test basic principles and models for the general question, how to cope with scarcity in the medical field and how to distribute goods in health care—and how to give the same option to everybody in need. The crucial question in organ allocation is of patients' utmost interests—it is the question 'who should live and who should die'.

First of all, Hartmut Kliemt identified a clear and well defined difference between scarcity as such and rationing. Rationing in a general sense is traditionally associated with queuing, waiting and hoping that at the end of the queue someone will receive something that cannot be obtained by other means, respectively which can only be received through paying a higher price. Rationing therefore has nothing to do with taking away, on the contrary, rationing is associated with receiving something. The definition of rationing according to Hartmut Kliemt is the distribution of limited resources below market prices to all people in need of these resources. Therefore, rationing is a basic component of every kind of human health care system. However, the crucial problem is the question of rules for this distribution and therefore the question of justice under the premise that every patient should have the same chance of receiving the same or an individually necessary part of the limited resource.

In the case of organ transplants this difference between scarcity and rationing and the role of physicians is quite obvious and impressive, however, not particularly well realized by most physicians. The essential role of the physician is to diagnose the patient's need for a transplant. After this diagnosis, the patient is put on a waiting list for a transplant instead of immediately receiving such a transplant as a result of an organ shortage. This first step of becoming a candidate for a transplant is absolutely uncritical and does not affect the relationship of trust between a physician and patient. The second act, however, to

allocate an organ to one individual patient on the waiting list is a typical act of rationing and is highly critical for the trust relationship because giving an organ to one patient inevitably ignores the demand for an organ of other patients.

Due to medical problems in the pioneer phase of organ transplantation there was no other way but to give decision—making powers in organ allocation to physicians or surgeons respectively. Nowadays as the transplanting of organs has largely become a routine procedure with standardized allocation factors, the question arises why only physicians should decide on selection and weigh factors of organ allocation criteria. In other words, it is quite unclear why physicians afflict the physician-patient trust-relationship in such a critical and unnecessary manner and physicians turn themselves into “rationing agents of the society” (term by Hartmut Kliemt). Without any doubt, medical professionals have to be involved in selection of criteria, and the weighing of factors etc. in a more general sense on the so-called macro level of allocation. In the micro allocation level which afflicts individual patients’ interest directly, rationing decisions should only be taken by a third party using generally accepted rules. On this level the difference between need, scarcity and rationing becomes obvious: The physicians decide on the need by putting the patient on the waiting list, but they should not decide on rationing by allocating one organ to one special patient (see above) rather than another. It is a common misunderstanding that decision making on the individual micro allocation level is understood as a typical physician’s task and that decisions on the macro allocation level should be done by people other than physicians. Under conditions of scarcity and rationing, it has to be done vice versa concerning the micro allocation level! In this context the current system run by Eurotransplant can be universally accepted. The crucial question, however, arises in context of the macro allocation level: why is the selection of criteria and the weighing of factors a decision by medical professionals or an exclusive decision by the medical association? The second crucial question is why only medical criteria are accepted and—by advice of the medical society—authorized by legislation (German Transplantation Law §12(3)).

Apart from the traditional role of physicians in the organ allocation process which includes establishing rules for allocation in the pioneer phase and apart from the fact that physicians may like being in this powerful position of making life or death decisions in relation to organ transplants, one reason may be that medical criteria are generally considered as being just and fair. Medical criteria can objectively be decided upon only by physicians. Thus, especially in the political sphere, medical criteria are well accepted and the decision-making is consequently in the hands of physicians and their professional associations only, with the consequence that all other people including politicians can leave this difficult task to the physicians. The second critical question, however, is whether or not medical criteria are the only important ones and whether non-medical criteria are unjust and unfair a priori. Of course, there is a general consent that the financial power of a patient should play no role in receiving any kind of treatment in social health care systems. The same is true of discriminating factors such as religion, nationality, and various kinds of behaviour etc..

On the other hand, non-medical criteria exist which are relevant to decisions on organ transplants. In fact, some of these criteria have been applied since the beginning of the practice of transplants, e.g. the primary distribution of organs within a country or the old rule that one of two kidneys of the donor remain in the donor region for a patient of the local center carrying out transplants (this rule is no longer applied in Germany). These rules are based on principles of reciprocity without any medical basis. And these rules were well accepted. Another example is the factor of waiting time, generally considered a fair criterion. The medical component of waiting time, however, is urgency. The remainder is a non-medical time factor.

An example is as follows: two patients with identical medical criteria including urgency for receiving one given donor organ are waiting for a long time: the first patient for 8 years and 7 days and the second patient for 8 years and 8 days. Under the current allocation system the second patient would receive the organ as a result of having waited one day longer which in this case is a purely non-medical factor. The question of justice arises acutely in this case if you know that the first patient is a potential willing donor or has already served as a living donor and the second patient has declared that he is against organ donation and will on his own death refuse to donate his healthy organs. (It is a fact, that patients on waiting lists are generally not asked whether or not they are potential donors. Moreover, some of these patients are not willing to donate their own healthy organs in case of brain death.) This example illustrates that non-medical criteria are equally involved in classic allocation and that other non-medical criteria are closely related to the issue of organ transplants. This is especially true in relation to the question of individual willingness to donate organs. The question why non-medical criteria especially donation willingness are not accepted as factor for organ allocation cannot be easily answered. Maybe in the political sphere, people try to avoid potentially controversial public discussions and consider that it is more acceptable to leave decisions to physicians who evaluate medical criteria only. However, the ignorance of non-medical criteria will not improve justice and fairness in the organ allocation system.

In consequence, which criteria should be used and how should these criteria be evaluated?

My basic principle and proposal are as follows:

Non-medical criteria should generally be accepted and authorized. A precondition for the acceptance of a criterion—medical or non-medical—is that the criterion has to be relevant to the question of organ transplants.

Justification: There is no doubt that medical criteria exist without any relevance to the outcome in the field of organ transplants. Equally, there is no doubt that non-medical criteria exist with high relevance to the transplanting of organs such as willingness to donate organs.

Hartmut Kliemt's basic principle and proposal are as follows:

The selection of factors and the combination and weighting of these factors is only acceptable if they are strictly related to individuals. Any kind of collective factor must be avoided.

Justification: The case of organ allocation and selecting and weighting of factors in order to determine the 'winner of the match' for one given organ is a very old problem, and has an ancient precursor: The decathlon. In this discipline it would be absolutely unacceptable to give collective points for being member of a certain group. E.g. it would not be acceptable if all American runners get a 10% credit on their running time and all African runners get one second added to each runner's time result. In contrast, in formula 1 race points are given for belonging to a certain racing stable. In a complete different field of society, it is well accepted giving priority to EU citizens for receiving jobs in Europe. It is surprising that collective points such as nationality are accepted in the organ allocation system: being an Austrian patient respectively living in Austria and waiting on the Austrian waiting list is much more promising for receiving an organ by Eurotransplant than being a German patient on a German waiting list.

Hartmut Kliemt has done a lot of research especially in this field. Many publications indicate the tremendous work done by him, either alone, or together with others, inter alia, in larger research groups. I was involved in some of these projects.

As an example of our mutual research, I would like to present our so-called 'solidarity model' which was developed on the basis of reciprocity-ideas beginning with the club model, and resulted in a well designed additional allocation system with defined principles, the potential of practical application and positive legal and social implications.

## **The Solidarity Model**

### **Definition and Essential Characteristics**

A system of organ donation and organ allocation is a solidarity system or a system based on solidarity if it gives relative priority to those potential recipients of organs who themselves are declared potential donors of organs.

Those who declare their willingness to donate, in particular before developing their disease and being put on a waiting list, are given higher priority as organ recipients. In the case of a kidney transplant, those who have already served as a living donor will receive highest priority should their second kidney fail after their donation. It should be clearly noted that a community of organ donors founded on principles of solidarity does not constitute itself as a

club which excludes non-members. It is a community of individuals who insist that, in addition to the main medical criteria that dominate our current organ allocation systems, a patient's own willingness to donate should be included in assigning priority of treatment. According to the solidarity model, people want to show solidarity with all other people suffering from severe diseases, but even more so in relation to those who themselves show solidarity.

### Potential Realization

As previously stated, the solidarity model suggested here intends to establish reciprocity as an additional factor of organ allocation to improve rather than to substitute the current system. Therefore, the details of the model must be adapted to the several specific system requirements in different countries. In general, reciprocity should have a decisive influence only on priority decisions concerning patients of the elective category to whom neither special urgency nor other special requirements apply. Thus, patients belonging to the high urgency category, highly immunized patients, and children should receive transplants as a matter of priority throughout.

Under this proviso, the solidarity model could quite easily be adapted to the special conditions, say, of Eurotransplant in the following way: Eurotransplant allocates kidneys according to the so-called Wujciak-Opelz model. According to this procedure which was introduced in March 1996, five factors determine allocation decisions. Each of the factors is measured according to a different ranking point scale. These scales have different maximum ranking points and, thus, are of different potential importance. If an organ becomes available, for each patient a point value along each scale is determined and then aggregated to a total. The patient with the highest total number receives the organ. The five factors are HLA-compatibility (maximum 400 points), 1-year probability of a better HLA-compatibility (maximum 100 points), waiting time (maximum 200 points), national balance of organ donation (maximum 200 points), regional donation rate (maximum 300 points). According to the view proposed here, the regional donation rate, which is a kind of reciprocity consideration with respect to regional transplantation centers anyway should be substituted by a reciprocity norm concerning individuals. Along this scale, the number of ranking points should depend on whether or not somebody is a potential donor of cadaveric organs, and has served as a living donor, and on the time span between declaring the will to donate and entering the waiting list. Evidently, the implementation of the solidarity model as suggested here presupposes that central institution for registering the individual donation will—either for or against—be established, as is the case in Sweden.

### Predicted Results

1. *More justice and more beneficence.* Justice requires that those whose behavior increases the scarcity of organs, other things being equal, should not have precedence over those who are more benevolent. According to the

solidarity rule, at least in those cases in which two patients meet standard medical criteria for one specific organ to the same extent, the person who has previously declared her own willingness to donate has priority over a competitor who did not previously do so. Thus, the solidarity model avoids the moral problem that an equally needy and suitable individual who, for instance, opted out as a donor nevertheless gets access to the organ with the same probability as the willing donor. Although excessive retributive measures towards people who have severe illnesses are inappropriate, it seems to be a clear requirement of justice to put some positive premium on more responsible past behavior. This premium quite predictably can further the willingness to donate and, therefore, along with increasing justice, can enhance and broaden the scope for showing beneficence towards those who might need an organ transplant in the future.

2. *Enhanced involvement of individuals and hospitals.* In view of the other institutions of our legal order, it seems desirable that organ donation and organ allocation should, as far as possible, be based on autonomous decisions of the individuals concerned. The general ethical acceptance and acceptability of organ transplants in society will be enhanced if the number of individuals who explicitly express their consent to serve as potential organ donors is increased. The solidarity model provides ethically acceptable, nonmonetary incentives to endorse the transplanting of organs explicitly and, thus, enhances/increases the active solidarity of individuals in the transplanting of organs.

The very moment a central register of intent to donate or not to donate is in place and a higher proportion of the population has expressed its willingness to donate, the status of the transplanting of organs in society and public opinion presumably would change dramatically. Under an institutional amendment as proposed here, only those who needed a transplant and expressed their willingness to donate one of their organs (or actually donated one) could claim to be part of the solidarity scheme. Having shown solidarity themselves, they could then demand that no one hinder them in receiving organs others have donated. Those hospitals that are nowadays still very reluctant to support the donating of organs would have to participate more actively by carrying out donations from every potential donor. Clearly, this would increase the number of available organs and, thus, alleviate rationing problems.

3. *Fair treatment of dissenting minorities, local residents, and nonresidents.* If organs are allocated solely on medical grounds, groups which, for ideological, religious, or other reasons, resent donation, but accept donated organs nevertheless are privileged at the expense of groups who endorse organ donation. Discrimination against groups is completely unacceptable in a Western legal order. In our systems, equity requires that we focus on the individual. Accordingly, the solidarity rule discriminates against those

individuals who want to participate but do not contribute without discriminating against groups.

This also solves the problem of how to deal with individuals who travel to another country to get on waiting lists there. If organs are allocated according to medical criteria alone, there is no way to exclude nonresident aliens from entering a waiting list on an equal footing with residents. As observed in several countries, this invites rich foreigners who never would have been potential donors for the local population to 'fly in' and attempt to receive an organ which has been locally donated. Certainly, such severely ill individuals are personally not to blame for their behavior. However, those who have to serve as guardians of the interests of local communities are treating members of their own communities in a grossly unfair manner in denying them access to organs by treating noncontributors on an equal footing with potential contributors to the local pool of donated organs. Again, the solidarity model can solve this problem to a large extent and in an equitable manner.

## Final Remarks

*A small step for organ transplantation, a great step for patients.* It seems obvious that all existing schemes of organ donation and allocation must, in principle, be open for further adaptation and improvement. Because no convincing normative reasons have been offered so far as to why only those factors included in present practices must determine organ allocation, there is nothing that would in principle and on a priori grounds preclude such minor and highly desirable amendments to existing practices as those proposed here. But why has the solidarity model never been discussed seriously, neither in the medical professional nor in the political or public sphere? As the solidarity model requires only small amendments in addition to the current system, the reason for this model not having been discussed must be a general or political one. The people not in favor of the solidarity model tried to avoid discussion by invoking the frequent argument that the solidarity model is unconstitutional. In fact, this is not true. Most interestingly and remarkably a former judge of the German Constitutional Court Professor Paul Kirchhoff proposed a model very similar to the solidarity model in his celebration lecture at the national congress of the transplant society 2001 in Heidelberg. He proposed a reciprocity model on the basis of personal organ donation willingness and justified his proposal by pointing out that such a model would work within the same ethical category of the individuals strictly avoiding categories such as the financial one. In conclusion, this was the perfect endorsement and justification for Hartmut Kliemt's and my solidarity model on the question of its constitutionality. Nevertheless nothing happened after Paul Kirchhoff's statement.

Joshua Lederberg anticipated a lot of problems in the field of organ transplants when commenting on 10<sup>th</sup> December 1967 in the Washington Post on the first heart transplant. Most of these problems are still current. They concern scarcity and rationing problems, and now, 42 years on, it is more and more urgent to solve these problems and to deal with the consequences. The recent Congress of the German Medical Society made it quite obvious that there is a great need to discuss rationing in health care publicly. More and more physicians are willing to take part in the public discussion including in relation to decision-making for rationing. This should be welcomed by the public. The hidden shortage and the latent rationing in health care should be made subject to a honest and public discussion by all players in this field. However, there is still a long way to go. Hartmut Kliemt has contributed to this aim tremendously by his work and by providing important perspectives for the future: Hartmut Kliemt's work is a great step towards future developments in the health care system in our society.