

How Should Deceased Donor Organs Be Allocated? The Patient's Perspective Derived from Semi-Structured Interviews

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Purpose: The gap between the supply and demand for deceased donor organs is increasing worldwide, while patients on waiting lists for organ transplantation die. This situation requires ethical donor organ allocation rules. The patients' perspective on donor organ allocation rules offers a highly relevant and unique perspective that may differ from the perspectives of physicians and the general public.

Patients and Methods: Semi-structured telephone interviews were conducted with the regional group coordinators of the federal self-help organization for organ transplanted patients and their relatives in Germany in early 2021. Twelve interviews were conducted with patients and relatives of transplantation patients who received transplants for the affected organs including the lungs, heart, kidney, and liver. Transcripts were analyzed using the deductive framework method which was based on an earlier study. All criteria were reported following the COREQ statement.

Results: Participants emphasized aspects of “medical urgency” and “effectiveness/benefit” of transplantation and associated trade-offs as well as the recipient's responsibility for organ failure (“own fault”), the appreciation for the gifted graft and the patient's capability of taking care of it (“appreciation/responsibility”). Patients acknowledged that urgent patients should be prioritized and they showed a clear preference toward allocation rules that strive to maximize both the life years and quality of life gained by transplantation.

Conclusion: The patients' perspective is unique in that patients agree on certain rules for allocation and share many preferences, but also have a hard time finding clear cutoff points when considering selecting a participant for allocation. Patient representatives should therefore be consulted in the debate on donor organ allocation rules.

Keywords: organ transplantation, organ allocation, scarce medical resources, distributive justice, qualitative research

Introduction

Heart, lung, liver and kidney transplantation remains the treatment of choice for end-stage organ failure.¹ The increasing mismatch between the availability of suitable deceased donor organs and the number of potential recipients is leading to numerous deaths on transplant waiting lists. The scarcity of deceased donor organs results in serious ethical challenges for the establishment and adaptation of current organ allocation rules.² In Germany, Section 12 of the German Transplantation Law (“Transplantationsgesetz”) requires that organs are allocated by weighing the “urgency” and the “chance of success”,³ which is a contradictory trade-off in most cases since urgent patients frequently have smaller chances for transplant success, while less urgent patients usually have better chances.⁴ Several studies have been published on the factors that should or should not play a role in the allocation of deceased donor organs, covering the perspectives of the general public, transplant patients and professionals.^{5,6} Professionals act as advocates for their patients, basing their decision-making on suitability and clinical factors with the goal of saving as many lives as possible

while also trying to guarantee equity and equality.⁷⁻⁹ The public is the backbone of the transplantation system, providing the required resources for transplantation, including deceased donor organs. The perspective of the public gives high importance to both the (successful) outcome of transplantation and the selection of the most urgent candidates.⁶

Patients can be expected to be caught to a certain degree between the perspectives of transplant professionals and the general public. Patients are knowledgeable in a very different way than professionals due to their direct personal confrontation with both their threatening and frequently crippling disease and their personal experiences with the health care and transplant system as a long-term patient. On the other hand, they are not medical experts, and they cannot see the transplant system and their disease in the same way as professionals do due to their disease-specific personal involvement and the resulting, usually palpable threats to their personal survival. This makes their unique perspective very valuable for health care research, especially in priority setting, because health care and transplant systems should be patient-centered. The inclusion of patients' perspectives is therefore seen as very beneficial because it adds key perspectives for the development of ethical policies, including organ allocation rules.¹⁰ Therefore, as part of a multidimensional research project,¹¹ we decided to explore the patient's perspective on the question of deceased donor organ allocation priorities for solid organ transplantation.

Methods

Study Design

A qualitative design using semi-structured interviews was chosen, as they provide powerful data and insights into the interviewee's mindset and experiences.¹² The guide for these interviews was based on earlier systematic reviews^{5,6} and qualitative studies^{9,13} in the field of organ allocation and was extensively pilot tested to guarantee the credibility, confirmability and dependability of the results.¹⁴ The guidelines incorporated two main questions and left room for the interviewees to talk about their experience and what mattered to them with respect to organ allocation. The main questions were as follows:

1. How do you assess the criteria currently in use, namely, "urgency" and "benefit"?
2. If it was up to you, what (additional) criteria would you use for the allocation of donor organs?

Additionally, the participants were asked some more questions regarding the relative importance of the identified criteria, whether different criteria should be used for different organs and their work as a volunteer. The complete guidelines can be found in the [Appendix 1](#). This study received approval from the ethics committee of Hannover Medical School (vote number: 7921_BO_K_2018).

Recruitment and Data Collection

In Germany, there are several patient associations for recipients of organ transplants, with the largest being the "Federal Association of the Organ-transplanted" ("Bundesverband der Organtransplantierten (BDO)"), which includes transplant patients and their relatives at all stages of the transplantation process and across all types of organs. At the time this study was conducted, the BDO was divided into 23 regional groups. To obtain a balanced picture of the situation, each regional group's coordinator was asked to participate in this study via telephone. The regional coordinators were chosen in order to obtain a most encompassing assessment of the situation due to their special role not only as organizers, but also as patients/relatives themselves, contact points and persons of trust for patients and relatives in their region. Of the 23 regional groups, 4 groups had no coordinator, and 5 groups had a coordinator that was already included in the study due to his or her role as the coordinator of another regional group, which left 14 regional coordinators for inclusion. One was not available, and one decided against participation in this study. Therefore, 12 interviews were conducted, which resulted in a participation rate of 86% (12/14). The interviews were facilitated by TB and accompanied and supported by CO, who also took field notes. Both had previous experience with qualitative research in the field of organ transplantation and no established relationship to any of the participants.^{9,13} The interviews lasted between 30 and 60 minutes. The interviews were conducted in German with only both researchers (TB and CO) and the participant present on the phone call. Before starting the interview, the patients

gave verbal consent to the recording of the study and anonymous transcription of the record and confirmed this consent in writing after the interviews were conducted. The participants received no compensation for participating in the interviews.

Data Analysis

The data gathered from these interviews were analyzed following the deductive framework method¹⁵ by identifying the core statements and motivations of the interviewees and sorting them into a category system deducted from an earlier systematic review.⁶ This framework uses seven categories to sort the nature of statements regarding the allocation of donor organs: “Egalitarianism”, “Effectiveness/Benefit”, “Medical Urgency”, “Own fault”, “Value for society”, “Medical background” and “Sociodemographic status”, with several sub-categories. Statements that did not fit into any of the seven groups were added into an eighth group for “new codes”, and statements that provided no additional information than what had already been said in another statement were discarded to avoid duplication.

The analysis of the transcripts was carried out by TB and CO with MAXQDA2020, and followed the “Consolidated Criteria for Reporting Qualitative Research” (COREQ)-Statement.¹⁶

Results

Participant Characteristics

The participants’ characteristics can be seen in Table 1. All of the regional groups reached were based in former West Germany.

Induction in the Framework

The selected framework⁶ was well suited for this study. Only a few statements went beyond the scope of the framework so that two new categories had to be created, first “different organs” for statements that compared different types of organs with each other and highlighted differences in the relevant allocation policies, and second “appreciation/responsibility”, a category used to categorize those statements, where participants believed that a key criterion for the allocation should be the fact that the potential recipient is grateful for the allocation and handles it with the necessary responsibility and care.

Table 1 Patient Characteristics

	Participants
Age	28–79
Gender	
Women	7
Men	5
Relation	
Patients	10
Relatives	2
Affected organ	
Lung	5
Kidney*	4
Heart*	3
Liver	1

Note: *One participant received both a kidney and a heart.

Of the existing categories, “Effectiveness/Benefit” and “Medical Urgency” were most heavily discussed. Comparatively little attention was given to categories regarding “Value for Society” and the “Medical Background”. “Appreciation/Responsibility” turned out to be one of the most interesting and challenging categories for transplantation patients, as shown by their emotional involvement on this topic (see Table 2).

Table 2 Quantitative Overview

Category	No. of Interviews the Topic is Mentioned in	Total No. of Statements Regarding the Topic
Effectiveness/benefit		
Post-transplant life expectancy	9	23
Post-transplant quality of life	10	21
Medical urgency		
Waiting time	11	25
Pre-transplant life expectancy	6	11
Pre-transplant quality of life	5	10
Own fault		
Individual role in causing the failure	9	22
Alcohol abuse	8	11
Smoking	8	11
Non-compliance	10	31
Drug abuse and addiction	1	1
Value for society		
Family responsibility	8	11
Registered donor	3	5
Criminal behavior	4	4
Community value	1	1
Medical background		
Transplantation history	1	1
Comorbidities	6	13
Medical comp. betw. donor and recip.	5	8
Obesity	0	0
Mental disorders	2	2
Physical disorders	1	1
Sociodemographic status		
Age	11	36
Financial status	2	2

(Continued)

Table 2 (Continued).

Category	No. of Interviews the Topic is Mentioned in	Total No. of Statements Regarding the Topic
Sex	1	1
Employment status	1	3
Education status	0	0
Religion	0	0
Social support	9	11
Egalitarianism		
Egalitarianism	6	16
Newly identified codes		
Different organs	6	7
Appreciation/responsibility	7	17

Effectiveness/Benefit

The category “Effectiveness/Benefit” of organ transplantation was extensively discussed by the participants. Successful transplantation was defined by the interviewees as the absence of immunologic rejection of the transplanted organ and long graft survival with a high quality of life. Most participants believed that the post-transplant quality of life should be of higher importance than the simple gain of life years.

To me, quality of life beats life years gained in every case. Because quality of life includes a lot of things, like the physical condition, medical aspects, how often do I need to go into hospital care, what side effects do I or don't I experience. It includes a lot, and eventually I would rank it higher. Let me put it like this, I prefer to live ten very good years over living fifteen or twenty with steadily declining quality of life. – Interview 11

Most patients mentioned that the effectiveness of transplantation should always be considered together with the urgency of transplantation.

Medical Urgency

In the category “Medical Urgency”, the opinions of the participants varied: While some believed that urgency should always be second in importance to benefit, others preferred allocating by urgency with the goal of rescuing the most urgent patients based on a sickest-first principle. Participants acknowledged the fact that the comparatively large lack of deceased donor organs in Germany results in diminished chances for transplantation for everybody waiting. They further acknowledged that sociodemographic criteria such as age and gender have an indirect influence on urgency aspects. Most participants had great difficulties when it came to defining clear limitations for the allocation of donor organs to individual patients with specific characteristics because in their view everybody deserves to live and thus to be granted the same survival chances.

Interviewer 1: How high would the chance of success in percentage need to be in order for you to consider someone eligible for a donor organ?

Respondent: Fifty?

Interviewer 1: That high, okay. Therefore, if there was a patient with ten, maybe twenty percent chance of success, would that be an exclusion criterion for you?

Respondent: That is a mean question. I remember the doctors telling me, I had a 1% chance of survival when I had my daughter, and I did survive. It would've been a pity if they gave up, just because of a percentage. Therefore, I think, everybody should get a chance regardless. – Interview 07

When talking about the waiting time, the participants acknowledged that it is not solely a criterion of urgency, but also one of fairness: A long waiting time usually indicates a bad condition and is closely tied to the feeling of “deserving” a donor organ. A long waiting time further indicates a decrease in pre-transplant quality of life, with the potential recipient deteriorating both physically and psychologically.

The longer you wait, the greater the pressure on the patient increases, both morally and organically. I can talk from experience, we waited three years, you get older and there is this cutoff age when you are not being considered for transplantation anymore. This fear is constantly burdening you as a wait-listed patient. – Interview 02

Further, the participants briefly discussed the topic of organ replacement therapies such as hemodialysis for patients waiting for a kidney. While they acknowledged the life support that these therapies enable, they also feel that these organ replacement therapies are only slowing down the process and it still becomes increasingly urgent for the patient to get transplantation while losing valuable quality of life.

Own Fault

This category describes the behavior of patients that is damaging to their organ function and their health. Participants clearly stated that the allocation of a donor organ should only be granted to recipients who are fully abstinent from alcohol with the goal of increasing the transplantation benefit. Some went even further, stating that earlier self-damaging behavior should lead to ineligibility for transplantation:

I have to say, I neither smoke nor drink. I am not allowed to have these guilty pleasures. In addition, I wouldn't find it fair [to see somebody who used to smoke or drink to receive a donor organ]. There are other people who are not at fault for needing a transplantation. – Interview 12

Another highly important topic was the compliance of potential organ recipients. Most participants agreed that this was the most important factor and an essential prerequisite for organ allocation. Participants see noncompliance as an equivalent to wasting an organ. Noncompliant behavior of potential organ recipients is therefore seen as disqualifying. Although compliance was seen as the major gatekeeping attribute for being transplanted or not, some participants showed some leniency by explicitly not excluding patients who lost an earlier organ due to noncompliance, stating that everybody deserved a second but not necessarily a third chance.

A friend of mine did just that, she gambled it away. After her second organ, they told her, that this would be her final one. And I believe this to be the right thing to do. I saw her doing all that stuff, and I told her: “You cannot act like this with a donor organ!”, but she said she wanted to “live her life”. – Interview 05

As expressed in the statement above, aspects of the categories “Own fault” and “Appreciation/Responsibility” seem to overlap in the participants' views.

Value for Society

This category was one of the least discussed, with participants agreeing that transplantation does not only affect the patient, but also the family and the social surroundings. Some believed that (younger) parents should be of higher priority, while others thought this should play no role in the allocation of donor organs.

I would prefer everyone to get [an organ]. However, if you have to make a decision? Why not prefer young parents? – Interview 12

Of course, it is horrible for the relatives, if the father dies and leaves his children behind, but this would not mean to me that those without children should have to die earlier. – Interview 04

Some voiced that those willing to donate organs themselves should possibly be prioritized over those not showing this solidarity.

Medical Background

Participants agreed that the medical compatibility between donor and recipient characteristics is a nonnegotiable prerequisite for donor organ allocation. When talking about comorbidities, they agreed that these have an influence on the effectiveness of a transplantation.

You have to draw a line somewhere. We have too few organs and therefore I would select by chance of success. In addition, if somebody has possibly soon-to-be lethal co-morbidities, then I am sorry, but they should not receive an organ. That's throwing pearls before swine. [...] And if it was me, I honestly have to say that I would understand that. Bad luck. But life has to end at some point. That's how I would explain it to myself. And maybe then it is salvation. Especially with such comorbidities. – Interview 01

While some believed that comorbidities should be a factor to rule out people for organ transplantation, others believed that this is a difficult decision from an ethical point of view. Some also argued that with the right medical care, most comorbidities should not pose an insurmountable problem to transplantation.

Sociodemographic Status

The majority of the participants thought that younger patients should be prioritized in donor organ allocation, either because they were thought to have better chances of success, or because they still have “a life to live”. Additionally, aspects of allocating young organs to young recipients and old organs to old recipients were favorably discussed.

I truly like this idea [of transplanting old organs to old people]. I am slightly older myself at 61 years of age, and I would never want to take the organ away from a younger patient if I ever need one again. I think this is completely fine. – Interview 12

Others believed that older age implied higher medical urgency, and therefore older patients should be prioritized over younger ones. It became clear that age was often used as a proxy for other criteria. Participants associated a younger/older age with higher/lower chances of success, lower/higher urgency, higher/lower quality of life and longer/shorter waiting time.

Some participants voiced their views on social support, which demonstrated the consensus that it is very important for the success of transplantation, while a lack of social support should not be a reason to exclude patients from access to transplantation.

Egalitarianism

When talking about aspects of egalitarianism, participants voiced their beliefs that everybody deserved a deceased donor organ, regardless of their behavior, their past life, their chances of success, and their surroundings.

New Categories: “Different Organs” and “Appreciation/Responsibility”

In the first group, participants stated that donor organ allocation for kidney transplantation should be regarded differently compared to the transplantation of other organs, because hemodialysis can reduce the urgency for kidney transplantation.

“Appreciation/Responsibility” was assigned to statements that referred to the donor organ as a gift that needs to be taken care of in a special way. Participants believed that organ recipients should be grateful for their organ, as it is such a rare and valuable gift. Furthermore, participants expressed the view that such a gift implies a high degree of responsibility of the organ recipient to take good care of their organ. Attitudes that demonstrate a lack of appreciation for the gift were seen as ethically unacceptable.

The surgeons get to know the patient over years and that's how they get an understanding of whether the patient shows up regularly, whether they take their medicine and whether they are responsible. Those are the things that should impact [the decision of organ allocation] [...]. Therefore, what's important to me: The organ is a very big gift and someone else didn't get it, but I got it, so I have to handle it with care. – Interview 08

Discussion

The unique perspective of transplant patients and their relatives on donor organ allocation policies is very valuable for ethical priority-setting because health care services and transplant systems should be primarily patient-centered. To date, there is still a substantial lack of knowledge on patients' views and beliefs on ethical deceased donor organ allocation for transplantation. A previously published systematic review⁵ identified only three studies that deployed qualitative research methods with the goal of describing the views and beliefs of patients on organ allocation.^{17–19} All of these previously published studies were focused solely on patients who were wait-listed for kidney transplantation, while this study is focused on donor organ allocation for all types of solid organ transplantation. Including patients and relatives after transplantation has the advantage that the participants ought to be free of self-centered biases in their preferences on organ allocation. It is understandably hard for someone on the organ waiting list to talk about an age cutoff for example, if they are an elderly participant who is waiting themselves.

Tong et al, 2012¹⁹ reported that patients believed that individuals who can be expected to gain in both quality of life and life expectancy due to transplantation should have access to kidney transplantation, whereas equal access for all and priority for those most deserving was of high importance. This was expressed in high adherence to post-transplant treatment and high respect for the precious resource that they have been gifted in the form of a donated organ. The same aspects were also highly relevant in the eyes of the patients and their relatives who were interviewed for this study. This shows that respect for the precious resource should be included in the framework used in this study for the analysis of the statements of patients and their relatives. Furthermore, the current study clearly shows that great respect for deceased donor organs and the associated highly responsible handling and care for donated organs is very important to the patients and their relatives, which is obviously independent of the type of donated organ. Most respondents in this study expressed their desire to allocate organs primarily to those recipients with the highest potential gain in life expectancy or quality of life, with a priority for the latter, to maximize the effect of a scarce resource. This further emphasizes the importance of responsible handling and care. The interviewed patients and their relatives know the struggles associated with waiting for an organ for transplantation from their first-hand experience. They know how it feels to wait for an organ, while others get transplanted due to factors beyond their control. This experience could possibly explain why they value donor organs and especially the way a potential recipient handles the gift of a donor graft so highly, a trait that could not be observed in studies focusing on the general public¹³ or transplantation surgeons.⁹ Transplantation surgeons are prone to seeing the system as a whole, partly due to their influence of working in this system, and therefore focus on the status quo of organ allocation and the influence of their decisions on the system.⁹ In contrast, members of the general public have difficulty making final decisions on how to allocate organs, resulting in them preferring a combination of different criteria rather than a single criterion.¹³ The public has been found to prefer saving as many lives as possible by giving higher priority to those with high chances of success, therefore maximizing the outcome of the transplantation. Nevertheless, the criterion of medical urgency was still apparent in their discussions and influenced their assessments as well. Here similarities can be observed between the public and the patients, because members of the public act with uncertainty, not knowing if they might be in need of an organ in the future.¹³

Contrary to their high preference for maximizing the usage of donor organs patients were aware of the ethical aspects regarding egalitarianism and generally considered everyone deserving of an organ, especially those with limited time left without one. They acknowledged the divergence of these two ethically conflicting allocation goals during the interviews, and when asked how to handle the situation, they often argued that these decisions should ultimately be made by physicians. While patients acknowledge the ethical principle of treating all potential donor organ recipients as equals, they do have clear ideas on how to allocate donor organs to recipients based on the capability of potential recipients to appreciate the gift of a donated organ and to responsibly care for this organ. Prioritizing one recipient over another is something that, understandably, triggers emotional discomfort. This explains why, even though participants in this study have a clear image of whom to allocate an organ to (and even more whom not to), they have the tendency to defend society's ethical principles by falling back on egalitarianism as well as aspects of effectiveness and benefit by stating, ever so often, that everyone is equally deserving of a transplant.

At the moment, the broad consensus in the Western world is that everybody should receive the best possible medical treatment regardless of their condition. However, this consensus is currently challenged due to increasing economic pressures and

ethical concerns that typically arise in the treatment of the terminally ill or in the treatment of patients with a very limited prognosis. In such cases, the limitation of treatment is frequently initiated by changing treatment goals from curing disease to palliative treatment and/or best supportive care. The widening gap between the supply and demand of suitable deceased donor organs for transplantation also forces treatment limitations in the field of transplantation for patients who otherwise would have a good prognosis with transplantation. This situation raises serious ethical questions in distributive justice and priority setting for donor organ allocation. In a situation where the aspect of urgency does not influence society's moral compass in the allocation of deceased donor organs, patients would most likely distribute the grafts less by aspects of urgency and more by the aspects that are truly important to them: effectiveness and appreciation for the graft.

Strengths & Limitations

Due to the COVID-19 pandemic, the interviews that initially were to be focus group discussions with multiple patients had to be conducted via telephone. To guarantee the best possible coverage of this topic while still staying within a realistic scope, it was decided to contact every regional group coordinator for an interview. It is possible that focus group discussions might have brought other aspects to light that were not obtainable via telephone interviews. However, the conducted interviews had the advantage of creating a more intimate and secure atmosphere in which participants may have voiced opinions and thoughts they would not have voiced among others.

It must be acknowledged that the selection of interview partners could induce a certain selection bias because patients with a positive outcome or experience regarding transplantation are probably more likely to accept proactive and responsible roles in a national self-help organization.

Important aspects may be underrepresented, especially when they are likely to be more relevant for patients with predominantly negative experiences with organ transplantation. Unfortunately, this group of patients is typically very difficult to reach for inclusion in qualitative research.

The transcripts were not returned to the participants for comment or correction after transcription. This approach was chosen due to early anonymization of the participants' data. Furthermore, participants were not asked to provide their feedback on the findings of this study.

Conclusion

Patients' perspectives differ substantially from both the general public and transplant physicians in regard to their opinion on priority setting in donor organ allocation. Patients should therefore be considered equal stakeholders among the two other groups in the debate on donor organ allocation policies. From the perspective of patients, the maximization of graft utility for potential recipients is of paramount relevance, and qualifying donor organ recipients are expected to be able to appreciate a donor organ as a very precious gift, which is associated with the responsibility of taking meticulous care for after transplantation. Transplantation patients are aware of the ethical duality between urgency and benefit and consider that, on the basis of the equality principle, that everyone in need should have access to transplantation. Due to the ubiquitous shortage of suitable organ donors, patients think that organ allocation priorities should be given to those patients with predicted higher life expectancy and good quality of life after transplantation with emphasis on the latter.

Ethics Approval and Informed Consent

This study has received ethics approval by the ethics committee of Hannover Medical School (vote number: 7921_BO_K_2018). All participants have given both verbal and written consent to usage and publication of their anonymized interviews for the purpose of this study. We confirm that all organs were donated voluntarily with written informed consent, and that the transplants were conducted in accordance with the Declaration of Istanbul. However, this interview study includes neither the allocation nor the donation of donated organs, and is not anyhow linked to the participant's transplantations.

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