Why Would Opt-Out System for Organ Procurement Be Fairer?

Abstract

The possibility of organ transplantation has created new problems for medical ethics as well as clinical medicine. One of them, organ procurement, is tried to be solved mainly by two systems. Many countries have adopted the 'opt-in system', which aims to raise awareness and make the individuals donate their organs by their own will. The other system, 'opt-out' or 'presumed consent', which considers all members of society as potential donors, was adopted by some countries. In this system, individuals should state that they do not wish to donate their organs; otherwise they are considered as donors. By trying to ground our argument with various justifications, we claim that opt-out system for organ procurement is a fairer option regarding the right to access to healthcare needed, and therefore it should be implemented instead of opt-in.

Key words

organ transplantation, tissue and organ procurement, presumed consent, medical ethics

The realisation of the possibility of organ transplantation has immediately created two new problems for medical ethics as well as clinical medicine. One of them has been how to find the needed organs, and the other one is how to allocate them according to the needs of patients. The imbalance between needs and resources has led to the organ procurement problem, which is basically due to the difficulty of finding adequate organs at the right time and in the right place. In the USA for instance, organ donation rates have changed little in the past two decades, whereas the need for donated organs has grown five times faster than the number of available organs of deceased donors.\(^1\) By the 2008, there were more than 8,000 people in the UK awaiting organ transplants, and the numbers are rising by about 8% every year. Over 1,000 people die every year waiting for a transplant in this country.\(^2\) In Turkey, 44,000 people are on the national waiting list, and 8,000 new patients

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are added every year. In 2007, only 244 donors’ organs could be used for 699 patients, and 7,000 people lost their lives awaiting organs.3

Methods of organ procurement

Opt-in

Today thousands of patients must endure longer waiting times and a greater risk of death before an organ becomes available. To address this problem, a number of legislative and policies, which have had varying success in increasing supply, have either been proposed or implemented.4 There are mainly two systems all over the world which aim to increase the number of organs that could be used for transplantations. Many countries have adopted the ‘opt-in system’, which aims to raise awareness by educating the society and make the individuals donate their organs by their own will. As Chouhan emphasised, if a person dies without having her donation card in her possession, relatives have the right to override the wishes of the deceased person.5 This is the system in practice in Turkey also.

Opt-out

The other system, ‘opt-out’ or ‘presumed consent’, which considers all members of society as potential donors, was adopted by some countries, such as Spain, Austria, Belgium, France, and Singapore. In this system, individuals should specifically state that they do not wish to donate their organs in order to opt-out from the system; otherwise they are considered as donors. In the context of organ donation, presumed consent is regarded as a default position in which persons who do not explicitly state that they do not wish to donate (i.e., they do not opt-out) are regarded as consenting to donation.6 Presumed consent may be either ‘hard’ or ‘soft’.7 In the soft system, which is used in Spain and France, the family of an individual who has not opted-out may refuse to donate the organs of that individual after death. In the hard system, which is used in Austria, relatives of an individual who has not opted-out cannot refuse donation.

Incentives

Another system proposed to increase the number of organs to be transplanted is using incentives. It is claimed that paying the funeral expenses for families who agree to donate, setting a national organ selling system governed and financed by the state for the individuals and families who agree to donate organs, and/or giving precedence in the transplanting list for the people who donate their organs, may provide solutions for the lack of organs.8

Mandated choice

Mandated choice requires all persons in a community to consider organ donation and to register their decision. In this system, all competent adults would be required to decide whether they agree or refuse to donate organs after death.9 Individuals would be able to choose whether or not to donate and, if so, which organs they wish to donate. However, they could not refuse to register their wishes. Individuals could also choose to let their relatives make decisions for them after death. However, if these relatives are not explicitly granted this right, they would not have the power to veto the decedent’s decision, either in favour of or against donation.10
Mandatory donation

Mandatory donation may be defined as presumed consent without the option to opt-out. Thus, mandatory donation presupposes a community or nation’s right to harvest the organs of any individual after death. This right would be based either on the supposition that the greater society owns the body of the deceased or that all citizens have an enforceable moral duty to allow their organs to be retrieved after death.\textsuperscript{11}

Iran is the only country which has some kind of incentive system governed by the state.\textsuperscript{12} Opt-in and opt-out systems are the most accepted and practised ones in the rest of the world. As we are in principle against any kind of system which uses financial incentives as motivators, we would like to compare the opt-out system with opt-in system in this presentation. Mandated choice and mandatory donation systems are still in a theoretical phase. Besides, we believe that the transition from opt-in to these systems is more difficult than the opt-out, for we think that the preparation for transition seems to be more complex. It seems, also, that much effort and time is needed for the social acceptability of these systems.

What is needed for a healthcare system to be fair?

We think that we should define the term \textit{fair} in this context, before comparing the two systems to be discussed. The right of access to the needed healthcare is our basic departure point here. Everyone should be able to flourish as a human being, and the potential for individual flourishing is diminished

\textsuperscript{3} It was not possible to access the official numbers about organ transplantation in Turkey, so media was used as a resource. Those figures given were retrieved from two sources:


\textsuperscript{7} Pfeiffer, T. Organ donation: opt in or opt out? Currents 2007. Available at: \url{http://tlp.law.pitt.edu/SP_Organ%20Donation%20Article.pdf} (cited 30 July 2008).


in proportion to any serious physical disability created by disease. This is also an issue of great importance for the society as a whole, for if people are deprived of their health, they will be less likely to fulfil their potential, and therefore make less of a contribution to society. Of course, health is not solely determined by the existence of healthcare services; shelter, nutrition, working conditions, environment, education, social class, and genetic factors also influence the health level of individual. This multi-determination is stated in the Article 25 of the Universal Declaration of Human Rights:

“Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.”

For the sake of our argument about organ procurement systems in this context, we will first focus on the right to healthcare. We accept that, as a basic human right, everybody has a right to get the adequate healthcare he or she needs. If individuals are not able to receive healthcare services when they need them, they will be put at a great disadvantage in terms of achieving their potential and their self-development may thus be impeded. It can also be reasonable that the possibility of using their other rights will also be diminished. Therefore, although it is a third generation human right, the right to healthcare is indeed basic.

If we accept the right to healthcare, then, to be fair, ‘equity’ should be the principle in order to allocate the resources, not ‘equality’, because every individual has different sets of healthcare needs, which may not be equal. If it is so, resources should be allocated based on the level of each patient’s medical needs. Therefore, our understanding of the term fair in this paper is related to the equal access to healthcare according to our needs in order to fulfil our potentials as individuals and to make a full contribution to society.

Besides fair allocation of existing resources, in order to attain the highest standard of health, the ways to increase the quantity and quality of healthcare resources should be sought as well, because existing resources can be scarce and insufficient to meet the needs. However, that does not necessarily mean that resources will always be limited. Rather, the availability or scarcity of resources is a dynamic and never-ending cycle that changes according to predictable and unpredictable factors alike. Monitoring and evaluation practices should be carried out continuously and the distribution of such resources should be flexible enough and organised in such a way that the resources will be most effectively used. And more importantly, increasing the healthcare resources will help to improve and promote the health level of all the people in need. In summary, a healthcare system, which serves for providing the necessities of right to healthcare, allocates the resources by the principle of equity and provides more resources, is fairer than the others. And vice versa: a system which uses resources of less than available amount and quality, and adopts the discourse of ‘limitedness of resources’ by accepting the actual conditions as permanent, lessens the possibility to serve adequately to the people in need. Therefore, the latter system is unfair.

**Opt-out serves the right to healthcare better**

Now we would like to evaluate two systems by comparing their features, and determine their fairness by taking into consideration the degree of serving the right to healthcare. First of all, one can easily claim that opt-out would obviously provide more organs, and would expectedly save more lives than
the opt-in system. The main aim of any kind of procurement system is to increase the resources, and the opt-out system is more appropriate to that aim. As Hamm compiled, a growing body of evidence supports this claim. A study in 2006 compared 22 countries over 10 years, and it took account of the determinants that might affect donation rates, such as gross domestic product per capita, health expenditure, religious beliefs, legislative system, and the number of deaths from traffic accidents and cerebrovascular diseases. Authors concluded that when other determinants of donation rates are accounted for, presumed consent countries have roughly 25–30% higher donation rates than informed consent countries. A study in 2003 found similar results. The successful results observed in Spain did not necessarily result from presumed consent, as the infrastructure and educational system in Spain showed great improvements during the same period of time. However, presumed consent may have played a role. Donation rates increased in Belgium, Singapore, and Austria after presumed consent was initiated. These findings suggest that the adoption of opt-out would increase donation rates, and, consequently, would fulfill the requirements of the right to healthcare more appropriately.

Increase in the number of organs in the opt-out system provides several more advantages. It could be reasonably expected that the need for living donors would decrease. As a general principle of medical ethics, any medical intervention should care about harming as minimal as possible while being beneficial as much as medical knowledge and technology enable. In the case of organ transplantation from living donors, there is an additional side than it is the case in the classical patient-physician relationship, and as Ors stated clearly, this side, donor, is someone who makes a sacrifice at the expense of a serious risk concerning his/her health. The risks taken by the living donors include infections, organ failure, overall decrease in quality of life, and even death. Increasing the number of deceased donors’ organs would decrease the need for living donors, and thus also the risks. This is not directly related to the right to healthcare of donors, but it obviously affects the health of the potential donors positively by preventing them from taking serious risks. Therefore, one might say that it is related to right to health in a serious way. It is certainly not justifiable to practice more risky intervention/system while the expected result is less than in the alternatives.

Another side effect of increasing the number of deceased donors’ organs by opt-out would be decreasing the volume of illegal transplantation practices. It has been suggested that, if the demand for organs were met legally, individu-
als needing organs would have less incentive to obtain organs illegally and that the black market for organs would diminish. Organ trafficking, mainly in kidneys, is a growing phenomenon according to the WHO that mostly threatens poor donors and makes their life conditions worse. This is due to the absence of any kind of medical follow-up, hard physical work and an unhealthy lifestyle connected to inadequate nutrition and a high consumption of alcohol. Most illegal donors are thus forced to undergo dialysis for certain periods of time or eventually receive kidney transplantation themselves. As Glaser quoted, a study in 2002 found that 86% of Indian organ donors reported significant declines in their health within three years after surgery, and another study by Organs Watch found that 79% of Moldovan donors experienced health problems after their procedures. Of course, decreasing the demand for living donors, and consequently the illegal market, would not diminish poverty itself, but it would definitely decrease this human tragedy. A system presuming that people have consented to donating their organs would help the relatives of the deceased by removing the burden of making donation decision, and would prevent adding unnecessary sorrow to their grief. As Gavin-Lewellyn states, the first few moments after a loved one has died is a time of shock and denial:

“Your thoughts processes aren’t working rationally. You can’t believe your loved one is dead but you have to believe it because there is the lifeless body. But maybe there is hope. Someone could do something, couldn’t they? This is not the optimum time to approach a grieving person about donating their loved ones’ organs.”

In the opt-out system, decisions to donate organs are not made by the family immediately after death. Instead, individuals make their decision when applying to a public service or during a bureaucratic procedure, for instance. It saves time and effort, and it improves the healthcare the doctors provide. In soft opt-out system which still asks the family consent, this advantage is not available though.

As a last justification, an opt-out system lowers costs to the government. Compared with dialysis, kidney transplant enhances the quality of life of the patient while reducing total costs. In the case of Spain, the 10,000 renal transplants that have been performed in a year have saved an estimated $207 million. Saving financial resources is obviously an opportunity to provide better healthcare services, and this feature of opt-out system makes it fairer in the light of the reasons we explained above.

In sum, we argue that the opt-out system for organ procurement serves right to healthcare better when we consider its advantages, and therefore is a fairer option.

Proposal for an opt-out system

We think that in order to set up a proper opt-out system, certain conditions must be met. First of all, it should be decided whether the system will be soft, which requires the relatives’ consent, or hard, which considers only the existence of refusal by the person. After that, widespread public education and information campaigns should be carried out so that people would be sufficiently informed when making their choices. Another aim of this activity is to soften the possible social reactions by correcting misunderstandings and establishing a sincere communication. Education must be given continuously and reach every individual of the society; educational activities in that scale are only possible with widespread and specifically organised institutions such
as healthcare centres. Its campaigns should be carried out as a part of public education which is a part of primary healthcare services. Besides, accessible and effective mechanisms should be established to ensure that all individuals can register their objections easily. Internet, health centres, and post offices can be used to that aim. As Watson has stated, a good program should provide putative donors a reasonable amount of time to opt-out of the system after being informed about the process and everything involved with it. 31 On the healthcare system side, it should be ensured that the information about individuals’ donation wishes is stored in easily accessible medium by the healthcare workers and managers. A legal framework is important, but seems not enough. The evidence from Spain has shown that other measures are needed for the organ procurement system to be successful. 32 Educating the healthcare workers to ensure that relatives are treated appropriately and sensitively, and that they are familiar with the arrangement of organ donation, is necessary. Appropriate infrastructure and resources should be arranged in order to operate the system properly. And as Quigley has stated, some of these measures can be put into place without altering current laws. 33

In a soft system, which we propose as an option only for a certain transition period, relatives of a deceased individual would be told that the individual had not opted-out of donation and that his/her organs will be harvested, unless they object – either because these relatives know that the deceased individual had later objected to donation or because the donation would cause these relatives major distress. 34 This practice can be seen as contradictory, especially in the light of information of relatives’ refusal rate can be really high; in 2007, 319 of 563 (56.7%) of families refused to donate their deceased relative’s organs in

26 Ibid.
33 Ibid.
Turkey. Nevertheless, it may be regarded as a safeguard that aims to decrease possible lack of confidence issues.

**Possible counter-arguments**

We think that the counter-arguments claiming that the opt-out system would not be morally justified should be dealt with in this context, in addition to defending it. It has been suggested that presumed consent will result in a system in which only the wealthy, educated, or other advantaged groups would opt-out, while less advantaged individuals, such as the poor or uneducated, would not be aware of their ability to do so.\(^{35}\) It may be true, if the education and information campaigns would not be effective as much as they should; so, as stated above, public education initiatives should be organised and last continuously. This is a must for the viability and acceptability of the system by the society.

Another criticism frequently asserted is that opt-out system does not respect the individual autonomy.\(^{36}\) This view can be summarised as ‘the state decides in the name of me; and it is against my autonomy’. But this is simply misinterpreting the case. Quite obviously, the state does not automatically confiscate the organs of the deceased; it is the mandatory donation system whereby this is realised. The individual’s autonomy is still respected, as in the opt-in system, and she has her options to opt-in or opt-out. The only coercion opt-out has is thinking about the situation of the patients whom we could save following our deaths. What the state does by adopting the opt-out system is that people would like to help each other after their death and take a position by preferring this value and promoting solidarity in social life. It makes an arrangement which claims that the society would be a better place to live in.

Furthermore, we argue that the opt-out system respects one’s autonomy more than opt-in. Because it is well-known that most of the people are willing to donate their organs but only few of them do actually donate. Many researches have found that 70–95\% of people are willing to donate while only 20–24\% of them actually register their wish to do so.\(^{37,38,39,40,41}\) So, as English correctly emphasises, unless opinion polls are wrong, presuming that an individual wishes to donate would likely reinforce the autonomy of that individual rather than presuming an individual does not wish to donate.\(^{42}\)

More importantly and practically, some people may be concerned that donation procedures may be started before they are actually dead, or else that the effort to keep them alive would not be made.\(^{43}\) These concerns arise out of the knowledge of the serious shortage of organs, increasing the value of donated organs. In addition, some people do not regard brain death as actual death and may therefore object to harvesting organs at the time of brain death.\(^{44}\) This is an important issue that should be handled with carefully; because it is essential to maintain the trust in the patient-physician relationship and the medicine-society relations in general, in order to provide healthcare services in the maximum efficiency possible. And also, it is so important to show to the public that organisers and workers of organ procurement system are very-well aware of the relationship between the donor and the patient, and that they are sensitive about the issue that donors cannot be used inattentively as mere means. First of all, sincerity and accountability in state-society relationships is basic; people must be ensured that their interests are trying to be protected by the administrators and policy-makers in the best possible way.
feeling, accompanied with justice, should be common, and creating it is the responsibility of those who have the power to govern. Secondly, with public education, all misunderstandings about the definition of brain death should be taken into account, and it should be declared that brain death is irreversible; otherwise medicine would not call it as death. And lastly, everybody should know for sure that any deliberately abusive treatment in that context would nearly be equal to killing, and would be harshly punished, such as the cancellation of medical licence.

Conclusion

It is clear that transition to a new procurement system is not an easy task. But as we have tried to show, opt-out system is fairer than opt-in, and therefore it should be put into practice as soon as possible, as every day that is lost in the debates means that people lose their lives needlessly. It is obvious that the opt-out system would not create a miracle; but for the reasons we have tried to argue, it significantly saves more lives. Of course, legal shifting must be accompanied by infrastructural changes, and most importantly by political willingness.

In addition, we should see the problem in a wider perspective, and try to find solutions to such questions as: Why are there so many people who need organ transplantation? What are the reasons? Are they preventable? Are our roads and vehicles safe enough, or should we find better transportation systems? Do all people have access to the healthcare they need in the right time and place? Are the primary healthcare services good enough qualitatively and quantitatively after we have privatised them? Do we have enough intensive care beds? Is it morally justifiable to hope that the “invisible hand” of the market dynamics would organise the healthcare system? For how long? It is possible to multiply these questions; but, as a last word, we would like to stress that the universal availability and accessibility to healthcare services is crucial for overcoming the shortage of transplantable organs.

37 Ibid.
43 Ibid.
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Zašto bi opt-out sustav za pribavljanje organa bio pravedniji?

Sažetak
Mogućnost transplantacije organa je otvorila nove probleme kako u medicinskoj etici tako i u kliničkoj medicini. Jedan od njih, pribavljanje organa, pokušava se riješiti uglavnom pomoću dva sustava. Mnoge države su prihvatile 'opt-in' sustav, koji teži širenju svijesti o problemu i vlastitom izboru pojedinca da donira svoje organe. Drugi sustav, 'opt-out' ili 'pretpostavljeni pristanak', u kojem se svi članovi društva smatraju potencijalnim donorima, uveden je u nekoliko zemalja. U tom sustavu, pojedinci trebaju izričito navesti da ne žele donirati svoje organe; u suprotnom se smatraju donorima. U pokušaju utemeljenja našeg argumenta na različitim opravdanjima, tvrdimo da je 'opt-out' sustav pribavljanja organa pravednija opcija, uzimajući u obzir pravo na pristup potrebnoj zdravstvenoj skrbi, te bi stoga treba biti uveden umjesto 'opt-in' sustava.

Ključne riječi
transplantacija organa, pribavljanje organa i tkiva, pretpostavljeni pristanak, medicinska etika

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Warum wäre das Opt-out-System zur Organbeschaffung fairer?

Zusammenfassung

Schlüsselwörter
Organtransplantation, Gewebe- und Organbeschaffung, angenommene Zustimmung, Medizinethik

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Pourquoi le système opt-out pour l’approvisionnement en organes serait-il plus juste ?

Résumé
La possibilité de transplantation d’organes a posé de nouveaux problèmes à l’éthique médicale aussi bien qu’à la médecine clinique. Deux systèmes tentent de résoudre l’un de ces problèmes, celui qui concerne l’approvisionnement de organe. Nombre d’États ont adopté le système « opt-in » qui cherche à répandre la conscience du problème et du choix personnel de l’individu de faire le don de ses organes. Un autre système, appelé « opt-out » ou « accord tacite », où tous les membres de la société sont considérés comme donateurs potentiels, a été introduit dans certains pays. Dans ce système, les individus doivent indiquer explicitement qu’ils ne souhaitent pas donner leurs organes, faute de quoi ils sont considérés comme donateurs. En essayant de baser notre argumentaire sur les diverses justifications, nous soutenons que le système « opt-out » est plus juste, compte tenu du droit à l’accès aux soins médicaux nécessaires. Il devrait par conséquent être introduit à la place de « opt-in ».

Mots-clés
transplantations d’organes, approvisionnement en organes et en tissus, accord tacite, éthique médicale