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Reciprocity and Priority Allocation System for Organ Transplant: <u>An Ethical Analysis</u>

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INTRODUCTION

Organ transplant has been an integral part of modern medicine for decades. For most organs such as heart, lung, liver, bone marrow/stems cell etc., it is the last resort for saving the life of a critically ill patient. While not necessary for saving life, a kidney transplant can significantly improve the quality of life for a patient in end-stage renal failure that would otherwise require dialysis. Yet the demand for organs far outnumber the supply. Recent advances in xenotransplantation (Golriz et al, 2012; Cooper, 2021; Reardon 2022) may one day solve the problem. But it will take years, if not decades, for this to become clinically viable. The first animal to human heart transplant was done in 1984 (Jonasson & Hardy, 1985) and no progress has occurred in almost forty years. In the foreseeable future, each year thousands of patients still will die while waiting for an organ. Currently there are about 107,000 Americans on the waiting list for an organ transplant. On the average, 17 people die every day due to the lack of available organs for transplantation surgery (American Transplant Foundation, 2021). How to increase the supply of organs has been a question occupying the minds of transplant specialists since the inception of the technology.

One novel policy to increase the supply of organs is to implement a Reciprocity and Priority Allocation (RPA) system. In this system, registered donors or actual donors (alive or deceased) receive points that will allow them (if still alive) and their family members to have priority in receiving an organ (Trotter 2008). Currently, only Israel (Albertsen, 2017; Levy, 2018); Singapore (Iyer, 1987), and Chili (Zúñiga-Fajuri, 2015) have implemented such a system. Unlike Israel, Singapore also has an "opt-out system" – one is presumed to be a donor unless explicitly registered to be a non-donor. If a person is opposed to donating the organs upon death, he/she will not have priority for receiving an organ if it is needed in the future (Zúñiga-Fajuri, 2015). This paper focuses on the Israeli system, rather than the Singaporean one, because an "opt-out system" is not in alignment with the principle of Autonomy, which will be discussed in the next section.

The RPA system has the potential to incentivize donors. However, a robust discussion on its merit is needed if such a system is to be implemented. Public acceptance of the RPA system will depend on it being found to be ethically acceptable. In this paper, we want to critique previous ethical analyses of the RPA system. We will apply two formal theoretical ethics models: The Medical Ethics framework, and the Care Ethics framework, to analyze implications of the RPA system.

PRIOR ANALYSES

Most articles in the academic literature on this subject are on the Israeli system. It appears to be successful in increasing the number of registered donors (Stoler et al., 2016) though the increase was not substantial (increased from 13% to 15% in the five years since the introduction of the system [Guttman et al. 2020]). Shapiro & DePergola (2020) presented the RPA system as an enhanced version of the opt-in system. They argued that an opt-out system is more ethically acceptable. However, they did not discuss any ethical implications of the RPA system.

Several authors have discussed some ethical issues directly related to the RPA system. Quigley et al. (2012) argue that the system as implemented disadvantaged those with few first-degree relatives (siblings), and there is a chance to game the system by registering as a donor but instructing family

members to refuse donation upon death. Lavee and Brock (Lavee & Brock, 2012; Lavee, 2014) found the law effective and ethical in dealing with "free-riders" – those who oppose being a donor but will receive an organ. Guttman et al (2011) found that laypeople have concerns regarding the system being misused. These discussions are empirical and mainly focus on loopholes at the operational level. This paper goes beyond the operational issues. We attempt to apply two formal ethics frameworks to evaluate the RPA system.

MEDICAL ETHICS FRAMEWORK AND THE RECIPROCITY AND PRIORITY ALLOCATION SYSTEM

Autonomy, Justice, Beneficence, and Non-maleficence are the four nearly universally accepted principles in medical ethics. They are also applicable to organ transplants. This section will discuss how the RPA system fairs under this framework.

Autonomy

Autonomy refers to patients having the right to make decisions on their care and body. Because of this principle, organ harvesting without proper consent from even a deceased person is considered a gross violation of ethical principles. Autonomy is one of the most often cited arguments against an "opt-out" system (Farsides, 2012; Prabhu, 2019). An "opt-out" system is built upon presumed consent: if the individual did not object organ donation when he/she was still alive, then consent is presumed and thus organs can be removed from the body upon death. There are two versions of presumed consent: Strong presumption and weak presumption. In the former the medical professionals have the right to remove the organs from the deceased without consulting his/her family members, whereas in the latter approval form the family members is required (dos Santos & Feito, 2017). Presumption is definitely problematic. Specifically, some religious doctrines entail the integrity of the dead body. For example, some Jews believe that when the Kingdom of God arrives, the people of God would resurrect, and thus it is important to be buried intact (Ashkenazi et al., 2019). Presumption violates people's religious rights when the person didn't have a chance to opt out. The logic of strong presumed consent is: "If you say nothing, I can do whatever I see fit." Following this line of reasoning, the state can expand its power to other domains of society. In addition, potential donors in a critical condition may not have the chance to make an informed decision to opt-out.

The RPA system is consistent with the concept of Autonomy. In an "opt-in" system, each person retains full control over whether they want to be a donor or not. In an "opt-out" system, the above concern will not change but this system may give people more incentive and motivation to reflect and explicitly express their desire while they are healthy and alert.

Justice

In delivering medical care, the principle of justice refers to a fair and equitable distribution of health resources (Zapata & Moriates, 2015). How to procure and distribute organs is a thorny issue in transplant ethics. This is one of the primary reasons against paying for an organ: especially liver and kidney from living donors because the poor will be exploited (Adair & Wigmore, 2011). One of the vocal oppositions is from the American Medical Association, which affirms that paying donors would dehumanize them by viewing human beings as mere commodities or even objects, and in such a market system the rich would exploit the poor (Cohen, 2014). Currently, buying or selling of kidneys is only legal in Iran (Major, 2008), although it is well-known that black markets exist in several countries. Even when legally buying an organ is prohibited, those with resources are in a much better position to find a living donor. They can professionally package their appeal to the public and outreach to a wide geographic area to locate potential donors. "Transplant tourism" is another way to evade the prohibition on organ sales. People could travel with the "donors" to other countries, such as Turkey, South Africa, Bulgaria, Azerbaijan, or Sri Lanka, or meet with the foreign sellers there for the

transplantation surgery (Lavee & Stoler, 2014). One might argue that there is nothing unjust if the organ sellers are voluntary. As a matter of fact, in many cases the sellers are coerced or tricked into selling their organs. In certain organ markets, such as Bangladesh or Pakistan, rather than offering other ways to help poor people improve their financial conditions, the agent offered selling organs as the only acceptable choice (Cohen, 2014).

To encourage cadaver donation, the possibility of paying the family of the deceased for funeral expenses was discussed in the U.S. and U.K., but not implemented. In the U.S., the concern is that this may violate the law which prohibit paying for an organ (Post-Gazette, 2002).

In the U.S., minority groups are less willing to become organ donors because they are concerned about the disparity in care and that they have less chances to receive an organ (Bratton et al, 2011). This issue has been persisting and even worsening for two decades. A 2018 study indicates that out of 453,162 adult first-time kidney transplant candidates between 1995 to 2014, the portion of White patents increased from 7% to 11.4%, the share of Asians increased slightly (from 5.1% to 5.6%), while the portion of both Black and Hispanics vastly decreased (from 3.4% to 2.9%, and from 6.8% to 5.9%, respectively) (Purnell et al, 2018).

Compared with Whites, African-Americans were less likely to sign a donor card (39.1% vs 64.9%). They tended to give lower ratings on the Trust in the Health Care System scale (Siminoff et al, 2006). To increase the willingness to become a donor, the public must perceive the system to be just and fair. "Justice must be seen to be done". The impacts of the RPA system on justice can work in several ways. One must ask the fundamental question: Is it fair for someone willing to donate to get preferential treatment for oneself or family members? Different theories of distributive justice will yield different conclusions. It is intuitive that someone who wants to receive an organ but refuses to donate, is a "free-rider" and is unfair to others. "There is no free lunch". Meritocracy also will argue that it is fair for those willing to contribute to get a return.

On the other hand, Rawls' (1971) Difference Principle argues that some preferential treatment must be given to the disadvantaged. A patient with no family member is already disadvantaged because they have little chances to receive a living donor organ from a relative. Being assigned a lower priority on the transplant waiting list because there is no family registered as donors further disadvantages them. Rawls' Difference Principle is tied to Pareto efficiency (Health, 2014; Norman, 2015), which implies that it is very difficult, if not impossible, to allocate resources to make one individual or group better off without making at least another individual or party worse off. The criterion for choosing which party should be scarified is based on another fairness principle of Rawls' theory: Fair equality of opportunity, which asserts that when resources are finite, our society should benefit the worse-off or the disadvantaged rather than the best-off and the privileged.

Experience from Israel reviewed that there is a mixed perception on such system. While many see the system as fairer, some laypersons are concerned about people cheating the system and the system causing erosion of social solidarity and increase divisiveness (Guttman et al, 2011). Other concerns include the problem of setting back people who are not qualified to be donors due to genetic deficiencies. And as mentioned before, some Jews do not want to donate for religious reasons (Albertsen, 2017). Moreover, some researchers argued that experience from Israel may not be transferable and generalizable to other cultural settings. In several countries, including the US and Canada, the public view towards such a reciprocal system was divided (Burkell et al, 2013; Guttman et al., 2020).

Overall, it is fair to say that the verdict is still out on how the RPA system will affect justice. But some of the negative concerns are operational issues that can be adjusted by tweaking the system to make it more just. For example, those with siblings should be limited on how many points they can receive, and family members cannot object to a donor's wish upon death. The latter change is not just about practicality (avoid gaming the system); rather, it could appeal to philosophical reasonings.

Besides upholding justice, it also addresses the principal of Autonomy. Based on the principle of Autonomy, one has the right to decide how one's own body is treated after death. If so, why are family members enabled to override the will of the donor? Does it violate one's autonomy? (Ravelingien & Krom, 2005). Another practice concern is frustration caused by over-expectations. Guttman et al. (2020) documented that in some cases registered donors and their family members treated the registration as a guarantee for organ transplant, and were very upset when the "promise" was unfulfilled. Hence, it is important for the system to convey the message that registration with RPA should not be equated with a guaranteed ticket or a trade.

Beneficence

Beneficence is defined as an act of charity, mercy, and kindness with a strong connotation of doing good to others including moral obligation (Kinsinger, 2009). Organ donation is a cardinal act of beneficence. It is a type of altruistic behavior. Interestingly, in order to uphold the principle of beneficence, some ethicists assert that any form of award or recognition must be prohibited. In 2008 a law was passed in the U.S. to allow any organ donor being eligible for a Stephanie Tubbs Jones Gift of Life Medal. However, the same law prohibits using any federal funds to create or bestow this medal, and so far, no organ donor received such award (Niederle & Roth, 2014). After all, it is extremely unlikely that someone would be motivated by receiving a medal to donate an organ. By the same token, earning Priority Points would neither encouraging extrinsic motivation nor degrading generosity when the so-called award or reward is not highly tangible like cash. The points given didn't guarantee an organ when it is needed.

When altruism is used as the sole motivator for organ donation, its effectiveness is limited. Selfishness can be a big motivator too. If the strict principle of altruism is insisted by downplaying any form of exchange or self-serving purposes, then one may argue against a donor's direction for giving their organs to family members or friends because she/he might expect to receive something in return from the family member or friends. Nonetheless, this is human nature to put our family first (Choi et al, 2014). Economists and psychologists have long argued that selfishness is a positive driving force for advancement. Specifically, inclusive fitness theory states that people tend to help those who are genetically related to them because relatives share a kin altruism gene and are able to pass it along (Schriver et al. 2019). The RPA system can be an ethical way to appeal to the selfishness of human beings to encourage them to become organ donors.

Compared to paying for organs, receiving Priority Points from registering to donate or actual donation is much less likely to cause the poor to be exploited. The Priority Points are only valuable when the donor or family members require a transplant. The chance of this happening is very low. As long as the Priority Points cannot be traded, it will not trigger any organ trading. This practice is consistent with other nonpayment incentives used to encourage organ donation (Levy, 2018).

Nonmaleficence

"Do no harm" is the number one tenet in healthcare. That is one reason many have a reservation on liver or kidney donation from living donors, especially when donating to an unknown patient. There is a significant risk associated with being a living donor, up to death (Ratner & Sandoval, 2010).

This is much less an issue for cadaver donation. Except for the conspiracy theory that doctors may be less willing to save a dying organ donor to harvest his/her organs (absolutely no evidence of such event), organ donation from a deceased has no chance of further harming the donor. Because of this concern, the transplant system ought to focus on increasing the support of cadaver organs. Nonetheless, a potential harm could happen to the family members of the deceased donor. Research indicates that under a weak presumed consent system when medical professionals discussed with the family members on the issue of donation immediately after being informed of death, this action could

be perceived as offensive to the family (dos Santos & Feito, 2017). The RPA system can prevent this from happening because prior arrangement is made. In addition, If the RPA system can increase the supply of deceased donors, it will reduce the need for living donors. And therefore, it is consistent with the non-maleficence principle.

Medical Ethics Framework Summary

Based on the above analysis, it appears that the RPA system does not pose major ethical issues when evaluated against the four pillars of Medical Ethics. There are some Justice concerns with the Israeli system, but those are operational issues that can be fixed.

ETHICS OF CARE AND THE RECIPROCITY AND PRIORITY ALLOCATION SYSTEM

While the four constructs of Medical Ethics are well accepted for evaluating medical decisions, we want to add another ethics principle to analyzing the RPA system. This is because Medical Ethics primarily involves a relationship between the care provider (e.g., physician) and patient. In the RPA system, donors may be trying to benefit other family members. This adds additional consideration to the analysis.

The Ethics of Care model is particularly appropriate for this analysis. This model originated as a feminist response to classical ethical theories. Proponents of this model argued that while classical ethical models emphasize abstract philosophical notions, generalizable standards, and impartiality, Ethics of Care emphasizes the importance of responding to the wellbeing of the individual. The focus is on relationship and response, rather than rules (Pettersen, 2011). The model is particularly useful in a healthcare-setting, since medicine is both an art and a science, and relationship and response are paramount in care. Autonomy, Beneficence, and Non-maleficence are all heavily relationship-oriented.

Tronto (1992, 1998, 2005, 2013a, 2013b) is one of the major authors in the Ethics of Care. In Tronto's view, the concept of ethics is not only about reasons and rules devoid of social contexts; rather, it is about how to live a good life. According to Tronto (1998), "our moral sensibilities will be greatly enhanced if we learn to think more thoughtfully about the morality of everyday life embodied in an ethics of care" (p.16). "Care" is a multi-facet concept. First, care is a human quality that defines us or make people human. Second, care is an action, not a set of abstract principles or rules. Third, although care has a standard, but it is flexible and practical. We care for others so that we can make the world better. She stated that there are four ethical qualities of care: Attentiveness, Responsibility, Competence, and Responsiveness. She accepted the suggestion to add a fifth quality, Trust, in 2013. We will compare the RPA system with Tronto's five qualities of care.

Attentiveness

Attentiveness, also known as "caring about," refers to recognizing the needs of others. Attentiveness entails listening to articulated needs and recognizing unspoken needs, rather than imposing our will on others. In the sense "caring about" is incompatible with an "opt-out" system while it is especially important in an "opt-in" system. It is self-evidence that the RPA system will increase donor Attentiveness when it requires donor's awareness of the issue. To be more specific, no sensible person would sign up something that he/she has no idea of what it is about.

Responsibility

The Ethics of Care is very pragmatic in how it views Responsibility, also known as "caring for." Responsibility is closely linked to a relationship. Noddings (1984) argued that the scope of caring duty is limited. The caring Responsibility is a set of concentric circles. We have more Responsibility to those we have a close relationship with (e.g., family members). But we still have some Responsibility to care for distant others, although we may never be able to care for them. This means that when the resource is

limited, we have an ethical duty to first care for those that are close to us. This is a strong argument against the notion that directing organ donation to family members or close friends is questionable due to benefit exchange.

Noddings also distinguished Responsibility from Obligation. An Obligation is something by rule we must do. A Responsibility is something morally we should do. The term "donation" could be misleading because people might perceive that it is nothing more than a voluntary gift. Nonetheless, some ethicist argued that organ donation is a matter of fulfilling one's duty to help and contribute. It is compatible with the principle of the Samaritan duty: One should help another who is in desperate need when such action is not too costly and the potential helper is in a unique position to offer help (Ravelingien & Krom, 2005). The RPA system is a very good match for this ethical construct. Becoming an organ donor is a Responsibility, though not an Obligation. The RPA system enables donors to first care for immediate family members. But increasing the supply of organs will extend this circle of care to the whole society.

Competence

Competence, also known as "caregiving" means taking the right action. In other words, the caregiver needs to possess the required knowledge and perform the necessary caring tasks. In organ donation, this construct simply means registering as a donor or not opting out.

Responsiveness

Responsiveness is also called "care receiving." This construct refers to the "responsiveness of the care receiver to the care". Tronto (1993) states that caregivers should pay attention to the responses of the care receivers to the care given, no matter whether the caregiving was successful or not. Hence, Responsiveness represents a different way of understanding the needs of others (Bozalek et al, 2014).

The RPA system could make organ receivers less appreciative of the donors because the donation is now less altruistic. The receiver may also have a stronger sense of entitlement for an organ because he/she or his/her family has signed up as donors. This will be a negative impact on the ethics of organ donation.

Trust

Sevenhuijsen (2003) introduced trust as the fifth qualify of care and Tronto (2013a) acknowledged this construct later. For an organ donation system to function properly, it is essential to have Trust from the public. It is important to point out that care involves power dynamics. To be specific, it takes a powerful state to implement the system. When power is perceived to be asymmetrical, trusting the powerful becomes an issue (Tronto, 1998), and therefore the system needs to be checked and monitored to avoid abuse. Further, studies from Israel have raised the question on the public mistrusting the RPA system. It is possible to cheat by registering as a donor but instructing family members to refuse organ harvesting upon death. On the other hand, it can be argued that a donor knowing him/her and his/her family members will have a higher chance of receiving an organ may increase Trust in the system. We believe that concern for abuse is an operational level issue that if managed properly, will eventually disappear. The RPA system will not reduce overall Trust in the long run.

Self-Care

In addition to the five qualities of care, Tronto also emphasized the importance of Self-Care. She noted that one must first meet his/her own needs before being able to attend to the need of others. Giving Priority Points to the registered donor is a way to improve Self-Care.

Care Ethics Summary

The RPA system relates strongly to the quality of Responsibility. It should have a minor positive effect on Attentiveness but a minor negative effect on Responsiveness. We believe that in the long run and with proper management, it would have a positive effect on Trust. In addition, The RPA system should also have a positive impact on Self-Care.

CONCLUSION AND NEXT STEPS

With the advance in medicine, it is foreseeable that the need for organ transplants will keep increasing. Until the time we can mass-produce human organs from stem cells, or xenotransplantation becomes feasible and acceptable, we need to drastically increase the supply of human organs ethically and practically.

An "opt-out" system can significantly improve the supply of organs. But due to political and cultural opposition, it is unlikely that many countries can implement such a system. The RPA system may be a relatively non-controversial approach to encourage registering for organ donation since other nonpayment incentives have been offered to donors and families.

But outside Israel, the ethics of such a system has not received much attention. We argue that it is time for the public to give a closer look at the RPA system and debate its pros and cons. Our analysis finds that this approach does not conflict with the classic Medical Ethics model and is quite consistent with the Ethics of Care model. However, further analyses incorporating specific cultural and political issues are needed to see if such a system is appropriate for each country.

Furthermore, we must go beyond theoretical discussions and engage the public in this debate. Bioethicists suggested that empirical findings on the diverse perspectives to RPA could provide additional arguments and practical concerns regarding this controversy (Guttman et al. 2020). An important follow-up study is to collect both quantitative and qualitative data on how the US public will perceive the RPA system and to understand constructs affecting their acceptance of such system.

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