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Priority to Organ Donors: Personal Responsibility, Equal Access and the Priority Rule in Organ Procurement

Diametros nr 51, 137-152

2017

Diametros 51 (2017): 137–152
doi: 10.13153/diam.51.2017.1035

PRIORITY TO ORGAN DONORS: PERSONAL RESPONSIBILITY, EQUAL ACCESS AND THE PRIORITY RULE IN ORGAN PROCUREMENT

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Abstract. In the effort to address the persistent organ shortage it is sometimes suggested that we should incentivize people to sign up as organ donors. One way of doing so is to give priority in the allocation of organs to those who are themselves registered as donors. Israel introduced such a scheme recently and the preliminary reports indicate increased donation rates. How should we evaluate such initiatives from an ethical perspective? Luck egalitarianism, a responsibility-sensitive approach to distributive justice, provides one possible justification: Those who decide against being organ donors limit the health care resources available to others. As such, a priority rule can be justified by a luck egalitarian approach to distributive justice. Furthermore, a priority rule inspired by luck egalitarianism is well equipped to avoid prominent criticisms of such a procurement system. Luck egalitarianism provides us with reaons to exempt people who are not responsible for their inability to donate from receiving lower priority, provide sufficient information about donation, and mitigate social and natural circumstances affecting people's choice to donate.

Keywords: organ shortage, priority rule, priority to organ donors, luck egalitarianism, personal responsibility, reciprocity, club model, incentive to organ donation, equal access, Israel, organ donation, organ transplantation, distributive justice.

The organ shortage and the priority rule

Around the world people are suffering because there is an immense and growing shortage of organs available for organ transplantations. A wide range of policies have been implemented or proposed in the effort to increase the supply of organs. In what follows one such proposal, introducing a priority rule, is assessed. A priority rule means that registered donors receive priority on the waiting list to receive an organ transplantation. A priority rule has been introduced in Singapore,[1] Israel[2] and Chile.[3] This proposal reflects the thought that the allocation of

[1] Schmidt, Lim [2004].

[2] Lavee et al. [2010].

[3] Zúñiga-Fajuri [2015].

organs between potential recipients influences people's willingness to donate and, thus, the number of available organs. Such a proposal is assessed from the perspective of luck egalitarianism, an influential responsibility-sensitive theory of distributive justice. Roughly stated, luck egalitarians assess distributions as just if, and only if, people's relative positions reflect their exercises of responsibility. In this paper, first, theoretical expectations and actual experiences with the priority rule are presented, then the existing theoretical literature on the possible effects of introducing a priority rule is surveyed. Then the normative discussion of the priority rule is presented, and finally the priority rule is assessed from a luck egalitarian perspective.

Theoretical expectations and empirical data

We can imagine a number of mechanisms through which introducing the priority rule may increase the donation rate in a population. The first mechanism is increasing the perceived distributive fairness of the procurement system. Organ procurement systems without the priority rule are subject to free riding, in the sense that they provide a good even to those who did not participate in making that good available. In short, systems without the priority rule allow non-donors to receive a donated organ on equal terms with those who had agreed to contribute through registering as donors. Free riding may be one reason to consider a procurement system unfair. Therefore, a priority rule explicitly aimed at eliminating free riding may convince more people to register as donors. The possibility of freeriding was a significant part of the public debate about low donation rates in Israel prior to the introduction of a priority rule.[4] The second mechanism relates to people's self-interest rather than their preferences for fairness. Introducing the priority rule effectively increases the risk of not being a donor. Thus, the priority rule internalizes the costs of being a non-donor to the person choosing not to donate. This could work as an incentive to donate. Based on the expectation that people will react to incentives and be more likely to react when a cost/risk is seemingly concentrated on them rather than equally spread over a large group of people, we could reasonably expect that the priority rule would make more people register as donors. Thirdly, one might expect that the very process of altering the procurement process would spark the kind of public debate which may increase awareness about the organ shortage and increase the donation rate.

These theoretical considerations can be supplemented with experimental data. Experiments conducted by Kessler and Roth found that changing the alloca-

[4] Chandler, Burkell, Shemie [2012].

tion rule to a priority rule yields a sizeable increase in the organ donation rate.[5] To test this, the authors enroll subjects in a game consisting of a number of rounds with events designed to reflect the different aspects of organ donation, such as the possibility of brain death and kidney failure.[6] For each round that the subject avoids brain death and both of their kidneys failing they receive a small monetary reward. Each event is assigned a fixed probability. Before each round the subjects decide whether to be a kidney donor in the event that they become brain dead. If their kidneys fail, they receive kidneys in accordance with a known allocation system. The game is set up to give people a real (monetary) interest in staying alive, and played under different allocation scheme. The allocation scheme structured as the priority rule yielded the highest donation rates.[7] In other experiments, Li et al. found a similar effect of the priority rule.[8] That particular study also addressed the question across the opt-in and opt-out divide, and concluded that the combination of opt-out and the priority rule is superior to other combinations. In attempts to realize such expected gains by introducing the priority rule, it should be noted that the success of this is contingent on how the priority rule is implemented. Further experiments by Kessler and Roth show that it is detrimental to the effect of the priority rule if free riding remains a possibility.[9] Free riding would remain a possibility if a person could sign up as a donor when that person needs to receive a transplant. However, the experiments generally suggest that introducing the priority rule will increase donation rates.

In light of these theoretical and experimental expectations, it seems useful to briefly review the actual experience from three countries which have introduced the rule. The earliest introduction of the priority rule came in Singapore. In 1987, Singapore passed the Human Organ Transplant Act which applies the priority rule to an opt-out system.[10] The bill stated that "a person who has not registered any objection […] shall have priority over a person who has registered such objection."[11] Though it should be noted that this was introduced along with

[5] Kessler, Roth [2012].

[6] The study does not present this to the subjects in the language of organs and donations.

[7] Ibidem.

[8] Li, Hawley, Schnier [2013].

[9] Kessler, Roth [2014].

[10] Understood as a system where people are considered donors unless they explicitly chose not to be. This is often contrasted with opt-in systems where people are only considered donors if they explicitly chose to be.

[11] Iyer [1987].

a number of other changes to the procurement system,[12] it is considered a modest success in terms of increasing the donation rate.[13] Israel introduced the priority rule in 2010. The rule gives priority to candidates who have either been registered as organ donors for at least 3 years before being listed, or have a first degree relative who has been a deceased organ donor, or have previously donated a kidney or a liver-lobe as a living donor.[14] Any potential transplant recipient receives priority points for each of these criteria they fulfill.[15] The preliminary reports on the experience in Israel is that they are positive in terms of increasing the donation rate.[16] Studies of public discourse in Israel and Singapore suggest a sensitivity to reciprocity in the context of organ procurement.[17] Studies in Israel found much more support for the priority rule than for economic incentives.[18] The last country to have experience with the priority rule provides a somewhat bleaker tale.[19] Chile experienced difficulties when introducing the opt-out legislation in 2010. In the following years people opted out in very large numbers.[20] The priority rule was introduced in an explicit response to this development, and braught the process to a halt.[21] The experience from Chile should not be considered a clear-cut embarrassment for the priority rule. As it stands, the problematic feature in that case seems to be the opt-out system, to which people did not respond as the government had expected. Nonetheless, the priority rule's ability to halt worryingly high opt-out levels is somewhat below what its proponents would expect.[22]

In his theoretical defense of the priority rule, Kolber admits that the successful implementation of the rule requires a) a donor register, b) promoting knowledge about this register (and the priority rule), c) respect for decisions to donate, and d) providing some priority to registered donors.[23] However, the prior-

[12] Schmidt, Lim [2004].

[13] Teo [1991].

[14] Ashkenazi, Lavee, Mor [2015].

[15] Lavee et al. [2010] p. 1132.

[16] Lavee et al. [2013]; Stoler et al. [2016a, 2016b].

[17] Chandler, Burkell, Shemie [2012].

[18] Sperling, Gurman [2012].

[19] Japan is sometimes considered as having a priority rule, but seemingly this is only within the family, see Aita [2011].

[20] Domínguez, Rojas [2013].

[21] Zúñiga-Fajuri [2015].

[22] One prominent example of a non-government driven priority rule would be lifesharers in the US. Calandrillo, Cohen, Undis [2004].

[23] Kolber [2002].

ity rule can be implemented in numerous ways. The basic idea of giving priority to those who have signed up as donors is compatible with different conceptions of what it means to be registered as an organ donor. In principle, the priority rule could be introduced in both opt-in systems where you are only considered a donor if you register to be so, and opt-out systems where you are considered a donor if you do not register an objection to being so. Our current experiences illustrate this in that Singapore and Chili has an opt-out system, while Israel has an opt-in system for organ procurement.[24] In principle, the priority rule could also co-exist with other forms of incentives, including economic incentives. But, as it is often presented as a more acceptable incentive than economic incentives,[25] such a combination is unlikely. Perhaps it should be mentioned that at least an effective implementation of the priority rule is somewhat at odds with the existence of a family veto which allows the family to retract the consent to donation by a deceased person, an observation also following from Kolbers c) above.[26] The possibility of such a retraction seems to invite free riding and thus lessen the strength of the incentive from the priority rule and the extent to which it eliminates unfairness.

The ethical debate

In the literature on ethics, there is a wide range of articles arguing in favor of introducing the priority rule to increase donation rates.[27] A recent discussion highlights that 38 articles have been published on this topic and that the main reasons provided for supporting the priority rule pertain to the good consequences in terms of increasing the number of available organs, and the value of reciprocity.[28] In response to such proposals, a number of criticisms have been put forward. One prominent criticism is that the system departs from justice in introducing something other than need in the allocation process.[29] Such a criticism relies at first on the idea that justice in health care corresponds to the need-based allocation. In the allocation of organs, this could be considered controversial, as those with the greatest need may simply not be those who will benefit most from receiving a transplantation (if at all). The idea that current allocation systems are only based

[24] Shepherd, O'Carroll, Ferguson [2014].

[25] Ravitsky [2013]; Trotter [2008].

[26] Wilkinson, Wilkinson [2011].

[27] Bramstedt [2006]; Lavee, Brock [2012]; Jacoby [2004]; Kolber [2002]; Murphy, Veatch [2006]; Nadel, Nadel [2005]; Nadel [2004]; Siegal [2014]; Steinberg [2004b, 2004a].

[28] Chandler, Burkell, Shemie [2012].

[29] Hartogh [2010].

on need is a simplification.[30] Across different allocation systems, time spent on the waiting list, age, geographical proximity to the deceased donor and expected benefit also play a role in deciding who gets an available organ.[31] If the critique is instead to be understood as the claim that the priority rule departs from justice, then this requires a firmer understanding of what justice means in this context. At least it is left open that the principle of distributive justice we endorse is one which is compatible with the priority rule.

Others present different critiques. Some accept that we should reward contribution, but admit that rewarding those who (express the wish to) contribute an organ, may overlook the myriad of ways in which people can be contributors.[32] Contrary to such a claim, Den Hartogh points out that, in a way, it makes sense to consider only contribution to the organ shortage, because other forms of contribution do not contribute to solving this (i.e. paying a lot of taxes).[33] A more practical, but none the less important, concern is the adverse selection problem. Specifically, those with the strongest incentive to register as donors under a priority rule procurement scheme are people who, due to genetic disadvantages, are most likely to need one (and less likely to become viable donors).[34] Other issues raised include that the priority rule sets back people who are ineligible as donors because of genetic deficiencies, and those who do not donate because they lack knowledge about the procurement system or the opportunity to donate.[35] A special problem is that the priority rule in effect gives lower priority to those who, for religious reasons, do not want to donate[36]. For decades, this has been the case for the large Muslim population in Singapore and the orthodox Jews in Israel. These groups, and their unwillingness to donate, but willingness to receive transplantation, are sometimes mentioned as an important part of the discussion about freeriding in the Israeli procurement system before the introduction of the priority rule.[37] Having presented these possible critiques of the priority rule, the next section addresses them in the context of a priority rule justified by and designed in adherence to luck egalitarian principles.

[30] Dudzinski [2004]; Hartogh [2010]; Nadel, Nadel [2005] p. 231.

[31] Koch [2002]; Veatch [2000].

[32] Saunders [2012].

[33] Hartogh [2010]; Biller-Andorno [2004]; Nelson [2004].

[34] Trotter [2008] p. 161.

[35] Gruenbaum, Jotkowitz [2010] p. 4477.

[36] Allhoff [2004]; Hackler [2004]; Jotkowitz [2004]. Some concerns regard vulnerable minorities; Goering, Dula [2004]; List [2004].

[37] Chandler, Burkell, Shemie [2012].

Distributive justice: Luck egalitarianism, personal responsibility and equal access

This section assesses the luck egalitarian view on distributive justice, and the extent to which it can support the introduction of a priority rule.[38] Several critics and proponents of the priority rule evaluate the justness or fairness of such a system. Cronin submits that the priority rule moves the allocation system away from justice and equity,[39] while Undis considers the priority rule an extension of the principle of justice that we should treat like cases alike.[40] One prominent view on distributive justice is luck egalitarianism.[41] Dicussing it in the context of health follows from a number of recent attempts to apply and discuss luck egalitarianism in the context of health.[42] While luck egalitarianism can be formulated in various ways, it will suffice for our purpose here to understand it as the view that distributions are just if, and only if, people's relative positions reflect their exercises of responsibility.[43] When would an introduction of the priority rule be a good thing evaluated from such a perspective? The important aspect would be whether the priority rule increases or decreases the extent to which people's situation reflects their exercises of responsibility. This can happen in a number of ways: a) decreasing the number of persons who are (dis)advantaged through events not reflecting their exercises of responsibility; and b) increasing the number of people who are (dis)advantaged in accordance with their exercises of responsibility. The case at hand raises a number of important issues in that regard: Whether introducing a seemingly responsibility-sensitive policy in one area risks creating an overall more unjust distribution (because of some social or natural facts in other spheres of society); whether the improvement in terms of a) are due to an increase in the number of organs to be distributed or the priority rule as such; whether the improvement in terms of b) are due to a sufficiently plausible connection between what people do and what they are responsible for.[44] Furthermore, it should also be

[38] This does not imply that this is the only way to justify such a scheme, another alternative would be approaches based on a duty to contribute to the arrangements from which you benefit, see: Simmons [1979]; Hart [1999].

[39] Cronin [2014] p. 2.

[40] Undis [2005].

[41] Arneson [1989]; Cohen [1989]; Lippert-Rasmussen [1999]; Knight [2009]; Knight [2013].

[42] Albertsen, Knight [2015]; Albertsen [2015a, 2015b, 2016b]; Cappelen, Norheim [2005]; Cappelen, Norheim [2006]; Le Grand [2013]; Segall [2007, 2010, 2013b, 2012, 2011]; Voigt [2013]. For important recent critiques, see Andersen et al. [2013]; Anderson [1999]; Buyx, Prainsack [2012]; Brown [2013]; Bærøe, Cappelen [2015]; Daniels [2011]; Feiring [2008]; Fleck [2011]; Nielsen [2013]; Nielsen, Axelsen [2012]; Schmidt [2009]; Wikler [2004].

[43] This formulation is inspired by Lippert-Rasmussen [1999].

[44] The closest we get to such a discussion is the one by Dietrich [2002].

discussed how a priority rule grounded in luck egalitarianism would fare in relation to the criticisms presented above.

To remove one layer of complexity, let us assume that everyone who needs an organ transplantation is not responsible for their medical need.[45] Under this assumption any policy which increases the number of organs available for transplantation would for that reason alone remove substantial amounts of disadvantage not reflecting people's exercises of responsibility. This cannot be the whole story about the extent to which luck egalitarianism is compatible with the priority rule. The priority rule after all also disadvantages some. On the already stated assumption about no difference regarding responsibility for need, the question to address is whether we have luck egalitarian reasons to adopt a priority rule. That is, reasons which go beyond our increased ability to meet disadvantages people are not responsible for. To evaluate it from a luck egalitarian perspective, we should therefore also ask whether those disadvantaged through this rule can complain on luck egalitarian grounds.

The first thing to note is that the discussion is somewhat different than existing attempts to apply luck egalitarianism in the context of health. This discussion is usually conducted in the context of people who are (to some extent) responsible for their bad health, and considers which institutional response would be appropriate in that regard, including different ways of holding people responsible. The discussion conducted here, in the context of the priority rule, is a somewhat different story. Those needing an organ are equal in terms of not being responsible for their medical need but unequal in their choices regarding donation. Could we have luck egalitarian reasons to let those choices count against non-donors? Important lines of reasoning in the luck egalitarian literature makes this view on distributive justice compatible with the priority rule. Importantly, luck egalitarians oppose cost displacement. The general idea is that if you choose to live a life which is costly, you should not be allowed to pass on those costs to others.[46] In the usual applications of luck egalitarianism to health, this means that to the extent that people are responsible for their medical need, they should be treated differently (perhaps making a co-payment, being asked to wait longer to be treated etc.). The rationale behind this is that treating them on a par with others

[45] Accepting luck egalitarianism as an approach to distributive justice would probably also include further changes to the allocation process. Those who need an organ due to their exercise of responsibility should receive lower priority in the allocation of organs on the luck egalitarian account. For a discussion of this, see Albertsen [2016a]. The parallel between such luck egalitarian schemes and the priority rule is part of Fox and Taylor's critique of the latter: Fox, Allee, Taylor [2004].

[46] Cohen [1989]; Dworkin [1981]; Rakowski [1993].

would allow those who are responsible for their choices to pass on the costs of those choices to others. Doing so would in effect mean that fewer resources are available to others. In what way could not registering as a donor be compared to such choices? On consideration, there is an important similarity. In the traditional luck egalitarian approach, people are given lower priority in the allocation of organs because they have worsened the scarcity through their exercises of responsibility (their risky behavior brings about a medical need). Giving them an equal chance to receive an organ compared with others who are not responsible for their need is problematic on a luck egalitarian account of justice. If we consider the decision to not be a donor, regardless of whether this takes the form of not opting in or opting out, this decision has a structural similarity to the creation of a need. By refusing to donate, one decreases the chance that others get the treatment they need. Is this a plausible interpretation? Admittedly, it is a different use of the term 'cost', but one which is defensible based on the structural similarity between laying claim on a donated organ and refusing to donate an organ. In terms of the consequences for those needing an organ, there is little difference between the cases. Treating those who have chosen to worsen the scarcity on an equal footing with those who have not, is problematic on the luck egalitarian account for the same reason it is problematic to treat those who have created their need on an equal footing with those who have not. Therefore, luck egalitarianism is able to endorse a priority rule.

Another important aspect of luck egalitarianism is the commitment to equal opportunity. The idea that our relative positions should reflect our exercises of responsibility implies a strong aversion to social and natural circumstances differentially influencing people's opportunities and positions. In the context of the priority rule, this is important in relation to many of the practical concerns already mentioned. From this commitment it follows that we can only be justified in treating donors and non-donors differently if they had equal opportunities for choosing as they did. While it remains a complex task well beyond the scope of this article to settle in detail the question of what it means for people to have equal opportunities, there are important lessons to be drawn nonetheless.[47] In the context of the priority rule, it would be uncontroversial to state that equalizing opportunities, including what Arneson calls people's ability to negotiate such opportunities,[48] would commit luck egalitarianism to provide sufficient information for

[47] For some of the recent important contributions to this questions, see Fishkin [2014]; Roemer [1998]; Segall [2013a].

[48] Lippert-Rasmussen [1999].

people to make the choice about whether to donate. It would also require a specific approach to those who are not responsible for their inability to become donors. For those who are ineligible to donate, but not responsible for this, luck egalitarians must be committed to treating them on equal footing with those would-be donors.[49] This is to avoid the situation in which those who have bad organs, but are not responsible for this, fare worse as a consequence of the priority rule. For those ineligible to donate due to bad social circumstances, the luck egalitarian commitment to distributive justice goes beyond how we allocate organs. There is a clear luck egalitarian commitment to address those adverse social circumstances.[50] A priority rule amended in these ways, introduced in a society which has lessened or removed social and natural inequalities, is well equipped to avoid disadvantaging people who are unable to become donors or who are ill-informed in some important way.

Conclusion

The luck egalitarian theory of distributive justice can recommend the priority rule. Not only because the expected increase of available organs would make it possible to help more people, who are disadvantaged in ways not reflecting their responsibility. A priority rule based on the luck egalitarian theory of distributive justice would ensure that no one is unfairly disadvantaged by such a rule. Those disadvantaged by the priority rule are those who, through their choices not to donate, have incurred costs on others. On a reasonable interpretation of what costs mean, the luck egalitarian commitment to avoid cost displacement allows for a luck egalitarian endorsement of the priority rule. This, however, is only the case if a number of initiatives, also part and parcel of luck egalitarianism, are introduced in healthcare, including: exempting people who are not responsible for their inability to donate from receiving lower priority, providing sufficient information about donation, and mitigating social and natural circumstances affecting people's choice to donate[51].

[49] The article remains neutral on whom to count as not responsible. This would depend on one's specifc theory of responsibility, and admittedly a larger discussion about responsibility for religious beliefs will also have to be a part of the discussion in the context of organ procurement. For some elements in the latter discussion, see Cohen [2004]; Knight [2009, 2006].

[50] Albertsen [2015a].

[51] This article has benefitted hugely from comments received on a number of occasions. It was presented at the 'Should personal responsibility play a role in fair healthcare' at Oslo University, October 2016; at the Annual Meeting in the Danish Political Science Association in Vejle, October 2016; at the 'Equality, Freedom and the Good Life' workshop in Aarhus December 2016. I am very grateful for insightful comments provided by David V. Axelsen, Greg Bognar, Jens Damgaard Thaysen, Kristine Bærøe, Siba Harb, Robert Huseby, Holly Lawford-Smith, Kasper Lippert-

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