

Ethical and Logistical Issues Raised by the Advanced Donation Program “Pay It Forward” Scheme

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The advanced donation program was proposed in 2014 to allow an individual to donate a kidney in order to provide a voucher for a kidney in the future for a particular loved one. In this article, we explore the logistical and ethical issues that such a program raises. We argue that such a program is ethical in principle but there are many logistical issues that need to be addressed to ensure that the actual program is fair to both those who do and do not participate in this program.

Keywords: *advanced donation program, ethics, kidney chains, living donors*

I. BACKGROUND

In 2016, 19,062 kidney transplants were performed. There were 13,431 kidney transplants from 9,116 deceased donors and 5,631 kidney transplants from 5,630 living kidney donors ([Organ Procurement and Transplantation Network, 2017](#)). The problem is that over 98,000 individuals were on the kidney waitlist. Demand greatly exceeds supply and the gap is growing, despite numerous initiatives to increase the donor organ supply. In the past 25 years, there has been a growing willingness to accept less ideal deceased donors ([Gagandeep et al., 2006](#); [Morrissey and Monaco, 2014](#)), and a greater

willingness to accept genetically unrelated living donors (first spouses, then friends, followed by strangers [Spital, 2000]), and even efforts to promote or “champion” living donation (Garonzik-Wang et al., 2012; Rodrigue et al., 2014). The result has been an increase of approximately 4,800 deceased kidney donors (or about 9,600 kidney transplants) annually from 1990 (4,306 deceased donors) to 2016 (9,116 deceased donors) and an increase of living donors from 2,094 in 1990 to a peak of 6, 647 living donors in 2004 that has stabilized at 5,600–5,700 kidney donors since 2011 (Organ Procurement and Transplantation Network, 2017).

One attempt to increase living donation has been the adoption of kidney exchanges in which, traditionally, two incompatible donor–recipient pairs engage in a swap in which Donor 1 donates a kidney to Recipient 2 and Donor 2 donates a kidney to Recipient 1 (see fig. 1). First proposed by Rapaport in the United States in 1986 (Rapaport, 1986), the earliest exchanges took place in Korea in the early 1990s (Park et al., 1999a) and are now performed in many countries (Ferrari et al., 2015). The idea of a kidney chain was first proposed by Montgomery et al. (2006) and first reported by Rees et al. (2009). This concept involves a series of kidney transplants that are catalyzed by a nondirected kidney donor (NDD). The NDD (Donor 0) donates to Recipient 1 whose living donor (Donor 1) then donates to Recipient 2. Donor 2 then donates to Recipient 3 and the chain continues until the final donor (Donor N) donates to a recipient without a living donor (a candidate on the waitlist [Recipient Z]; see fig. 2).

Although Ross et al. discussed how to overcome the ethics and practical obstacles of kidney exchanges in 1997 (Ross et al., 1997), the first kidney exchange in the United States was not carried out until 2000 at Rhode Island Hospital (Wallis et al., 2011). Several exchange programs then emerged (Segev et al., 2005; Hanto, Reitsma, and Delmonico, 2008). However, kidney paired donation did not take off in the United States until after the passage of the Charlie Norwood Act in 2007, which clarified that exchanges were not a “form of valuable consideration” and were legally permissible in the United

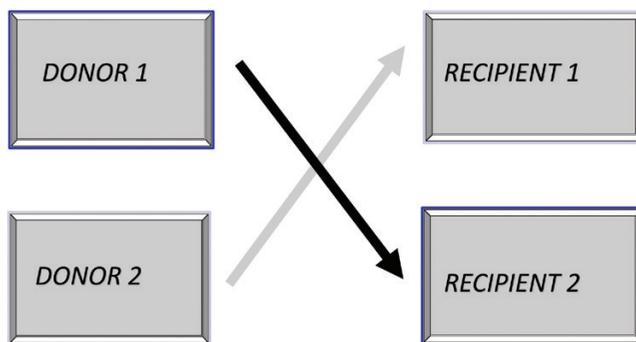


Fig. 1. An exchange of organs between two donor-recipient pairs.

States (United States Congress, 2007). In 2007, Garet Hil created the National Kidney Registry (NKR), a private not-for-profit organization developed to facilitate exchanges. In 2008, NKR facilitated 21 transplants and that number has increased annually to 399 in 2016 (National Kidney Registry, 2017c). Today, NKR is “a voluntary network of 65 transplant centers in 28 states” (Flechner et al., 2015). Although some transplant centers are large enough to facilitate their own exchanges (Bingaman et al., 2012), NKR coordinates multiple institutions, as does the Alliance for Paired Kidney Donation, which was founded initially in 2001 when Ohio’s nine transplant centers joined together to engage in kidney paired exchanges as the Ohio Solid Organ Transplantation Consortium (Ellison, 2014, 14). The Ohio Consortium had little success and in May of 2006 the group reorganized as the Alliance. Finally, although the United Network for Organ Sharing (UNOS) proposed a Kidney Paired Donation Pilot Program in 2004, UNOS did not perform its first match until 2010. Although UNOS partners with over half of living donor programs, it has facilitated fewer exchanges than both NKR and the Alliance for Paired Kidney Donation (Ellison, 2014, 15). In 2013, there were seven active multicenter kidney paired exchange registries in the United States plus several single-center registries (Melcher et al., 2013).

Each program that performs kidney paired exchanges uses their own algorithm to match donor and recipient pairs. The NKR algorithm has evolved over time. It considers many factors, including optimizing for blood type, histocompatibility, age considerations, travel restrictions, and other donor/recipient preferences. As explained by Veale and Hil:

Most of the early systems were based on integer programming algorithms which were the best tools to solve the complex mathematical problem presented by the traditional paired exchange reciprocity requirement. With the advent of chains, these original integer programming solutions had to be modified to accommodate the radically different mathematical challenge presented by chains. The NKR system

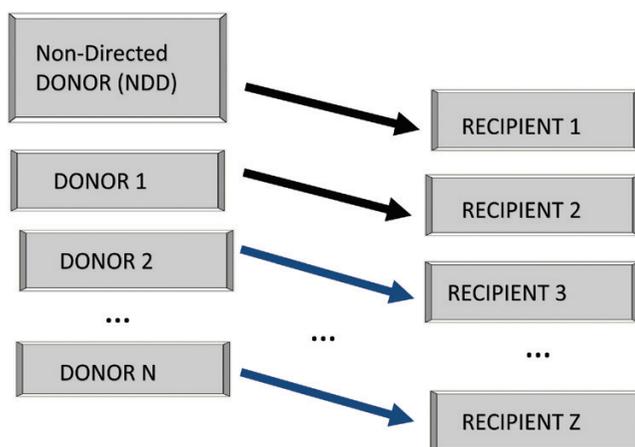


Fig. 2. Kidney Chain catalyzed by a nondirected donor (NDD).

was initially created based solely on the chain matching model utilizing technology components employed by modern capital market exchange systems (e.g., New York Stock Exchange) departing from integer programming algorithms historically used for paired exchange. In 2011 the Simultaneous Mutually Exclusive Loops and Chains (SMELAC) matching algorithm was implemented, further increasing the match capture rates by combining loops and chains into a single search. (Veale and Hil, 2009, 256)

Kidney exchanges have evolved. Initially, all surgeries in an exchange were done simultaneously and locally; now they are done nonsimultaneously and many involve shipping organs across the country. Kidney transplants also expanded from exchanges between two incompatible donor–recipient pairs to multiple donor–recipient pairs, and some may include compatible pairs. The encouragement of compatible pairs in these chains is ethically controversial (Ross and Woodle, 2000; Veatch, 2006; Steinberg, 2011; Fortin, 2013). Transplant programs may include compatible pairs to increase the length of the chains and/or to match hard-to-match pairs (Gentry et al., 2007). Compatible pairs are most helpful for both of these goals when the donor is of blood type O and his or her intended recipient is of blood type non-O, because O-donors are universal donors, meaning they can donate to candidates of any blood type. Most incompatible pairs, in contrast, have an O-recipient who requires an O-donor.

The main ethical problem with the participation of compatible pairs in chains and exchanges is how to invite the compatible pair to participate in a way that does not make the pair feel undue pressure. Because a compatible pair does not need to participate in an exchange, the compatible pair may find this invitation an unwanted request but feel compelled to participate either because they were invited by their providers to whom they may feel a debt of gratitude or because they do not want to be perceived as selfish. If the compatible donor–recipient pairs are at odds about participating, the offer may have introduced additional strain in an already stressful situation. Now, it is also possible that the compatible pair is eager to participate because the other donor is younger and healthier (i.e., out of self-interest) or because they are eager to help others (i.e., out of altruism). How to invite their participation in a way that does not create undue pressure and enables potential donors freely to enroll or decline to participate needs further study. One potential solution may be to raise the option and gauge interest even before blood type testing is done and before it is known whether the donor is compatible.

A second ethical issue is how to deal with a bad outcome. Compatible pairs must understand that if they participate in an exchange and they have a bad outcome (e.g., the other donor’s kidney does not work), they are not entitled to another kidney. This may create ill-will and distrust in living donors, even though the same result could have happened if the donor had donated directly.

Kidney chains have also evolved. Initially, all surgeries were done simultaneously, but now chains are often done sequentially, particularly when started by a nondirected donor, because then each recipient of a donor–recipient pair receives a kidney before his or her donor donates (“pay it forward”) (Ashlagi et al., 2011). In some chains, however, the donors may donate before their paired recipient gets an organ, with the parties trusting that the recipient will get the designated kidney (Butt et al., 2009).

In 2014, Howard Broadman conceived of the idea of an “advanced donation” (Hawryluk, 2016). Broadman’s grandson was born with a congenital kidney abnormality and was expected to need a kidney transplant by young adulthood. Broadman, who was 64 years old when his 4-year-old grandson was diagnosed, realized he might be too old to donate when his grandson might need a kidney and proposed donating now in exchange for providing his grandson with a kidney voucher to be utilized when he needed it. The Advanced Donation Program (ADP) was created to allow individuals to donate a kidney in exchange for a voucher for one of up to five specified individuals who might require a kidney transplant in the future. Broadman is not the only one to donate under this system. In 2007, Garet Hil, the founder of NKR, was unable to donate to his daughter due to a positive crossmatch. His experience in finding her a kidney was the inspiration behind his creation of NKR. Although a cousin who was a match eventually donated to Hil’s daughter, Hil has donated one of his kidneys to provide a voucher for his daughter in case she needs a second transplant in the future (GoodNewsNetwork, 2016).

The practice of donating a kidney in advance of one’s recipient getting a kidney had actually occurred several times in the NKR program before Broadman’s idea was proposed. In a news article about the ADP, several cases were described, including a 2008 donation by a police officer who donated several weeks before his intended recipient cousin was ready, and a 2012 donation by a Naval officer who wanted to donate on behalf of his mother but had to return to active duty before his mother was ready for the transplant (Hawryluk, 2016). This is now known as a short-term advanced donation in contrast to the donations by Broadman and Hil, which are known as voucher cases.

II. LOGISTICS OF NKR ADP

The philosophy behind the NKR allocation algorithm is to maximize the number of transplants performed. This is distinct from current deceased donor allocation policy which, according to the Final Rule, is obligated to balance efficiency (maximizing the number of transplants) with equity (fairness in distribution) (US Department of Health and Human Services, 1998).

Maximizing the number of transplants, however, is not the same as creating the longest chains possible, because some of these chains place donors on hold, while additional donor–recipient pairs are located (these donors are known as “bridge donors”) (Woodle et al., 2010). The problem is that bridge donors are more likely to drop out for many reasons, including, for example, their own health issues or the difficulty in donating due to other competing obligations that developed when they are finally contacted. It is also the case that just because a chain can be identified algorithmically does not mean that the chain will take place. It may not occur for many different reasons: because one donor–recipient pair does not accept a chain donor, because one donor–recipient pair drops out as the recipient got a deceased donor or participated in a chain by another facilitator, or because of health reasons that make one of the paired donors ineligible to donate, etc. Liu et al. describe the match offer data from the NKR database between March 1, 2011 and April 23, 2013:

Of the 3,180 match offers issued, 2,228 (70%) were accepted, 454 (14%) were rejected, and there was no center response for 498 (16%) match offers. To expedite the matching process, match offers were often withdrawn by the registry before the deadline because another center had already rejected one of the offers within the chain. In these situations, centers may not have responded yet to their match offers, accounting for most of the 498 nonresponders. Among the 2,228 accepted match offers, only 1,335 (42% of total offers, 59% of accepted offers) actually advanced to the next stage because 893 offers that were accepted did not proceed because they were part of chains that fell through. The NKR facilitated 690 kidney transplants within this period. Therefore, one in 4.6 match offers resulted in a transplant. (Liu et al., 2015, 1410)

In other words, only 22% of all match offers go on to transplantation.

Although the NKR goal is to maximize the number of transplants, the organization takes a long-term view. Thus, NKR seeks to maximize the number of transplants in a chain unless a match run allows for a difficult pair to be incorporated into a chain. Selecting difficult-to-match pairs to participate in a chain increases the number of transplants ultimately done because it includes pairs that may otherwise never get into a chain. The practice of giving priority to chains involving difficult-to-match pairs also promotes equity, because it ensures that all candidates have a fair chance of being allocated a kidney. This sometimes means moving forward with shorter rather than longer chains. Optimizing chain lengths, then, is a balance between the length of a chain with capturing hard-to-match pairs, patient sense of urgency, and many logistical issues, particularly as chains are formed that involve hospitals in different parts of the country (de Klerk et al., 2010; Anderson et al., 2015). As explained in the Medical Board Policies, when time is limited (e.g., an NDD with a limited timeframe for donation), NKR matches “to maximize the probability of making it to transplant within the allotted timeframe,” based

on factors such as whether the cross match has already been completed and found to be negative and whether the center has the capability to transplant within 3 days of receiving the offer ([National Kidney Registry, 2017b](#)). When adequate time is available and multiple possible match combinations exist, NKR gives preference to patients with the longest wait times in the NKR system and children. Matches are communicated to the partner transplant centers, which usually have 3 days to accept or reject the match and 10 days to perform the cross match ([National Kidney Registry, 2017b](#)).

Understanding the NKR algorithm for selecting matches is only part of the process. It is just as important to understand how a chain is terminated; that is, how Recipient Z from figure 2 is selected. According to the NKR website, top priority is given to an NKR NDD followed by patients whose donors have given a kidney but the swap failed, such that the paired recipients did not get a kidney ([National Kidney Registry, 2017b](#)). This may be due to a kidney damaged during procurement, a kidney lost in transit (very rare), or a kidney found to have pathology not otherwise expected. It may also occur if complications arise with a kidney chain donor (say, e.g., Donor 1 in fig. 2, who is donating to Recipient 2). NKR will try to contact the surgeons and stop the paired donor (Donor 2) from donating. If Donor 2 has already had the kidney removed or is at a point in surgery where stopping is no longer an option, the Donor 2 operation will proceed and the kidney will be donated to Recipient 3 and Recipient 2 will get priority for ending another chain (becoming Recipient Z) in the near future. Third priority is given to ADP voucher candidates. Next, priority is given to children and individuals who are highly sensitized (and therefore difficult to match) before giving priority to a waitlist candidate from the center at which the NDD donated ([National Kidney Registry, 2017b](#)).¹

III. IS THE ADP ETHICAL?

Below, we explore seven ethical and logistical concerns that challenge whether such a program can withstand strict ethical evaluation.

Issue 1: Does the Voucher Program Violate the “Valuable Consideration” Clause of NOTA?

One ethical concern with an ADP program is whether it violates the “valuable consideration” provision of NOTA (National Organ Transplantation Act) which prohibits the exchange of valuable consideration (money or the equivalent) for organs. This was a major concern when the ethics of exchanges were first discussed ([Ross et al., 1997](#)), but community consensus quickly concurred that exchanges are permissible ([Park et al., 1999b](#); [Delmonico, 2004](#); [Kranenburg et al., 2004](#)), although the legal permissibility was not codified in the United States until 2007, when legislation was passed that

specifically stated that paired organ exchange should not be interpreted as “valuable consideration” ([United States Congress, 2007](#)). Since ADP mirrors other asynchronous exchange, albeit with a longer time frame, we believe it should similarly not be viewed as violating the “valuable consideration” provision of NOTA. This longer time frame, however, creates some logistical issues. First, the recipient may never need a kidney transplant. In this case, there is no ethical issue because the ADP donor becomes just an NDD. Assuming the donor understands this possibility, no ethical problem is created. Second, even if the recipient needs a kidney, a matched kidney may never come available or the NKR may cease to exist. The NKR website states: “If the NKR was to undergo a change of control, the surviving organization must honor all ‘voucher’ liabilities with the same or better capacity to fulfill all outstanding ‘voucher’ obligations” ([National Kidney Registry, 2017a](#)). It is not clear, however, how this can be enforced, particularly if the US government agency were to decide to take over all chain/exchange facilitation. Thus, part of the consent must be to ensure that donors understand that a kidney for the voucher candidate cannot be guaranteed.

Issue 2: Which Kidneys Should Be Accessible to the Voucher Holder?

At minimum, voucher holders should have access to kidneys provided to NKR from other ADP donors. However, if voucher holders can only receive ADP donor kidneys, the program may not serve the voucher holders well. Assuming relatively small numbers of people would find it rational to enter into such contracts, the number of organs available at any one time will be small. Some ADP donated organs may not match any voucher holders at the time of donation, and as such, some organs donated into the contract program will be diverted to NKR candidates outside the ADP program. This will be especially true early in the program when the intended voucher beneficiaries are not yet ready to receive kidneys. But later on, there may be greater demand for voucher kidneys than ADP kidney supply.

Should voucher holders have access to all NKR organs as a means of fulfilling a promise to voucher holders, or should voucher holders only have access to organs that become available from others who enter the ADP contract program at a later time? To direct non-ADP kidneys (e.g., kidneys from NDDs) to voucher recipients raises efficiency and fairness questions which could be alleviated, at least partially, if the NDD agrees that his or her kidney may be given to a voucher holder, particularly if the voucher holder is given a kidney at the end of a chain. Giving chain-ending organs to voucher-holders still raises ethical questions, since those organs could go to those on the deceased donor waitlist who are otherwise hard to match. Alternatively, one could propose that all NDD enumerate up to five potential voucher recipients of their own, even if their voucher list members are unlikely to

need a kidney, which would thereby make all NDD organs eligible for the ADP payback scheme. What impact this will have on NDD is unknown, and whether it changes the motivation and satisfaction of NDDs would need to be evaluated.

The NKR solution, as explained on its medical policy board website, is to give voucher holders access to non-ADP donor kidneys by giving them relative (but not absolute) priority to end a chain. As described above, those who have higher priority are NKR nondirected donors who develop end-stage renal disease (ESRD) and NKR exchange recipients whose exchange or chain donation failed prior to transplantation ([National Kidney Registry, 2017b](#)). While this policy is clearly articulated on the website, ADP donors, NDD, and other NKR participants should also be informed about it during the consent process. Their consent to enroll in NKR, then, becomes their consent to this policy and procedure.

Now it is the case that voucher holders, like all candidates listed with NKR, can also be listed on the UNOS deceased donor waitlist. However, they do not and should not get priority for a deceased donor organ. Rather, voucher holders should only get priority for NKR kidneys because they have provided a living donor graft through the ADP to another NKR candidate. To give voucher candidates priority on the deceased donor waitlist would be unfair to those donors who have been waiting and lack a living kidney donor. In fact, allocating an organ from the deceased donor organ pool preferentially to a voucher candidate probably would violate the Organ Procurement Transplantation Network (OPTN) allocation rules giving access on the basis of a gift to a private group. However, given issues of cross-matching, variable quality of donor organs, and blood type, the voucher holders cannot be assured that an organ will be available through NKR when they need it. If only a very poor organ becomes available in the NKR match runs, it might be rational for a voucher holder to wait for a deceased donor or to seek a contemporaneous living donor and to keep their voucher priority for retransplantation.

Issue 3: Who Can Be Listed as a Voucher Holder?

ADP donors have the opportunity to name up to five candidate voucher holders and each voucher holder can be named by five ADP donors ([National Kidney Registry, 2017a](#)). However, the NKR policies are not clear about the criteria that must be met for an individual to be allowed to be listed as a voucher holder or about how this decision is made. The NKR website states that “Intended recipients must be a kidney transplant recipient or currently have, or be expected to have, some form of renal function impairment” ([National Kidney Registry, 2017a](#)). How much risk of ESRD must the potential voucher holder have? Without some quantification, this requirement is meaningless, because we are all at some risk of ESRD. If there is some

threshold, does this mean that when the ADP donor designates five voucher holders, that the voucher holders must undergo some sort of workup? And if so, who is responsible for the costs?

Some potential ADP donors may want to donate for a relative who may not meet standard deceased donor waitlisting criteria or for a relative who may meet the criteria at listing but lose eligibility for psychosocial reasons (e.g., active substance abuse). The potential donor might consider using ADP to gain a right of access to an organ for such a person, even though the individual would not otherwise qualify for an organ. Will transplant programs feel obligated or at least feel some “subtle” pressure to list a voucher holder, even if it is obvious that he is a questionable transplant candidate (e.g., noncompliance, multiple medical co-morbidities)? Does this mean that a voucher holder is guaranteed eligibility even if the transplant is likely to fail? Or can the NKR refuse to list (or even disqualify) a voucher holder at a future date? Clearly, these issues need to be clarified.

Issue 4: Voucher Holder Prioritization

The NKR website is transparent about the relative (although not absolute) prioritization given to voucher holders to end chains. It is also clear that voucher holders need to understand that they cannot be certain a kidney will be available if and when they need one, cannot be assured about the quality of a kidney that might become available, cannot know, in advance, how difficult they will be to match to potentially available kidneys, and will need to seek care at a program affiliated with the ADP program, even if it is not local. The NKR website explains that ADP donors and their voucher holders should assume that there is a chance the promise cannot be fulfilled, that the agency responsible for providing the kidney may not even exist when the kidney is needed, and that new technologies may make alternative treatments of the kidney disease possible, thus negating the value of the contract.

One criticism about giving voucher holders priority to end a chain is that it will have an impact on the type of chain that is created. One might argue that giving the ADP candidate this priority is unfair to some who would otherwise receive organs at the end of the chain or is inefficient because it shortens the chain. It is the case that the need to end a chain that matches a voucher recipient may change the algorithmic solution of the NKR, which will lead to different donor–recipient pairs being selected for a particular chain. Specifically, it may shorten the chain. Given that the NKR goal is to maximize the number of transplants performed, does fulfilling the ADP contract violate the NKR goal? Some might conclude that using an organ to fulfill the ADP contract is acceptable, even though it involves a shorter chain because the goal of maximizing the number of transplants is balanced by the fact that there is no single ideal allocation. Rather, NKR (and other

facilitators) often identify several different possible chains because there is a high rejection of proposed chains (Liu et al., 2015). In addition, one must evaluate the present value of an ADP kidney in relationship to the future payback, which may or may not be needed.

Two issues about voucher holder prioritization need further clarification. The first issue is how to arrange a transplant for hard-to-match voucher holders. One possible solution would be to allow voucher holders to have direct access to an NKR NDD and not direct the NDD to start a chain. This is not mentioned on the NKR website. It is ethically questionable whether it is acceptable to permit the voucher holder to have direct access to an NDD, since the kidneys from these donors could otherwise start a multi-transplant chain that benefits several others with strong claims (e.g., children or hard-to-match candidates). This should be clarified in the NKR allocation policies.

Now, what if there were a situation in which a voucher holder is such a difficult match that direct donation from an NDD would be the only possible match he or she will see for years? One solution would be to say that this could be done with the consent of the NDD. That is, it would require that all prospective NDDs be asked whether they would allow their kidney to be given directly to a voucher holder, in the rare case of a very difficult-to-match voucher holder—rather than to use their kidney to catalyze a longer chain. We do not support this. Rather, it is preferable for voucher holders to undergo some degree of desensitization to make it feasible to end a chain rather than receive a kidney directly from an NDD. Many of the centers listed as NKR participants do combine chains with desensitization programs (Pham, Lee, and Melcher, 2017). This approach is fairer and more consistent with the objective of the NKR, but it needs to be clearly stated in the NKR policies.

The second issue in need of clarification is prioritization among voucher holders. When seeking priority among voucher holders from different ADP donors, one question that still needs to be addressed is how to determine how much wait time is allotted to a voucher holder. Does one count the time since the voucher candidate develops ESRD, or does the voucher holder get to count the time accrued since the donation by the ADP donor? Given that an ADP donor may list up to five candidates, how is it determined who gets to use the voucher? Under the current NKR policy, the ADP donor (call her Teresa) cannot prioritize who among the recipient candidates gets priority; rather, the first candidate (call him Adam) to be eligible for the kidney can present his or her voucher card. Now, it may be that there is one family member who is favored (a young child named Betty who has a congenital kidney disorder), but it is possible that Betty may never need a kidney. If Adam were to unexpectedly develop ESRD in 6 months after the ADP donated, the ADP donor and other family members may ask Adam to wait for a deceased donor kidney or to find another living donor, as there may have been a tacit agreement to see if Betty develops ESRD before adulthood. Now, Adam may

or may not agree, and the ADP donor cannot rescind the offer (according to the rules stated on the NKR website). The ADP donor and the other voucher holders can ask Adam to wait and to promise him that if he needs a retransplant and Betty still has not developed ESRD that he would be the preferred recipient. Again, Adam may or may not agree. At minimum, this will cause some intrafamilial strife, and this possibility needs to be explored with the ADP donor as he or she decides to whom to offer a voucher card. While listing up to five individuals increases the likelihood that there is a payback, it also creates tension among the voucher holders who all may want priority. If Betty is truly the preferred candidate, then maybe only Betty should be given a voucher card. If in the slim chance Betty never develops ESRD, then the gift was an insurance policy that was never redeemed. The ADP kidney ended up serving as an NDD kidney that helped strangers.

The fact that Adam can redeem the voucher and not wait to see if Betty develops ESRD also explains why a candidate, like Betty, may be listed by up to five ADP donors. This way, if Adam chooses to redeem his voucher from Teresa, Betty may still be eligible through an ADP donor other than Teresa.

An alternative way to deal with cases in which a donor has a preferred candidate, but also wants to list alternates, would be to permit the ADP donor to list candidates in priority order. (N.B.: this would require a change in NKR policy.) If permissible, then Teresa could list Betty first, Adam second, and so forth. Listing with priority status creates other problems, however, including significant intrafamilial tensions, particularly if numerous voucher holders develop ESRD. If Betty, the preferred candidate, is young and not expected to need a kidney for decades, this would hold up the voucher redemption, in effect disqualifying all the other lower priority candidates, unless Betty is definitively eliminated as no longer needing a kidney or no longer being eligible for a kidney transplant (due to serious comorbidities such as persistent vegetative state secondary to a car accident). In fact, the other voucher card holders must realize that Betty is not definitely eliminated even if she were to get a deceased donor kidney before an NKR chain was identified, because she still may need a retransplant years to decades later.

In sum, the surest way to ensure that Teresa's gift is paid back is to list five individuals without priority. However, the safest way for Teresa to be assured that Betty has a chance to receive an organ when she needs it is to name only Betty on her list of candidates, or, if prioritization were permitted, to list Betty first. In both cases, Teresa and Betty must understand that there is still no guarantee an organ will be available when Betty needs one.

Issue 5: Priority for the ADP Donor to Receive a Kidney?

The possibility that an ADP donor might himself or herself need an organ in the future is not as hypothetical as one might want to believe, with over 40

former living kidney donors being added to the UNOS/OPTN waitlist annually (Wainright et al., 2016). ADP donors, like all living donors, are eligible to get some priority for a deceased donor on the UNOS/OPTN waitlist.

But, are they eligible for priority for kidneys from other NKR living donors? Specifically, should ADP donors get priority for ending a chain? Currently, they are not given priority; rather, the only donors who develop ESRD who get priority are the NDDs who donated nondirectedly and started chains (National Kidney Registry, 2017b). However, ADP donors have the opportunity to name up to five recipients. It is ethically permissible for an ADP donor to list him- or herself as one of the five potential recipients for a future voucher kidney. If the donor were to list him- or herself and redeemed the voucher, there would be no kidney available for his or her other originally intended recipient(s). That is, each ADP donor gets to provide priority for one, and only one, recipient such that if he or she does not list him- or herself, then he or she is not eligible for a living donor registered with NKR, unless another ADP donor lists him or her on their voucher list. In contrast, NDDs who develop ESRD get priority precisely because they list no future recipients, and it is as if the NKR interprets this silence to mean that the only potential voucher holder is the NDD him- or herself. It is critical that ADP donors and NDDs understand these rules as they decide whether and how to donate.

Issue 6: Consent

Consent is a key concept in all living donor kidney transplants—for both the donors and the recipients. All donors and recipients must be told about the risks, benefits, and alternatives. For the donor, the physical risks are the same regardless of who the recipient is. The benefits, however, may depend on who the recipient is and how well the graft works. In chains and exchanges, all donors and all recipients must agree to giving or receiving a kidney from an unknown person. Although there may be some future opportunity to meet, this will only occur if all parties agree, and this will only occur post-transplant. For some, this may be a deal breaker.

For a donor involved in a chain or exchange, the benefits may depend more on how the exchange/chain kidney functions in their intended recipient rather than how their own kidney functions in a stranger. The risks include the fact that some donors may be disappointed that they did not directly help their loved one and/or that they may not feel that the exchange kidney is as good as the one that they provided.

For the ADP donor, the NKR website lists key requirements and disclosures related to the ADP program (National Kidney Registry, 2017a). Exploring these details is critically important for prospective ADP donors considering the risks and benefits and then deciding whether or not to participate. Whereas the risks of donation are the same for the ADP donor as for other

living donors, the benefits may or may not accrue during his or her lifetime, depending on when the voucher holder develops ESRD. Either way, the ADP donor may feel peace of mind for providing an insurance policy for his or her intended recipient. However, it is critical that ADP donors realize that they may never get a payback for their donated kidney and that the doctors cannot guarantee a kidney will be found when their loved one needs it (Hawryluk, 2016). It is also possible that the NKR will not exist at the time the intended voucher candidate needs a transplant, and although NKR asserts that future organizational leaders should uphold the contract, this may or may not be enforceable.

Additional issues must also be addressed with potential ADP donors. As described above, the ADP donor must decide how many voucher holders to name; if more than one voucher is given, the ADP donor must understand that, unless the rules are changed, he or she does not get to prioritize who redeems it or when it is redeemed. This can create intrafamilial strife and disappointment for the ADP donor him- or herself. Finally, before an ADP donor agrees to “pay it forward,” the ADP donor must clearly understand the alternatives. These options may include the fact that individuals with ESRD are eligible for deceased donor kidneys. If Betty is expected to develop ESRD in childhood, she will get priority on the standard deceased donor waitlist and may simply accept such an offer. Now, it still may make sense for Teresa to be an ADP donor in case Betty needs a second transplant (particularly, if the first kidney fails when Betty is an adult and no longer gets priority and may be hard to match due to sensitization). In fact, such a strategy may actually be in Betty’s interest. Of course, Teresa must understand Betty may never need a first or second kidney or that new treatments may become available that reduce the value of this voucher.

If Betty were to develop ESRD and redeem her voucher, the ADP donor must understand that any kidney graft, even a living kidney graft, may not work. If Betty were to get a kidney that did not function, the voucher is good for only one kidney, and Betty will have to wait for a second transplant without any special priority on the deceased donor waitlist unless another living donor comes forward. The risk of primary graft nonfunction in the recipient is a risk that all living donors take—regardless of who the recipient is.

Issue 7: Multiple Facilitators

Although currently NKR is the only facilitating organization that has created an ADP, NKR competes with other facilitating organizations and large single centers to enroll donor–recipient pairs. Centers can choose to cooperate with one or more of the facilitators and/or create their own exchanges. Donor–recipient pairs can also elect to enroll at one or more centers with one or more facilitating organizations. Even some moderate size centers may elect not to enroll a donor–recipient pair that is easy to match to create an internal two pair

exchange (Veale and Hil, 2011; Ashlagi and Roth, 2014). Easy-to-match pairs (e.g., pairs with O-donors and non-O recipients) are really useful for facilitating chains and exchanges, because they can serve in many different chains and, therefore, promote longer chains or chains that include hard-to-match donor–recipient pairs. However, centers have different financial incentives. For a particular transplant center, it may be more timely and efficient for the center to get two donor–recipient pairs transplanted from within their own program now than to be part of a chain that may take months to come to fruition and may collapse before the institution’s second donor–recipient pair is enrolled. Since centers cannot be required to list any particular donor–recipient pair with any facilitating organization, the practice of using easy-to-match donor–recipient pairs within an institution limits the efficiency of chains and exchanges in some of the larger programs like NKR. This problem could be resolved by creating a single list, as is done for deceased donor organs.

A single national list would both maximize the number of potential transplant chains and would also increase the possibility that hard-to-match pairs are matched and that longer chains are possible. Such a list has the advantage that all candidates would be considered for all organ matching attempts. From an equity perspective, this would seem fairest because it ensures that all candidates are considered for all chains and exchanges, which may be the only way for hard-to-match candidates to be included in a viable chain or exchange. There are obstacles, however, that argue against a single list. First, once a national list is used, the kidneys may have greater travel (ischemia time). However, the data show that waits of up to 24 h cause minimal harm to the kidney (Kayler, Srinivas, and Schold, 2011; Segev et al., 2011). Also, the algorithm can be tweaked to include distance as an important factor in the algorithm. Second, data show that very long chains may lead to more breaks (Veale and Hil, 2011, 274). Again, this can be incorporated into the algorithm to ensure long-term maximization of kidney transplants.

As long as there are multiple lists, however, donor–recipient pairs ethically must be told about these options; they may then choose to sign up for multiple lists. Since this may increase costs and could be time-consuming and only available to those who can afford to travel, doing so raises ethical questions about fairness. Whether multiple facilitating organizations could afford to have an ADP program is not clear. To be fair to ADP donors and their prospective voucher holders, it may be necessary to limit such programs to those that perform a large number of chains annually. Oversight from a national board like UNOS or at least mandatory reporting of data about voucher holder access to organs is necessary to ensure that un reputable programs do not attract ADP donors into a Ponzi scheme that leaves their voucher holders without paybacks.

If all living donor chains and exchanges were to be combined into a single list, decisions would have to be made about the permissibility of ADP. If there were consensus that the benefits that accrue from the present value of

the ADP kidney outweighs the risks of having to steer some chains to meet the needs of future voucher holders, then voucher holders would have a better chance of having a kidney available when needed.

IV. CONCLUDING REMARKS

We conclude that the concept of ADP is ethical in principle, but there are many logistical issues that will require further evaluation to avoid confusion, conflict, and complaints of lack of transparency. At minimum, NKR and other facilitating organizations need to ensure that allocation policies are comprehensive, transparent, and responsive to evolving practices, for all exchanges and chains, including those involving ADP donors and their voucher holders. They also need a board that will arbitrate conflict, and both donors and recipients will have to agree to such mediation. Last but not least, for such programs to be successful, public trust must be preserved by ensuring that all stakeholders—living donors, their intended recipients, transplant programs, and society—are fully informed about the relative risks and benefits of ADP participation.

NOTES

1. Although NKR focuses on maximizing the number of transplants (efficiency), their priorities for recipient Z are laudable in that they also incorporate a Rawlsian equity as fairness component (e.g., giving priority to difficult-to-match pairs and children helps those who are amongst the “worst off”) (Rawls, 1971).

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