

Not as Simple as Civic Duty: A Response to Andrew Michael Flescher's Argument to Increase Living Kidney Donations

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In The Organ Shortage Crisis in America: Incentives, Civic Duty, and Closing the Gap (2018), Andrew Michael Flescher analyzes and critiques proposed ways to solve the kidney shortage in the United States. He advocates removing disincentives to living donation and emphasizes types of nonmonetary compensation, eventually establishing “a gift exchange powered by civic engagement,” (p. 16) where the relational aspect of the exchange between donor and recipient is of primary importance. Unfortunately, the project fails. A reliance and emphasis on civic duty as the primary driver of living organ donation is unrealistic and potentially harmful. Without making structural changes to the current recruitment and distribution system to account for institutional biases within the healthcare system, there is no hope for a just solution to the organ shortage crisis. Relying on “civic virtue” requires a trustworthy healthcare system that uses a fair method to distribute organs. Empirical evidence demonstrates that we do not have either of those in the U.S. Policymakers could construe arguments that frame civic virtue as the most important missing ingredient in solving the organ shortage crisis as arguments that justify the current prejudicial framework. The U.S. should remove disincentives that deter donations, but that will be only a partial solution. Alternatives that can move the U.S. closer to an ethical solution include increasing access to primary and preventive care, to reduce the need for donor kidneys in the first place, and expanding the eligible donor pool.

INTRODUCTION

In the United States, thousands of people die each year waiting for organ transplants. The number of people on the waiting list far outstrips the number of deceased donors with viable organs. The lion's share of people on the organ transplant waiting list—84%—need kidneys (Organ Procurement and Transplantation Network (OPTN), 2021). Living donation kidney transplants are an option in addition to deceased donor kidney transplants.

In response to the gap between organs needed and those available, several sources have proposed establishing a market where kidneys and livers are available for selling and purchasing (Cohen, 2014; Halpern et al., 2010; Hippen et al., 2009; Sade, 1999). There are a variety of permutations of this proposal; some advocate for the government setting a price, acquiring, and distributing the organs (Major, 2008; Schweda & Schickltanz, 2009). Others propose either an open or heavily regulated market where buyers can directly contact sellers (Larijani et al., 2004; Matas, 2007). The one thing these proposals have in common is that they are extremely controversial and have generated a storm of literature in response. One of the most recent and comprehensive responses is *The Organ Shortage Crisis in America: Incentives, Civic Duty, and Closing the Gap*, by Andrew Michael Flescher, PhD (2018). Flescher advocates for removing disincentives to living organ donation and increasing alternative types of non-monetary compensation to persuade potential donors, eventually establishing “a gift exchange powered by civic engagement” (2018, p. 16). This proposal is similar to many others dis-

cussed in bioethical and medical literature that advocate making organ donation at least a financially neutral act, but it is the emphasis on civic duty that sets Flescher's plan apart.

Unfortunately, Dr. Flescher's proposed ethical solution to the organ shortage crisis fails because he does not propose any changes to the current organ donation system. Endorsement of the existing racially and socially biased system could continue to harm certain populations. His solution requires something unavailable in the U.S.: a just healthcare system that has the trust of the public. It is impossible to have an ethically and morally acceptable solution without addressing the structure and process of the current living organ donation system. In fact, his argument, advanced in the current American social and political climate, is harmful.

The issue of trust in the healthcare system is complex and ever-evolving. The point I wish to focus on is that Dr. Flescher concedes this requirement of public trust in order for his plan to work:

“Constraints of time and space prevent our delving too deeply into the question of how ethnicity, income, and race impacts [sic] attitudes about the formation of healthcare policy, but it is significant for purposes of the current discussion to call attention to what seems to be lacking in these vulnerable populations—namely, the feeling of trust and fellowship that optimize recruitment of donors in better-supported communities” (Flescher, 2018, p. 97).

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For the purposes of this article, I will focus on providing evidence of why this mistrust in the healthcare system could be justified, especially for particular populations, and how inspiring people with civic duty will not make these reasons go away.

After critiquing Flescher's arguments, this paper will briefly examine a solution that could lead to decreasing disparities in transplant rates and improving overall kidney health for all populations: increasing access to primary and preventive care, while expanding the pool of eligible living donors.

BACKGROUND

The scope of the kidney problem

Americans are in the middle of a kidney health crisis. Approximately 15% of the general population has chronic kidney disease (CKD), the worst and final stage of which is known as kidney failure (CDC, 2021). In 2018, over 785,000 Americans were living with kidney failure (NKF, 2021). For patients with kidney failure, the preferred treatment is a kidney transplant (Hippen et al., 2009). Until patients receive a transplant, or if they are ineligible for a transplant, the standard treatment for kidney failure is dialysis. The most common form, hemodialysis, is typically received three to four times a week, with the procedure taking around four hours each time (NKF, 2015). This is a huge time commitment and patients who choose hemodialysis must plan their lives around dialysis treatments, which can have a significant impact on their quality of life (Vandecasteele & Kurella Tamura, 2014).

In the U.S., getting a new kidney is a multistep, time- and labor-intensive ordeal. People who wish to receive a kidney must first be screened by a healthcare provider and then referred to a transplant center (NKF, 2017a). Patients can also contact transplant centers themselves to learn about their options (NKF, 2017a). Both deceased and living donations require a specialized center with the appropriate staff, equipment, and resources. There are many centers throughout the U.S., but they are not distributed evenly by geography or population. The transplant center then evaluates the person requesting the kidney, and if the patient meets that particular center's criteria for a transplant candidate, the patient will be placed on the national waiting list (NKF, 2017a). However, transplant centers do not all have the same donor criteria, and organs are sometimes allocated by geographical region, so some patients choose to get listed at more than one transplant center (NKF, 2017b). A patient can try and get on more than one institution's waiting list, but this often involves going through a separate evaluation with each of the other institutions. While kidney transplant candidates are on the transplant waiting list, the average wait time to receive a kidney is three to five years; however, it can be much less if the patient finds a living donor who is a good medical match (NKF, 2017a). So, patients who have access to specialty care

and/or who have friends or family members who are able to donate a kidney have a significant advantage over those who are waiting for a deceased donor or an altruistic donation.

Recipients, medical institutions, and donors are not allowed to offer money or other incentives to arrange a transplant. The National Organ Transplant Act (NOTA) of 1984, the legislation governing organ donation, outlaws any kind of "valuable consideration" from being exchanged between recipients and donors. The phrase "valuable consideration" is generally taken to mean no money may be exchanged for the organ itself. Federal legislation allows donors to be compensated for certain nonmedical expenses, including lost wages, housing and travel expenses, and child- or elder-care expenses incurred by the donor while donating (Removing Financial Disincentives to Living Organ Donation, 2020). However, the phrase "valuable consideration" is open to interpretation as to whether the donor may receive desirable, non-monetary benefits, like health insurance. Current bio-ethical debate about whether lack of donor compensation is fair or not has strong supporters on both sides. Some market proponents argue that donors are the only ones not to be paid of the many parties involved in kidney transplants; surgical teams, hospitals, and recipients all get something material out of the exchange (Larijani et al., 2004; Matas, 2007). In addition, other scholars argue that it would be just to compensate donors for their time, effort, and lost wages (Giubili-ni, 2015; Israni et al., 2005). However, even those who agree that compensation is justified are unsettled on what form the compensation should take, and who should be responsible for covering expenses. A lump sum of cash? Reimbursement for medical and/or nonmedical expenses (Israni et al., 2005; Sickland et al., 2009)? Others, including Flescher, are against openly paying for organs, but do advocate for nonfinancial or "in-kind" compensation. Some examples include having priority on a waiting list if the donor or one of their family members needs an organ in the future, tax incentives or credits, or even a "kidney voucher" to be used at a later time that facilitates "chronological incompatibilities" between donors and recipients (Veale et al., 2017, p. 2118).

FLESCHER'S ARGUMENT TO INCREASE LIVING DONATIONS OF KIDNEYS

Civic duty

Flescher believes that we can best solve the organ shortage by increasing the number of living donors. He proposes that this be done by replacing numbers and statistics about kidney transplants with faces and stories. Other authors have also concluded that stories about individuals have a significant impact on the public's sense of responsibility for different health conditions (Gollust & Lynch, 2011). Flescher hypothesizes that people who witness or form relationships with someone who needs a kidney will be compelled to donate. However, his plan has been criticized for failing to articulate

why exposure to the suffering of others would increase donation rates (Sonnenberg et al., 2018). Undergirding Flescher's main argument is his notion of civic duty:

Civic duty thus pertains to a recipient-generated inducement to care for those whose plights we know, as opposed to a moral requirement to "be a good person." When we are able to see ourselves as members of a connected society and learn more about what it means to be suffering, a sense of "ought" will begin to emanate from within that then induces us to act. It is *this* impetus to act—the action sprung from a deepening connection with the one in need—that is being proposed as a rival to the financial incentives that some believe will help living donor recruitment. (Italics in original; Flescher, 2018, pp. 103–104)

This idea is based on a communitarian vision where all citizens recognize their dependency on and interactions with each other (Bell, 2020). A particular type of society must exist in order to catalyze this civic duty, though: Flescher concedes that citizens must have a basic trust in the institutions or entities responsible for them (2018). So, in order for the panacea of a fulfilled civic duty to come into existence, there must be a state or organizational structure that the citizens trust.

A better way to attract donors

Numerous scholars have argued that while many people may be turned off by the idea of receiving money for their organs, non-monetary compensation for living organ donors is widely regarded as appropriate and fair (Giubilini 2015; Hippen et al., 2009; Schweda & Schicktanz, 2009). Flescher admits that few people become organ donors simply because it's a "nice thing to do." Donors frequently envision something in return, but that thing is not money. In addition to helping a fellow human being who is in trouble, donors expect some type of benefit, such as satisfaction at doing something good, a relationship with the person who received their kidney, and/or recognition for their good deed (Flescher, 2018; Garden & Murphree, 2007; Spital, 2004; Williams, 2018). Other studies have shown that the critical value under consideration for people who may become living organ donors is *reciprocity*:

Many participants [recipients]...seem to have found ways to cope with this feeling of indebtedness by "repaying" something, e.g., by engaging in self-help groups or public campaigns for organ donation. It is significant that such societal engagement seems to concentrate on activities aimed towards increasing the total number of donor organs. This circumstance might be attributable to the notion that the principle of reciprocity not only posits a debt, but also determines the "currency" of redemption (Schweda & Schicktanz, 2009, p. 1133).

Several studies have also indicated that the public recognizes and appreciates the difference between money and other forms of organ donor compensation, finding the latter more palatable (Cohen, 2014; Schweda & Schicktanz, 2009; Smith, 2009).

Flescher states that his ultimate goal is to establish "a gift exchange powered by civic engagement" where more living donors come forward to provide kidneys (2018, p. 16). He believes this can be achieved by better education among the public about how people live with kidney failure and what a dramatic difference a new kidney can make in their quality of life (Flescher, 2018). Additionally, he advocates for removing disincentives to organ donation that currently exist. While insurance typically covers most of the immediate medical costs associated with donating a kidney, there are many unseen and uncovered costs of donating (Przech et al., 2018). These include lost vacation or sick days, care of self while recovering, paying for medical problems after donation, increased insurance rates, even pet care expenses (Removing Financial Disincentives to Living Organ Donation, 2020). Several other sources currently advocate for legislation to remove disincentives to organ donation (Delmonico et al., 2015; Dockser Marcus, 2018; Giubilini, 2015; Tong et al., 2014; Wiseman, 2012). This plank of Flescher's plan seems to be a realistic step in today's society.

However, his next conclusion is suspect at best. Flescher predicts that the educational component, along with the removal of disincentives to donation, will trigger citizens' sense of civic duty, leading to more living donors. He also supports varying forms of non-monetary compensation, such as free admission to Disney World® or "catered mass benefits featuring major musical and comedy acts, each with the purpose of honoring the donor who sacrificed his or her organ" (Flescher, 2018, p. 154).

Flescher asks for a mere "Two to Four Hours of Your Life"—the title of the conclusion to his book—in order to grow compassion and understanding of what a fellow human being who lives with kidney failure goes through. By witnessing a kidney failure patient's poor quality of life, Flescher believes that our natural inclinations to be "social beings who exist to act on opportunities to help one another, provided we are supplied with a little help in seeing these opportunities come to fruition" will be set into motion (2018, p. 164). It is this insistence, that a change in communal attitude is the most important factor in ethically increasing living kidney donations, that sets Flescher's plan apart from other scholars' proposals.

CRITIQUE OF FLESCHER'S ARGUMENT

Flescher's argument rests on a faulty assumption: a reliable healthcare system that holds a high degree of trust from the public that will execute these transplants. He does not propose any changes to the current organ allocation and

distribution system. Flescher's recommendation, within the context of the current U.S. political and social climate, could ultimately prove damaging to individuals and society.

A trustworthy healthcare system

In order for Flescher's project to work, civic duty must be awakened, which requires a healthcare system that patients trust (Flescher, 2018). This is not the current U.S. political and social climate. The COVID-19 pandemic has exacerbated health and healthcare disparities among Americans, with people who belong to racial minorities and in lower socioeconomic classes being disproportionately affected, which has exacerbated pre-existing distrust among some communities (Baker, 2020; Okonkwo et al., 2021). Among lower income people, less than half agreed that "doctors can be trusted" (Blendon et al., 2014, p. 1571). Mistrust of the healthcare system leads to worsened clinical outcomes: patients who reported less trust in their physicians were more likely to be noncompliant with their medications (Egede & Ellis, 2008). A study conducted in 2017 indicated that Americans found honesty, reliability, and fairness lacking in the U.S. healthcare system (Prince, 2017). The lack of widespread acceptance of living donor programs may be due to the fact that people don't trust their healthcare systems to take care of them afterward.

Patient demographics have a significant impact on how much faith individuals have in their healthcare institutions. Based on results from a multidimensional trust survey about healthcare providers, institutions, and payers, Egede and Ellis found that "trust scores were significantly lower among women, African Americans, and Hispanics and those without a usual source of care" (2008, p. 811). African Americans distrust the healthcare system for a variety of historical and contemporary reasons (Baker, 2020; Sade, 1999). This lack of trust is one factor cited to explain low donation rates among minority communities (Bratton et al., 2011; Purnell et al., 2012). However, Flescher thinks that the donation rate disparity can be "loved away": "If we show vulnerable populations that we care about them for real, we will earn larger societal buy-in..." (2018, p. 98). This attitude ignores the structural inequalities within the organ allocation and healthcare systems themselves that prevent many people from donating.

Lack of trust in the current medical system and among our fellow citizens translates into less willingness to help others, especially when the benefit to ourselves is unclear (Ronnerstrand & Andersson Sundell, 2015). In an untrusted medical culture, why would healthy citizens willingly risk complications from donating an organ? As one physician put it, "when doubt becomes pervasive, it can erode the glue that binds society together, and the medicine that keeps us healthy" (Khullar, 2018, para. 22).

Justice issues with the current organ donation system

Flescher does not suggest changing the current organ distribution system, which is itself unjust. Even if more organs

became available for transplantation, the discrimination present in the current system would merely be reproduced. Empirical evidence shows that people have good reason to question the fairness of the established system. In the present organ allocation structure, every other donated kidney goes to a white recipient, while African American/Black recipients get every fifth kidney, even though each race makes up one third of the waiting list (Grubbs, 2018). The donation rates among minority communities are much smaller too, for both living and deceased donations (Purnell et al., 2018; Sade, 1999). Within the medical community itself, excuses like, "African Americans[...]immune systems are just so strong" continue to be offered (Grubbs, 2018, p. 44). Despite efforts to decrease this discrepancy, racial and ethnic disparities for living donation have actually "increased in recent years, even after accounting for differences in deceased donor kidney transplantation and death" (Purnell et al., 2018, p. 60). As nephrologist Dr. Vanessa Grubbs puts it, the current organ donation system involves "a cascade of requirements vulnerable to the effects of personal bias and racism at an institutional level" (2018, p. 216). Attempting to smooth over these institutional structural barriers by an appeal to humanity's good nature, as if the kidney donation problem would go away if each American just cared enough, can ultimately be harmful to those not in the privileged classes: "There are still winners and losers, the powerful and the powerless, and the claim that everyone is in it together is an eraser of the inconvenient realities of others" (Giridharadas, 2018, para. 17).

Currently in America there are large disparities in transplant rates among race and socio-economic classes who have kidney failure (Purnell et al., 2018). An ideal transplantation system would be equitable, drawing on the principle of justice: all levels of society should share the benefits and burdens of the organ donation system (Ross & Thistlethwaite, 2021; Smith, 2009). By insisting that disparities in the current system could be overcome if only people were motivated enough, Flescher feeds the root causes of these disparities: "Neglecting these structural conditions risks legitimating them" (Smith, 2009, p. 107).

With the current social climate in the U.S., Flescher's proposal could provide justification for continuing the current organ distribution system, which is rife with institutional bias and discrimination. In their study of public perceptions of "deservingness" in terms of healthcare, Gollust and Lynch found that public policy is significantly affected by "one's perceptions about the reasons for unequal health outcomes in society" (2011, p. 1085). In the U.S., professional advocacy is especially critical in shaping public perceptions (Blendon et al., 2014). By recommending a plan of action without confronting the many layers of discrimination in the current organ transplant system, Dr. Flescher, as an expert, can have a significant impact on future policy decisions. Merely "wishing" a new attitude into existence will not solve the organ

shortage crisis and giving the impression that lack of motivation is a major reason for the crisis is irresponsible.

An alternative amelioration of the kidney health crisis

Without changing the institutional biases of our healthcare system, we cannot hope to have a just solution to the organ shortage crisis. However, there is an option that can move closer to an ethical solution: increasing access to primary and preventive care and expanding the eligible donor pool.

Increasing access to primary care can reduce the need for donor kidneys in the first place and lead to increased trust in the wider healthcare system. Basic coverage gets people involved with the healthcare system where they can form relationships with providers and learn more about what options they have in terms of health. Patients with a consistent source of care tend to have higher levels of trust in healthcare providers (Egede & Ellis, 2008).

In addition, increasing access to primary care would go a long way in helping Americans maintain healthy kidneys. Early and frequent monitoring can identify the beginning of CKD before it progresses to kidney failure. Persons who have diabetes and hypertension are predisposed to developing CKD, so having a consistent primary care provider to monitor those patients would be helpful (Rosoff, 2018; Sade, 1999). Scholars seem to agree that this preventive medicine tactic is the most just solution to the kidney health problem (Glannon, 2018; Hippen et al., 2009; Szczech & Lazar, 2004; Vandecasteele & Kurella Tamura, 2014). In addition, catching a disease early is more cost effective and leads to better patient outcomes than treating the condition once it becomes chronic.

Nationally, OPTN has issued guidelines stating that donors must be in good physical and mental health, and have a social support network (OPTN, 2018). Recent expanded criteria for donors allow some people who test positive for HIV and hepatitis C and older donors to give organs. These criteria still exclude most people with chronic illnesses, even if those persons' kidneys would otherwise be a good match (Ansari et al., 2017). One particular example is patients with amyotrophic lateral sclerosis (ALS). In their study of neurologists who specialize in treating individuals with ALS, Ansari and colleagues (2017) found that nearly half (49%) had been approached by their patients about donating their organs. If half of the general population who qualify for organ donation were interested in donating, it would be truly amazing. And even though over two-thirds (67.3%) of the neurologists have no concerns with ALS patients being donors, this group is automatically excluded by current guidelines (Ansari et al., 2017). The current donation process could be modified to address vulnerability and safety concerns for ALS patients and others with certain chronic diseases who wish to donate and who are already engaged with the medical system.

Expanding the donor pool and increasing preventive care, especially for those most at risk of kidney disease, are not the only solutions that can help, but are far more effective than Flescher's proposal. In particular, the preventive care component will do more for the health of minority communities and be more helpful in avoiding future healthcare costs. It should be part of any long-term solution to America's organ shortage crisis.

CONCLUSION

Flescher is unable to create or will into existence an equitable, safe system of living organ donation if he does not make any structural changes to the current recruitment and distribution system. While packaged to sound appealing, an emphasis on civic duty as the main driver of living organ donation is unrealistic. More likely, policymakers could construe these arguments to justify the prejudicial system that is in place now. The U.S. should continue to remove financial disincentives that deter individuals from donating, but that will be only a partial solution. There should also be increased preventive care for all individuals in order to decrease the need for kidney transplants in the first place. Expansion of donor criteria to include those who may have healthy kidneys but have been rejected by the current prohibitions on chronic illnesses also has potential for generating more donors.

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