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## CONLEY ETHICS ESSAY CONTEST

### 2015 WINNING ESSAY

#### Can Social Media Help Increase the Organ Supply While Avoiding Exploitation and Trafficking?

Gowri Kabbur

The combined ethics committee of the Organ Procurement and Transplantation Network (OPTN) and the United Network for Organ Sharing (UNOS) issued a 2015 [white paper](#) explaining the ethical principles that should guide *allocation* of human organs. The white paper does not mention *procurement* of organs, other than to say that selling organs is prohibited. Must procurement of organs also adhere to certain ethical principles? If so, which principles and why? In view of your argument, is use of social media to solicit organ donation ethical?

#### Response

The need for more organ donation in the United States is an ongoing struggle for the transplant community. According to the US Department of Health and Human Services (HHS), approximately 22 people die daily awaiting an organ transplant [1]. As of October 2015, an estimated total of 122,440 people nationwide were on organ waiting lists, a roughly fivefold increase from 1991 [1]. Unfortunately, the number of organ transplants performed in 2014 remained stagnant at around 29,532, which is less than a twofold increase over a 23-year period [1]. Recent social media campaigns, described below, have focused on increasing online organ registry enrollment rates, an alternative to registering citizens through states' driver's licensure processes. The United States currently uses an "opt-in" system for organ donation, requiring "concrete action" from citizens to declare their intentions to donate [2]. An alternative option in the US is "mandated choice"; for example, in 2006, Illinois passed a first-person consent law, according to which citizens are required to indicate legally binding organ donation preferences when registering or renewing their driver's licenses [2]. In contrast, some European countries such as Spain, Belgium, and Austria use an ["opt-out" system](#) [2] in which consent to donate is presumed [3]. This presumed consent model generally applies to all organs; a model is termed "soft" if family views are taken into account or "hard" if only the patient's wishes are honored [3]. A 2006 study that followed the organ donation rates of 22 "presumed consent" countries over a 10-year period found that, after correcting for other determinants impacting donation, "cadaveric donation rates [were] 25-30% higher on average in presumed consent countries" [4]. This study suggests that increased organ donation rates are due to legislative changes, but the

impact of social media and ethical constraints of presumed consent laws are not discussed. The influence of social media on our daily lives cannot be denied, however, and the current technology-driven social and cultural landscape gives rise to numerous ethical issues in transplant medicine, which are discussed here.

### **Current Guiding Principles for Organ Allocation**

In the summer of 2015, the Organ Procurement and Transplantation Network (OPTN) and the United Network for Organ Sharing (UNOS) released a white paper outlining some ethical principles that can guide organ allocation [5]. In the paper, practical utilitarian considerations, such as the need to maximize quality-adjusted life years (QALYs) and to minimize harms such as morbidities, complications, and mortality, are balanced with attention to justice. According to the report, “Factors to be considered in the application of the principle of justice are: 1) medical urgency; 2) likelihood of finding a suitable organ in the future; 3) waiting list time; 4) first versus repeat transplants; 5) age; and 6) geographical fairness” [5]. UNOS also emphasizes that the organization “has long opposed donations directed to a social group (based on race, religion, gender, or sexual orientation)” [5]. Patient autonomy is given less weight in conflict resolution, since the authors do not consider this principle often to be in disagreement with utility and justice [5].

### **Ethical Considerations about Organ Procurement**

Although the OPTN/UNOS paper unequivocally states that an autonomous decision to sell organs for profit is unethical [5], not much is said on the topic of organ procurement, which is just as ethically significant as deciding where organs will go. Because organ procurement interferes with patients’ death processes and bodily integrity, it must be deliberated upon from an ethical point of view, just as we deliberate upon organ allocation. For organ donation and procurement, respect for patients’ autonomy becomes the foremost ethical principle, to be carefully balanced with justice and equality. Utility seems to be less important to consider in procurement than in allocation, since the need for organ donors is the driving force behind procurement. In addition to these ethical principles, I propose that confidentiality should also be considered in deliberations about ethical procurement of organs. In the following paragraphs, I will explore the application of these ethical principles to organ procurement, focusing in particular on how social media in moderation can be a strong tool for increasing organ donation and spreading awareness about organ procurement practices.

### **Autonomy: Is Social Media a Help or a Hindrance?**

A goal of the transplant community is to increase organ donation as much as possible, preferably through mass media campaigns [6]. If more people are registered as organ donors before life-threatening events, it might be easier for medical teams to discuss organ procurement with shocked or grieving family members. A patient’s prior indication of donation preferences could help medical care teams, including a patient’s family

members, fulfill the wishes of the deceased patient. The decision to donate rests solely with the individual and requires informed consent, which is what some national initiatives, such as the HHS Organ Donation Breakthrough Collaborative, strive to facilitate [6]. In this respect, social media could influence organ procurement by giving patients a nonlegal and generally accessible platform to use to express their wishes.

In 2012, Facebook announced that its 150 million users now had the option to indicate their organ donor statuses on their “Timelines” and share that life event with their extended friend networks [6]. Upon selecting their status as an organ donor, users are given a link to their state organ registry (if possible) to officially sign up. Researchers found that on the first day of the new initiative, approximately 13,054 users (who upgraded to the Timeline feature) updated their organ donor profile, representing a 21.1-fold increase in online donor registrations from the baseline rate [6]. Although it slowly diminished over the next 12 days, the substantial increase in registrations from baseline was termed “the Facebook effect” by Cameron et al. [6]. In contrast, state driver’s license signatories’ registration rates (control data for comparison from four states) remained relatively unchanged from baseline during the same period [6]. This study showed the powerful, immediate impact of social media on donor registration rates, especially on a social platform where the effect of one update can multiply across a vast social networking tree.

The organ donor profile on Facebook also has worldwide implications. In countries without registries, a Facebook profile might be the only document specifying an individual’s intentions [6]. Some critics who contend that media campaigns such as these lack transparency and act as propaganda fail to understand that these organizations’ goals are to educate the public and provide individuals ready access to information so they can make better informed decisions; the platform happens to be social networking sites [7, 8]. Profile updates can prove useful in advanced care planning, by helping care teams learn something about patients’ wishes.

### **Coercion and Organ Trafficking**

As evidenced above, social media has been shown to be a powerful tool to spread awareness and motivate action. However, social media also has the power to enable illegal and unethical practices in the realm of organ procurement, specifically organ trafficking. With organs being in such short supply in the United States, desperate people in need of a transplant turn to international black markets as a source of organs and transplant surgery [9]. Anthropologist Nancy Scheper-Hughes, founder of Organs Watch, an organization dedicated to tracking kidney suppliers worldwide, highlights the risks “transplant tourists” are willing to take to “purchase a stranger’s kidney” [9] and the vulnerable states of kidney sellers. She calls organ trafficking “international organized crime” involving patients, sellers, travel agents, brokers, lab technicians, “outlaw surgeons,” and more, defying laws and professional codes of ethics [9].

The sale of human organs is deemed unethical by UNOS [5] and illegal by the National Organ Transplant Act of 1984 [10], directly violating the principles of justice and, in some instances, respect for autonomy. Organ donation is often thought to be an [altruistic](#) act, carried out after [voluntary](#), informed consent [7]. The decision to sell an organ, however, might be colored by coercion, blackmail, or financial need, calling into question free decision making. For example, a desperate family could coerce and be willing to pay an individual for an organ, knowing that the donor could be poor. [The sale of human organs](#) could establish a free market system that unjustly allocates human organs to the highest bidder, widening health care disparities and violating the principle of justice [5].

A startling example of such coercion and violation of human rights is an organ procurement strategy used in China. A Chinese national law in 1984 legalized organ harvesting from executed Chinese prisoners for transplantation, with “consent” obtained seven days prior to execution after sentencing by a court of law [11]. Aside from the probable coercion occurring during the consent process, the use of vulnerable prisoners as organ farms is morally reprehensible, since members of this population lack many basic rights and the power to refuse without ramifications. A 2006 investigation by David Matas and David Kilgour [12] revealed an “on-demand organ harvesting system” [13] at the Falun Gong prison, allowing Chinese physicians to advertise a two-week waiting period for organ transplantation. This shortened wait time, compounded with social media access, has made China a frequent destination for transplant tourism [14].

This example underscores that, ethically and clinically, how we procure organs is just as important as how we allocate them. A person’s autonomy should not be violated for free market trade, especially if the commodity is traded without consent and at high risk to the person’s well-being. It is of utmost importance to respect the sanctity of autonomy and avoid coercive behaviors in gaining consent.

### **Maintaining Justice with Living Donors**

Although the majority of organ donations come from deceased donors, a growing number of people have opted to become living donors of certain organs and tissues, such as liver, kidneys, bone marrow, and skin. According to HHS, single kidney donations are the most frequent living organ donations [15]. Although the decision to become a living donor might be completely autonomous and altruistic in intent, the donation must abide by certain ethical principles—namely, justice—that in practice can be undermined. The Uniform Anatomical Gift Act of 1968, for example, allows families of the deceased to bypass the UNOS waiting list and direct organ donation to specific individuals [16]. This well-intentioned act inadvertently condoned public solicitation of organs outside the UNOS waiting list. As a result, websites for donor-patient matching such as [MatchingDonors.com](#) [17] have gained popularity.

These websites allow living donors to be paired with people looking for transplants through patient and donor profile webpages that permit pictures and personal biographies. This profile page set-up allows for “shopping” of potential recipients by donors, which puts the process in danger of becoming a “beauty contest” or a popularity contest that favors those with the best personal story, appealing background, or good looks [18]. This process of donor-patient matching violates the UNOS guidelines [5] and the principle of justice, which condemns discrimination by sex, race, sexual orientation, or religion. Additionally, this process of matching invites donors to establish stipulations for an organ, an unethical practice that impinges on the supposed altruistic nature of the donation. For example, one donor on MatchingDonors required the recipient not to be associated with a “killing” vocation, such as hunting or fishing [18]. In light of this phenomenon, it can be said that organ procurement should occur without stipulations and should be altruistic, without ulterior motives. In this instance, social media can act as an unfair arbiter of organ procurement by introducing popularity and social bias into the decision-making process about organ donation.

### **Confidentiality in the Social Sphere**

Social platforms are increasingly used by people seeking organs who attempt to solicit public empathy through personal human-interest stories, but sometimes patient confidentiality is put at risk. In one particular example published in *Science and Engineering Ethics*, a patient and his family were done a disservice by a social media violation of confidentiality [19]. After being involved in a terrible motor vehicle accident, an 18-year old woman experienced significant trauma, resulting in brain death. Before the family could be approached about the patient’s brain death and options for organ donation, news of the event spread via social networking sites and local media stations, prompting the patient’s friends and school to push for her organs to be donated. Unfortunately, due to this information breach, this woman’s family did not find out about her state from the hospital medical team. This case exemplifies social media exploitation of a tragic story and its use as a platform for organ donation. Social media should never influence the decision making of the medical team and family members at such a crucial time, and patient confidentiality should be upheld.

### **Concluding Thoughts**

In the course of discussion, we have established that organ procurement should be held to similar ethical standards as organ allocation, specifically with regard to respect for persons and justice. Autonomous, altruistic decision making can be aided by social media campaigns to raise awareness. But out of respect for justice and equality, organ donation via websites like MatchingDonors.com should be blinded and done independently of a patient’s background or demographics. Also, organ procurement in the setting of end-of-life care should be respected and protected from social media influences that could sway medical decision making. The power of social media should not be underestimated when it comes to coercion, illegal sales, public shaming, and peer pressure. The younger

generations thrive on social media; however, careful use of the Internet is essential to protect patient autonomy, confidentiality, and justice—a challenge that the future generation of technologically adept medical professionals should be prepared to handle. The US organ transplantation system must evolve with the times and use social media to increase organ supply and ensure an ethical and sustainable future for transplantation.

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**Gowri Kabbur** is a third-year medical student at Northeast Ohio Medical University in Rootstown, Ohio.

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