

Informative Essay:

“Just” Organ Donation

by

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Many people, including me, don't know anyone whose is spending their life in limbo between opportunity and mortality as they wait for an organ donation. Even fewer people know someone who has received an organ and had a second chance at life. Most people require a personal connection in order to become empathetic and passionate about an issue such as organ donation. Consequently, very few people really understand the problems in our organ donation system, or what the possible solutions might be. It is important for humans to be empathetic and seek out justice for unjust situations that we haven't experienced, or that our loved ones haven't experienced, including injustice in our nation's system of organ donation and reception. Justice doesn't exist in finite amounts, otherwise giving justice to some would mean less justice for others. When our communities seek justice for those who need a donation of healthy organs and tissues, it doesn't decrease the amount of justice available for others. Rather, more justice and life for the 11,000 people who will die this year before they receive an organ transplant means more justice and life for all of us. This is an issue that everyone should care about, whether or not they need an organ donation.

My mother's family is from Canada, and one of her cousins in Vancouver married a man with cystic fibrosis. Weddings are such hopeful, happy occasions, with the couple sharing their dreams for the future. I was too young to go to the wedding in 2008, but my mom told me that one of the dreams at this wedding was that George, the groom, would someday receive a double lung transplant, so he and his wife, Kim, could share a long life together. At the time of their wedding, George was functioning fairly normally as long as he received regular lung treatments, but that quickly changed. In 2010, after spending 200 days in the hospital, with his lung function dropping to 20%, George was dying. But then the call came, and George received a double lung

transplant. He hadn't been able to walk more than 20 steps before the transplant surgery, and now he bikes and runs again. He has even biked across British Columbia to raise awareness for organ transplants. After spending so much time in the hospital waiting for a transplant, he became a hospital chaplain after he got new lungs so he could continue to bless people who were living in the tension between hope and despair, a tension he understood so well. Because someone donated their lungs, George has the gift of life, and many people are blessed by his life.

Like the US, Canada is geographically large. Matching and transporting organs in a large area is a challenge. The more cooperation there is between geographical areas, the more likely it is that a "perfect match" can be made between a recipient and a donor. The problem of people waiting for organ donations needs to be changed in several ways. We need more people to donate, and we need increased efficiency in the donation process. In the US, Organ Procurement Organizations were designed as a supposedly streamlined way to procure organs for donation and match them with recipients. Instead, these organizations have been fraught with fraud, with taxpayer money being wasted and, more seriously, lives being lost. There is no accountability if OPOs are supposed to be investigating and monitoring themselves. This conflict of interest is a recipe for injustice, and the people who are suffering are those waiting for organ donations. Kidneys are the most needed organ. Medicare usually pays for kidney dialysis, so taxpayer-funded costs for dialysis would decrease if people on kidney dialysis would be able to receive kidneys. If OPOs were reformed to the point of working efficiently and honestly, it would only take 5 years for the waiting list for kidney donations decrease.

In addition to improving the transparency and efficiency of the organ donation process, we need a greater pool of organ donations. We can look at best practices in other countries, like

George's experience in Canada, to get ideas for how we could do things differently in the US.

The amazing stories of organ transplants on the OTAP website can be a catalyst for changing people's attitudes and encouraging them to make the choice to donate, but we also need systemic change.

Organ donations aren't always contingent on the death of a possible donor. Living donations are possible for several organs. Living donors can share a kidney, or a portion of their liver, lungs, pancreas and intestine. Living donors can also donate skin, blood, bone, bone marrow, and umbilical blood. One thing to change in the US is to ensure that living organ donors have their expenses cost, including childcare and lost wages. While it seems basic, the cost of retrieval of organs should not be borne by the family of the donor, whether the donor is living or expired. Some countries prohibit compensation of living donors as a way to stem organ trafficking. Other countries have vague and inconsistent responses to living donors, and yet others have legislation that covers childcare and some wages while the donor recovers from this major surgery. Many people have a seed of empathy in them and would be willing to help others if they knew there would be a support network to help them.

Another solution that would increase the number of organs donated in the United States would be for the US to have an "opt out" donation process, like Spain and the United Kingdom. People with religious or cultural reasons would be able to opt out, which is important, and there would be no disrespect for making this decision. It would be assumed that all others have consented to have their organs harvested upon their death and used to provide life for someone else. Changing to an "opt out" system doesn't mean that people will be shamed if they chose to keep their body intact after death. Education about organ donation and the normalization of

organ donation will help individuals and families be more comfortable with this process. When children in the US go to the doctor for their well-child check, the doctor asks if they buckle their seatbelt, wear a bike helmet, and are up-to-date on their vaccinations. These conversations with health care providers have helped normalize seat belts, bike helmets and vaccines. Adding a brief conversation about organ donation would normalize that process as well, so people feel informed and feel comfortable with the process.

In Australia, physicians and nurses are trained to have these conversations with patients in their clinics. They also follow up with the families of patients in the difficult and emotional time after the death of a loved one. We could do the same here in the US. Hopefully this level of investment would prevent people from feeling like the organs of their loved ones have been snatched or stolen, and family members will realize that they can give the gift of life. In hopes of improving their rates of organ donation, Australia has investigated and chosen some best practices from around the world. This includes training people to talk with family members after a loved one has died, so people understand the process and grieving families won't overturn the decision that their relative had made to donate their organs and tissue. It also includes improving the efficiency of their computer database, so it is easier to make a quick and precise match between a donor and a recipient. Organ matches are often, but not always, made within an ethnic group. An opt-out system would include all American ethnicities equally, which would hopefully balance the discrepancy between the need for and availability of organs among certain ethnicities. If there is still an imbalance in the supply and demand of a particular group, hopefully the increase of donors from other groups could compensate for this.

With an opt-out organ donation program, emergency personnel at the scene of an accident could assume that the bodies of those who have died need to be cared for in a way that would allow their organs to be harvested. Currently, even if the family knows that their loved one has registered to donate their organs, they might be distraught and forget to communicate the information. If the potential donor lives in a rural area, like we do, the closest transplant center might be several hours away, or even in a different state. An opt-out program would simplify and streamline this part of our organ donation program as emergency healthcare workers would assume that most people are potential donors.

Spain has the best organ donation system in the world for two reasons: they have a high rate of organ donation and a very efficient way of communicating between potential donors and recipients. Only 13% of people in Spain object to donating their tissue or organs. The most urgent need for organs is among children or those who will die within 72 hours. Because it is difficult to find an organ donor of a similar size and with the same blood/tissue types, these data bases are crucial. The US is a large country, much larger than Spain, so transporting organs around the country is a challenge, but we could have regional teams that coordinate these efforts. Spain also benefits from coordination with other European countries. This coordination benefits everyone in the area. Because the need for organs is so very specific, the system becomes more effective if the match is more compatible, which happens when a larger pool of people share their resources.

When our country has the potential to be “the best” at something, it is humbling when we fail to meet that opportunity, especially if the reason is not because we lack education or technology, but because of inefficiency, fraud or a lack of collective effort. The science and

research that is available in the US is terrific, such as the recent research at Stanford to measure protein in the blood and quickly treat the organ rejection. This is much more efficient than the previous treatment, which involved testing the function of the organ, and then taking a small biopsy of that organ if it wasn't functioning well. Another improvement is in understanding and treating diabetes mellitus after a transplant, which can affect up to 40% of organ recipients. Participating in the research and treatment of organ transplants is an amazing opportunity that most people will never get to participate in. However, anyone, with any career or degree, can contribute to a better system or organ donation registering to donate! Unlike researchers, doctors and nurses, the average person rarely gets an opportunity to help someone with a severe medical need. Lawmakers and people advocating for organ donation can improve the health of many people without any experience as a health care worker. Improving our nation's system of organ donation is an opportunity for people outside of the healthcare industry to impact the health of many people's lives.

Unfortunately, many kinds of injustice exist in the world. When people feel frustrated and angry because there is nothing they can do to change a situation in their life, some variety of injustice is probably impacting them. In these situations, victims of injustice usually rely on other people to use their power to step in and change things for us. The world is filled with people who passionately advocate for those oppressed by injustice. Caring for others seems to be a universal characteristic. Organ donation is an opportunity to utilize that empathy to extend care and compassion beyond our own lives, an opportunity to provide hope and redemption in a time of death. Compared to other global issues of injustice, it should be relatively easy to fix the problems of the organ donation system. This would have a positive impact on not only the

thousands of people who would receive donations, but also on living donors and on the family members of people who donate. A better, just organ donation system would improve our healthcare system as a whole, provide life for many individuals, and be something that our country could be proud of.

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