Why the U.S. Should Change to an Opt-Out System for Human Organ Donation

by
Lacee Louise-Joy Rainey

A THESIS

submitted to
Oregon State University
Honors College

in partial fulfillment of
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Honors Baccalaureate of Science in BioHealth Sciences
(Honors Associate)

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Courtney Campbell

In the U.S., the number of people waiting for an organ donation is increasing exponentially while the number of registered donors is slowly rising. This discrepancy leads to a great number of people dying while waiting for an organ donor. The opt-in system, lack of education around donation, and having to use personal time to register are just a few of the factors that prevent people from registering as organ donors. Some alternatives to the opt-in system have been suggested, but only one, the opt-out system, has been deemed ethically acceptable and possible based on the values of the U.S. Other countries have instated the opt-out system, being automatically registered as an organ donor, and have greatly improved their number of donor registrants. However, switching to the opt-out system in the U.S. would be difficult without education to supplement the change. Education within schools, doctors’ offices, and online resources can inform the public of organ donation at the same time legislation is being passed for an opt-out system. This greatly needed change in the U.S. is for the purpose of decreasing the gap between a shortage in supply and a high demand and to ultimately save peoples’ lives.

Key Words: Opt-in System, Opt-out System, Education, Organ Donor, Registered Donor

Corresponding e-mail address: raineyl@oregonstate.edu
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APPROVED:

________________________
Courtney Campbell, Mentor, representing the College of Liberal Arts

________________________
Marie Harvey, Committee Member, representing the College of Public Health and Human Sciences

________________________
Margaret Dolcini, Committee Member, representing the College of Public Health and Human Sciences

________________________
Toni Doolen, Dean, Oregon State University Honors College

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Lacee Louise-Joy Rainey, Author
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Prologue

As a future physician, issues related to the medical field are of upmost importance to me and are ones that I value with great pride and joy. Organ donation in the U.S. is a topic that caught my attention because of its ability to save lives using the contribution made by fellow Americans. With medical advancements and technology prolonging peoples’ lives, organ donation is a discussion more relevant now than ever before. The lack of awareness and public attention that the topic has received in the U.S. astounded me and inspired me to go forward with my research. I have found the research and discussions with others to be exciting and helpful in moving the topic one step closer to seeing change.
Introduction

A little girl sits on her father’s lap, her head laying on his chest as a soft tear rolls down her cheek to meet the collection that has gathered into a puddle on his shirt. The father holds his daughter, but his gaze is blank, empty, and desperate as his eyes stare off into the distance. He wears a wedding ring, one that matches the ring worn by the woman lying in the hospital bed across from him. The woman is still and lifeless, having just lost her fight to a disease that had been tormenting her for two years until her kidneys couldn’t handle the strain and weight of the world anymore. Machines and monitors surround her in an impersonal room of unfamiliarity, but the waiting and desperation for a glimpse of hope were an all too familiar and growing experience for her family. She waited patiently for a kidney transplant, but a donor was never found. The family is now left to face the despair and loss of their loved one, to stumble through their mourning and grief when one kidney could have saved her life.

This story, like many others, are undeniable realities for families all across the U.S. who lose loved ones due to the shortage of access to donated organs. In 2016, 7,000 people on the waiting list passed away (UNOS, n.d.). Yet, people often do not take the time out of their day or go out of their way to register as an organ donor. The opt-in system, having to actively choose to become a donor, and poor education are what prevent many people from becoming donors. Therefore, an opt-out system, being automatically registered as an organ donor and having to choose to unregister, and education about organ donation would help contribute to a rise in donors in the U.S. and thus, an increase in the amount of lives that could be saved. The donation of organs and
tissues from one individual can save eight lives; imagine how many more could be saved if a change was made.

Choosing to donate an organ is a sizable decision for anyone. Ultimately, the altruism that is connected to actively choosing to give up one’s organs is what makes organ donation at all possible in an opt-in system and an individualistic culture such as the U.S., as will be discussed in Chapter 1. Nonetheless, many people talk themselves out of donating due to the assumption that someone else will do it or that they do not need to. However, currently 115,000 people are waiting for an organ transplant and only 33,600 transplants that occurred in 2016 (UNOS, n.d.) There are about 326 million people living in the U.S. and although not everyone can register as a donor due to health or religious reasons, there are a large number of people who can register and have not (QuickFacts, n.d.). More donors are needed and the opt-in system is no longer the optimal choice for obtaining those donors.

In an opt-in system, organs are retrieved based on an individual’s choice to donate. If people do not take the active measures to register to donate their organs during their lifetime, then their families may be asked by an organ procurement organization representative about donating the organs of their deceased family member. The opt-in system simply does not account for the limited number of donors and time that are crucial to the process of organ retrieval and transplant. The contributing factors leading to the scarcity of donors will be discussed in Chapter 2.

Although a change to the opt-out system may be the most ethical way to increase donor rates, it is not the only option. There are other alternatives that have been considered by the President’s Council on Bioethics, as discussed in Chapter 3, that could
be made legal to try and increase the number of registered donors. However, for current policies in the U.S. and American culture, the primary discussion is about shifting from an opt-in system to an opt-out. Although the U.S. does have the highest rate of donors for a country on the opt-in system, there are countries with even higher donor rates and each of them is using an opt-out system in addition to campaigns, education, and other methods (Rudge, Matesanz, Delmonico, & Chapman, 2012). Thus, I think the U.S. could learn from other country’s practices and systems and improve upon them in order to increase its donor numbers.

The most effective approach in the U.S. to increase donor rates and save lives includes, as discussed in chapter 4, normalizing education on the meaning of being an organ donor and changing legislation to reflect an opt-out approach. Children should be educated in schools as part of their health classes and given assignments to talk about organ donation with their families. It should be a topic of discussion at doctor’s offices, as doctors could ask if their patients are donors, if they have questions about it, and be able to provide more information on it. Currently, the organ donation process is not discussed and often goes on without any awareness by the majority of the country, a fault that should be corrected.

As with any change in legislation versus education, there will be push back. Clearly defined exemptions and accommodations will be needed for those who either cannot donate or choose not to; how to do so will be discussed in Chapter 4. Education and clear communication on how every person is protected and that only once brain or cardiac death has been determined will an individual’s organs be procured. Additionally, the idea of altruism should still be conveyed as choosing to not unregister as an organ
donor is still choosing to be an organ donor. Families can still be very much involved and should be involved in educating their children and talking about what being a donor means. The opt-out system and education will simply work toward increasing the number of organs retrieved in a short period at a time of high organ need.

Organ donation is not an issue that is directly accessible to everyone. Instead, it seems to be an issue that just hangs in the clouds, first realized by people when they sign for their driver’s license at the DMV, a similar experience to mine. It is not an issue that is given time and explanation in a school setting or in pamphlets to reach all generations and walks of life. Therefore, education around organ donation would provide the public with the understanding and awareness of the donor process. Additionally, operating on an opt-out system would help increase the number of donors rapidly. Together, education and an opt-out system can lead to more lives saved and more lives lived.
Chapter 1: The Opt-In System in the U.S.

The world of medicine is exponentially evolving in its ability to eradicate diseases, perform surgeries with innovative technology, and ultimately cure patients. Vaccines have wiped out diseases such as polio, the mumps, and the measles, more and more battles with cancer are able to be fought and won, and medications are supplied for everything from preventing pain to clearing up allergies. Even though there are some communities of people who have fought against the changes and scientific evidence, the majority of people have supported it. With these kinds of advancements and growth in the medical field, it makes me wonder why parts of medicine have failed to upgrade, such as human organ donation. In 1991, there were only 6,953 organ donors in the U.S. with 23,198 individuals waiting for an organ and 15,756 transplants were performed (Organ Procurement and Transplantation Network., n.d.). In 2017, the number of registered organ donors almost tripled, reaching 16,473, and almost 35,000 transplants were performed, just over twice as many transplants as were performed in 1991 (Organ Donation and Transplantation Statistics: Graph Data., n.d.). Although the number of registered organ donors and transplants performed have increased, the number of people on the waiting list for an organ has grown by five times reaching 115,759 individuals, a record high, with the majority of people waiting for a kidney (Organ Donation and Transplantation Statistics: Graph Data., n.d.). The demand for kidneys in the U.S. has significantly increased due to the prevalence of diabetes and hypertension which cause stress on the kidneys and eventually lead to chronic kidney disease (UC Davis School of Medicine, 2016). Comparatively, the number of registered donors and transplants performed are increasing at a rate insufficient to meet the demand of organs needed
throughout the country. Unfortunately, it is not likely that this gap between registered organ donors, transplants, and the number of individuals on the waiting list will become any smaller without more attention to the issue and a change in policies to the current system.

What are the current policies in the U.S. for organ donation and what do they look like? The U.S. currently operates on an opt-in system for organ donation which means people have to make the conscious decision to register as organ donor and then take the time to sign up either online or at their local DMV. In other words, the default is that no one is a donor until they decide to be and then register to become one. This opt-in system helps provide a sense of security and comfortability with one’s body, an assurance that individuals still have control over what happens to them once they pass. It also allows people to feel like the choice to donate is still personal and that choosing to donate is a gift and an altruistic act, all of which they are in complete control. Yet, the process of registering as an organ donor is impersonal and somewhat foreign to a nation that is only made aware of the idea of organ donation when registering for a driver’s license. At this time, no government issued pamphlets of information are provided to people, no statewide education around organ donation has been provided in schools, and it is more likely than not that families have not discussed organ donation at home. So, asking an individual whether or not they would like to donate their organs in the setting of a DMV when they have no background about donation is unproductive, misplaced, and actually a bit morbid and is more likely than not going to result in people declining to register as donors.
Although 97% of organ donors register through a DMV and the three largest modes for registering are first time drivers, new residents, and current residents who chose not to register before, the efforts of the DMV alone are not enough to register the number of donors needed to match the number of organs that are needed nationwide (Donate Life America Announces 100 Millionth Organ, Eye and Tissue Donor Registered in the U.S., 2011). As of 2018, about 54% of Americans are registered as organ donors, however, over 116,000 people are waiting for an organ (Information about Organ, Eye, and Tissue Donation., n.d.). Comparatively, in many surveys conducted throughout the U.S., 95% of adults support organ donation and believe that more people should be donors, but many of those same people were not registered as donors themselves, an example, I think, of the inefficiency of the opt-in system (Information about Organ, Eye, and Tissue Donation., n.d.). It takes less than ten minutes to register (I know since I recently helped my mom register), yet, even that dedication of time is too much of a hassle in the American fast paced life style. Additionally, many adults who support organ donation may not be allowed to register as donors due to their own health conditions. However, a large majority of people do not register because they do not understand the process of organ donation and what it means to be a donor and, therefore, refuse to register. Thus, all of these factors, time, health conditions, and lack of education, are barriers to increasing the number of registered donors, but time and education are two factors that can be adjusted by a change in policy.

It is not entirely surprising that more people are not organ donors within a highly individualistic culture; getting to choose to donate one’s organs fits the individualism within the U.S. Part of the disparity between the number of registered donors in an opt-in
system versus the number of registered donors in an opt-out system is due to the context and frame of mind that surrounds the process of donating an organ. Research has shown how the views on donating an organ from people in opt-in and opt-out countries differ (Davidai, Gilovich, & Ross, 2012). For example, Americans think of donating an organ as a substantial action in the way of saving someone’s life. Participants equated donating an organ to leaving behind 50% of their estate to charity (Davidai et al., 2012). On the other hand, participants from opt-out countries thought it was a bigger deal to decide not to donate an organ; opting-out is viewed as an action that deems the individual an outcast from society (Davidai et al., 2012). It seems to me then, that in order for Americans to be on board with implementing an opt-out system, there would need to be some way to make the act of not opting-out as substantial as opting-in until the opt-out system became normalized. This could be done by an informational pop up that appears when people choose to unregister, telling people of the lives they could be saving or the hopes and dreams that they are taking away from their fellow Americans by choosing to opt-out. People are thinking of themselves, how to best better their own lives or the lives of those who are immediately connected to them. Getting to choose to donate one’s organs is almost the same as the largest financial burden experienced in one’s lifetime, an extreme sacrifice that should be acknowledged and recognized as such. An opt-out system fits more of the ideals of a collectivistic culture where individuals are continuously thinking about the needs and concerns of others and not the recognition associated with their actions. However, Americans can be taught and persuaded to begin thinking like this, thinking of others. It would take time to adopt these similar thinking patterns, and thus behavior changes, as collectivist cultures, but I believe it is possible.
Although an opt-out system may appear more fitting for a collectivist culture, people in the U.S. also find great pleasure in altruistic and generous acts. To consciously make the decision to put someone else’s life and well-being before their own is something people value and makes them feel good about their actions. As with generosity, people want to feel like they are making an effort to donate, like they are giving their organs away as a gift, but an opt-out system would take that away from them as the gift has already been given for them. Opt-out pushes the boundaries of the level of control we like to think we have over our bodies. Choosing to willingly sign up to donate one’s organs, to give them to others, to save a life is selfless and takes a conscious effort to help others. However, donating organs within an opt-out system can still be altruistic and an act of gift giving. By choosing not to unregister as a donor, a person is still choosing to donate and those who were unable to take the time to register before need not worry about the time in an opt-out system where they are already registered. In a society where the disparity between donors and the waiting list is only expanding, framing organ donation and altruism in this way within an opt-out system is a feasible option for increasing the amount of registered organ donors.
One organ donor can save eight lives, yet twenty people die every day in the U.S. waiting for an organ transplant (Information about Organ, Eye, and Tissue Donation., n.d.). Why is it that more people do not feel compelled to register as organ donors? In this chapter, my analysis will focus on four key reasons for low organ retrieval: lack of awareness, a culture of individualism, values that people hold, and the logistics of dying.

In the U.S., people are unaware of the need and process of organ donation. It is not an issue that is relevant to the majority of the public and with no education provided, individuals are not seeking out information on the donation process or the need. Most people only know about organ donation from how it is portrayed on doctor shows on television, which is more often than not misconstrued for dramatic effect and to draw the audience into the story. These shows often choose extremely rare cases or completely make up a scenario in which organ donation was involved. People then take these stories and generalize them to the whole experience and concept of being an organ donor. Unfortunately, the media has a strong influence over framing and presenting issues to the public and when it comes to real life application, people will turn to the media for answers on what they should or should not believe which will influence how they will or will not act (Morgan, Movius, & Cody, 2009). Simply witnessing horrific events related to organ donation is enough to convince people to protect themselves from those situations, most easily done by not registering as an organ donor (Morgan, Movius, & Cody, 2009). However, how can people be expected to know these stories are inflated and inaccurate representations of human organ donation when they are not being educated or made aware of what being an organ donor means or truly looks like? The
truth is, they cannot be expected to know the difference other than using their own discretion. The majority of people, however, could not explain how organ donation in the U.S. works or what it looks like practically to be a donor.

Even some of those who are aware of the need of organ donors and the process of donation hold onto the individualistic nature of American culture. Individualism entitles people to freedom of choice and action outside of governmental control and provides a sense of authority over oneself. Our culture values autonomy, we value getting to make our own decisions and actions independent from what anyone might tell us to do or decide for us. But being automatically signed up to donate their organs away may seem forceful to some people and impeding on their autonomy. Therefore, choosing to help others or contributing to the greater good are acts of altruism that people view as giving back to society, for going out of their way during their busy schedule to change the world around them.

In 2006, the Uniform Anatomical Gift Act allowed states to create donor registries (Wynn & Alexander, 2011). People could now express their desire to donate through the registry. This act gave people the final word over their own organs and they did not need to rely on family members to decide to donate their loved one’s organs or not (Wynn & Alexander, 2011). However, the early success that state registries had has not been sustained and there is continual growth of disparity between the need and access of organs (Wynn & Alexander, 2011).

Other factors that contribute to low donor registration rates were outlined in a study that found common values within qualitative literature that played a large role in peoples’ decisions (Irving et al., 2011). These values include relational ties and personal
connection to organ recipients, religion, culture, family influence, body integrity, and mistrust of the health care system (Irving et al., 2011). The first of these was relational ties and the consensus from the literature that people were more willing to donate an organ to a relative in need than they were to donate their organs after death (Irving et al., 2011).

A second factor concerned religious beliefs, which has a mix of understandings as to what is the correct view: to donate or not. Some religions or individual religious people believe that organ donation is a way of trying to be God and that if someone is dying, then God meant for them to die (Irving et al., 2011). Others believe that nothing was meant to be wasted and that includes organs, so if they can be donated, then that fits into their religious views (Irving et al., 2011). Most of all, however, some religious people believe they need a whole body in order to pass on to the next life and removing organs for donation would prevent that passage (Irving et al., 2011).

The next common theme was cultural beliefs. There are many cultures that believe in certain rituals and grieving processes after a person’s death and organ donation would only interrupt the process (Irving et al., 2011). Family influence is always a large part of many of the decisions that we make, including organ donation. It is less likely that a person will become an organ donor if their parents or siblings are not donors (Irving et al., 2011).

Another factor concerned body integrity. Some people were afraid their families may be traumatized by the thought of their loved one having been cut up and that their decision would impose upon the idea of an open casket funeral (even though it would not), which some people want (Irving et al., 2011). Another theme was mistrust in the
health care system. Some people think that if they become donors, then doctors will not provide them the same care as they would to non-donors as doctors just want to harvest their organs (Irving et al., 2011). Some people do not believe their post mortem bodies would be treated with the same kind of respect if they were a donor and others were afraid their organs would go to undeserving people (Irving et al., 2011).

Many people do not understand or overlook the fact that even though someone is registered as an organ donor, this does not guarantee they will get to donate their organs to people in need. Many people who register as organ donors die of old age and thus, their organs are not able to be passed on. Other donors die in accidents and their organs cannot be procured before the time limit for viable organ retrieval has expired. Some people are afraid that doctors will not try as hard to save them if they are signed as an organ donor, but that is a large misconception. Organs are only procured from an individual when brain or cardiovascular death is declared. In the US, brain death is legal death: no one has ever recovered from brain death (Siminoff, Burant, & Youngner, 2004). However, many people still do not fully understand what brain death means. Without the medical advancements that we have now, specifically ventilators and heart pumps, brain and cardiovascular death would just be death. The only reason the person is still “breathing” or “living” is because they are on a machine, and without it, the rest of the body would shut down and the person would pass. However, if the other organs shut down and the person dies, then the organs cannot be donated to save other people. Thus, people are kept on ventilators and declared brain dead or cardiovascularly dead in the hopes that the family will donate the individual’s organs. There are other types of brain injuries that make understanding brain death confusing. Comas and persistent vegetative
states involve some sort of injury or trauma to the brain, but are not legally the same as
death (Siminoff et al., 2004). This difference can be confusing to people when they are
addressed to donate their loved ones’ organs. If they are unable to separate the difference
between brain death and a coma, families may think that they would be killing their
family member if they were to allow their organs to be procured.

Due to the large disparity between need and accessibility of organs, hospitals
began to be required to contact their local organ procurement organization (OPO) as soon
as possible about a recently deceased patient so as many organs as possible can be
recovered to help save others (Wynn & Alexander, 2011). OPO and trained hospital staff
are now also required to approach the family of the deceased about being willing to
donate the organs of their deceased loved one in order to save the lives of others in need.
Although these actions and attempts on behalf of OPOs and hospital staff seem as though
they would help in closing the disparity gap, the annual number of organ donors in the
U.S. only barely increased (Wynn & Alexander, 2011).

A group of experts known as the Organ Donation Breakthrough Collaborative
gathered in 2001 in an attempt to identify the characteristics and practices of OPOs that
have high organ donation rates and use those to train other OPOs to also utilize those
practices (Wynn & Alexander, 2011). OPOs, donor hospitals, and other organizations
were trained and informed, yet, their efforts fell short and their high goals of increasing
donor rates were not very close to being met (Wynn & Alexander, 2011). Thus, the
Collaborative encouraged the Institute of Medicine to allow organ donation after cardiac
death to be an acceptable form of human organ donation, and they did (Wynn &
Alexander, 2011). Because organs are so scarce, Collaboratives, UNOS, and doctors are having to find new ways in which they can recover organs from deceased patients.

Kidneys are the organs in the highest demand in the U.S. (Wynn & Alexander, 2011). The requirements to be an eligible donor were expanded in an attempt to save more lives and close the gap between need and availability. A special classification group was created by the United Network for Organ Sharing (UNOS) called Expanded Criteria Donors (ECD) that allows any patient over age 60 to be an eligible organ donor and patients over 50 who have either had a history of high blood pressure, a creatinine level greater than or equal to 1.5, or death caused by a stroke to also be eligible donors (Wynn & Alexander, 2011). These patients are clearly not the most ideal sources for high functioning, normal kidneys, but the circumstances in the U.S. are driving UNOS and other organizations to their absolute limits and people are desperate to receive organ transplants. Recipients of ECD kidneys are informed of the fact they are receiving an ECD kidney and it is quite possible they will need another kidney transplant in the future from a non ECD donor (Wynn & Alexander, 2011). This ECD group is merely buying people time on the waiting list for a high functioning, healthy kidney. However, the number of discarded kidneys donated by someone classified as ECD is extremely high, so high in fact that the classification is having to be revised to insure a higher compatibility and successful transplant rate between donors and recipients (Wynn & Alexander, 2011). Unfortunately, this is going to exclude more people and make it very hard for people to become kidney donors.

Only about 3 in 1,000 people die in a way that allows for their organs to be donated and threats to health eliminate potential donors from an already limited pool of
volunteers (Information about Organ, Eye, and Tissue Donation., n.d.). Unfortunately, a combination of lack of awareness, individualism, personal values, and the logistics of dying prevents more people from joining the efforts to save potentially thousands of lives. Some people believe that if they do not choose to donate that somebody else will and easily dismiss the difference they could make. Be that as it may, the slow increase in donor rates and the exponential growth of the waiting list will ultimately lead to thousands of lives wasting away, waiting for an organ with a false reality of hope.
Chapter 3: The Alternatives

With the rapidly increasing organ donor waiting list and the slowly growing number of registered organ donors, alternative solutions to the opt-in system have been debated for how to increase the number of available organs for transplantation. The President’s Council on Bioethics (PCB) identified seven possible alternatives to the current giving and retrieving of the opt-in system: body conscription, unrestricted autonomy, state mandated protection, honoring and shaming, paying and providing, selling and buying, and the opt-out system (The President's Council on Bioethics, 2003). The PCB then divided these seven alternatives into ethically unacceptable and ethically acceptable categories based on five core values that Americans consider important when determining to register as an organ donor and would contribute to the success of the alternative donation system. These five values include respect for donor wishes, respect for the body, the importance of altruism and valuing donation as giving a gift, equal access to and fair allocation of organs, and the ultimate goal of saving lives (The President's Council on Bioethics, 2003). With these five values determined, body conscription, unrestricted autonomy, and state mandated protection were all categorized as ethically unacceptable alternatives to the current opt-in system (The President's Council on Bioethics, 2003). The remaining four alternatives, honoring and shaming, paying and providing, selling and buying, and the opt-out system, are all ethically acceptable alternatives and thus, could each potentially be successful in raising the rates of registered donors.

The first of the ethical alternatives is honoring and shaming. This alternative would award individuals, or their surviving family members, with medals or ceremonies
to recognize their donation (The President's Council on Bioethics, 2003). At the same time, individuals who do not donate their organs and their family refuses to donate their loved one’s organs would be subjected to shaming by means of the government informing the community of who did not donate their organs. It would seem then that this model could be easily adopted in the U.S. as American culture has grown to award individuals for merely participating in different groups. Everyone receives a trophy for playing on a team or receives a certificate for being in the band or receives a ribbon simply for their participation. I think it is actually kind of ridiculous how we award everyone to help make them feel good, but it is imbedded in our culture to award everyone for simply partaking in something. So, organ donation could be treated just the same. However, the reason for donating may simply become reflective of individuals wanting themselves or their families to be publicly recognized for their good deed rather than about the good deed and altruistic act itself. Additionally, some individuals have medical conditions or religious beliefs which prevent them from donating but should not subject them to shaming. Thus, although honoring and shaming may be ethically acceptable on some levels in the U.S., it goes against the values of equal access, viewing donation as strictly gift giving, and keeping the idea of saving lives as the primary goal as opposed to mere recognition.

The second ethically acceptable alternative is paying and providing. Paying and providing is also known as rewarded gifting in which individuals are compensated for their donation. Compensations could include full or partial reimbursement for funeral costs or could be in the form of tax credits or rebates (The President's Council on Bioethics, 2003). However, compensation would only be given to those, or to the family
of those, who are deceased donors, no compensation would be given for an organ from a live donor because that would be purchasing an organ (The President's Council on Bioethics, 2003). This alternative also takes the attention off of the idea of donation being a gift and turns it into a system of financial reward and families debating giving away the organs simply for the compensation. There would also be the same problem of exclusion of certain groups of people with this alternative, similar to the first alternative. Those with certain religious beliefs and medical conditions still cannot register to donate and, thus, they are not eligible to receive any compensation. Additionally, not everyone who signs up to be a donor is actually an eligible donor. Sometimes people’s organs are just not usable or transplantable after they die even if they are registered as a donor.

Therefore, does the person who signed up but could not actually donate get compensated? And what if someone is not registered but the family willingly allows the doctors to procure the organs of the deceased loved one, does the family get rewarded? And who would determine if the donation was worth the compensation of full burial prices or half, or how much tax credit to reward? The federal government? State government? The people? Having to compensate people to be donors though, in the long run, may become costly, and organ transplants are already a lengthy and expensive process.

The third ethical alternative is the selling and buying of organs in a free market. A free market of organs, a system in which vendors can buy, sell, and trade organs and in which individuals in need of an organ have the opportunity to pay for one is a system of business that the U.S. is already familiar with (The President's Council on Bioethics, 2003). This alternative seeks to expand autonomy over one’s body or over a family member’s body by allowing people to sell their organs before or after death. This
approach turns the whole body into property that can be bought and sold. However, just because the opportunity to purchase an organ is presented does not mean that individuals have the ability to pay for one, reflecting the disparity in incomes of the U.S. economy (Organ Donation: Opportunities for Action at NAP.edu., 2006). Additionally, poor individuals may be more willing to risk their lives to donate an organ in order to receive money they need for every day survival, a system which seems completely backwards (Organ Donation: Opportunities for Action at NAP.edu., 2006). A free market system with a lack of adequate education may also lead donors to underestimate the risks of donation and merely participate as a financial means, opposing the values of gift giving, body integrity, and saving lives (Organ Donation: Opportunities for Action at NAP.edu., 2006). Either way, a free market system would not necessarily close the gap between the number of donors and the number of individuals on the waiting list due to the risks involved in donation, even for a financial incentive, and the disparity of wealth in the U.S. economy.

The final ethical alternative is the opt-out system, which I believe is the only approach that would be fair to everyone and the most easily implementable. This alternative has the ability to save the most amount of lives in the shortest amount of time. The opt-out system is merely the reversal of the opt-in system: instead of choosing to become an organ donor and having to register, one would automatically be a donor and would have to unregister if they decided they did not wish to be a donor or could not be a donor due to medical conditions or religious beliefs (Organ Donation: Opportunities for Action at NAP.edu., 2006). The process to opt-out would be just as accessible as opt-in, by going online and unregistering. A criticism of this system includes people feeling like
they do not have a say over their own bodies. However, people have just as much say over their own body in the opt-out system as they do in the opt-in system, the process is merely reversed. Another problem faced with switching to the opt-out system is taking away the altruism that is highly valued in U.S. culture and its association with deciding to donate one’s organs. However, it can still be considered an act of altruism to decide not to unregister as a donor and therefore choose to continue to be a donor. Thus, I believe that the opt-out system is the most ethically justifiable for American culture.
Chapter 4: Opt-out and Education

The need for human organ donation is one that spans the globe. Countries all over the world are attempting to practice recovering and transplanting human organs in order to save lives. Two world-known organizations, World Health Assembly and World Health Organization, are at the forefront of a global agreement of international response needed to increase the number of organs donated. Traditionally, organ donations are expressed as donors per million of population (pmp). In 2009, the USA came in fourth for the number of human organ donations, landing right around 25 pmp, trailing Spain, Portugal, and Belgium (Rudge et al., 2012). However, these numbers only provide the number of potential donors, not the number of actual donors that come out of the pool of potential donors. These three countries, Spain, Belgium, and Portugal, all have one thing in common: they operate on the opt-out system. Countries like these that made changes from opt-in systems to opt-out would not have been successful with increasing the number of donors if they had not also coupled the change in legislation with an additional change such as educating the public or reorganizing the structure of communication within hospitals (Kennedy et al., 1998). Thus, simply working to change to an opt-out system in the U.S. with no education implemented or awareness promoted would surely fail. That is why I propose that a change to the opt-out system be made in addition to introducing education around human organ donation in schools and information on donation being provided in medical settings such as doctor’s offices and hospitals.

In 2009, Spain reached a donor rate of 34.4 pmp, the highest in the world (Rudge et al., 2012). They were able to achieve such a high donor rate by not only changing their legislation to an opt-out system, but by coupling this change with a developing
coordination between national, regional, and hospital level organization of donation (Rudge et al., 2012). They introduced transplant donor coordinators (TDC) who worked at the hospital level and who were responsible for approaching grieving families about donating their deceased loved one’s organs (Rudge et al., 2012). As mentioned in Chapter 2, U.S. OPOs are already responsible for approaching families of deceased patients about organ donation. However, because of the opt-in system, there are not enough OPO workers available to approach all of the families who are experiencing a loss of a loved one while TDCs in Spain do not have to approach the families of those who were automatically signed as a donor through the opt-out system (Rudge et al., 2012). Thus, in the U.S., a change to the opt-out system would provide more time for OPO workers to focus on asking families of the deceased who had opted out of donating if they wish to donate their loved one’s organs. As mentioned in Chapter 2, the majority of Americans support organ donation and simply do not take the time to register and the opt-out system would be merely fulfilling their support for donating their organs.

In Belgium, there was disagreement between organ transplant centers on whether or not a change from an opt-in system to an opt-out system was truly necessary or if simply implementing education around organ donation would increase donor rates (Kennedy et al., 1998). The Antwerp organ transplant center continued with an opt-in system that was accompanied by public and professional education. On the other hand, the Leuven organ transplant center adopted the opt-out system without any additional education (Kennedy et al., 1998). Antwerp’s organ donation rates remained unchanged and Leuven’s donation rates increased from 15 organ donors a year to 40 in just a three-year period (Kennedy et al., 1998). Since 1986, less than 2% of Belgium’s population has
decided to opt-out of organ donation and they have the third highest amount of organ donors in the world (Kennedy et al., 1998 and Rudge et al., 2012). Thus, changing to an opt-out system in the U.S. could significantly increase the number of organ donors especially since the majority of Americans support organ donation to begin with (Information about Organ, Eye, and Tissue Donation., n.d.). However, I recognize that progress in the U.S. in increasing the number of registered donors may be more gradual than what was achieved in Leuven. Behaviors, such as choosing to donate one’s organs and be altruistic, take time to change and develop, especially in an individualistic culture like the U.S. Like Antwerp, however, I also propose that an education program around organ donation is necessary for informing the public and having all information available to everyone on the change in legislation and what it means to be an organ donor.

What would switching to an opt-out system, implementing education, and increasing general awareness of organ donation in the U.S. look like? First, a legislative change from our current opt-in system to an opt-out system would have to be made by Congress, voted upon, and passed in order for it to become the new organ donation system of the U.S. Awareness, at that point, could begin with all homes in America being mailed information about organ donation, their local OPO, and how to unregister if they so choose. Not everyone would receive the mail or even take the time to read it for that matter, but millions of Americans could potentially be reached and informed through this process than by the current system. Additionally, national and local news stations could run a segment about the new opt-out system and how other countries have had success with increasing donor rates with this system. Commercials on television could introduce
organ donation and the ability of individuals to save lives and provide a website to visit for more information.

Secondly, education on organ donation in the school system could be coordinated by legislative changes that occur at the federal or state level. Preferably, the general education would occur at the federal level, providing all states and schools, and thus students, with the same information with the only differences occurring between discussion about local OPOs. This education I see occurring in 8th and 10th grade during one or two class periods of a health class. Currently, 10th grade is generally when students have their 16th birthday and when many sixteen-year-olds are learning how to drive and obtaining their license. Thus, just as our system operates now, when an individual registers for their license they are asked by the DMV if they would like to be an organ donor, only with the change to an opt-out system, individuals would be asked at this same time if they would like to opt-out of being an organ donor. If they do not decide to opt-out, then at age 16 and registering for their license, the individual will be automatically registered as an organ donor. However, just as in our opt-in system now, next of kin will have final say over the donation of the individual’s organs until they are 18. If children do not register for their license before the age of 18, then they will be automatically registered as an organ donor on their 18th birthday and contacted to inform them of their new status and how to unregister if they so choose. Thus, educating students, and families, before this moment in time about organ donation is an essential step of changing to the opt-out system and is why at least one or two class periods at two different critical school ages is a necessary part of the process. The education could cover what organ donation is, how many lives could be saved, how many people are on the waiting list,
how doctors procure organs, what OPOs are, and maybe include personal narratives by people whose lives were saved by organ donations, or maybe by a family member of someone who passed away waiting for an organ. Schools could get local doctors to come in and speak about organ donation and answer questions that students might have. Additionally, there could be some homework assignment that requires students to talk to their parents and families about organ donation, share what they are learning in school, hear their parent’s opinions on organ donation, and simply start a conversation within households about what it means to be an organ donor. Educated students turn into educated adults which can lead to a better educated population on the process of organ donation.

Thirdly, doctors should be taking their own measures to inform their patients about organ donation. They could provide pamphlets in the lobbies of their offices and ask their patients directly if they have questions or thoughts about organ donation. They could be helping in the awareness of the general population as a medical professional and educating as many people on the topic as they can. However, the burden of educating people should not solely fall upon doctors or schools, because not everyone goes to the doctor and sometimes students skip school or do not pay attention in class. The biggest change will be made within homes and by families. Information should be continuously accessible to people online, through email, by mail, and could be made to be seen on social media if creators are willing to partner with organizations to provide information. It is possible to spread the word on organ donation, it will simply require an allocation of resources and a willingness by educators, doctors, and families to have conversations.
Of course with any policy change, there is going to be pushback. Parents may worry about their children being automatically registered as an organ donor. As I mentioned before, the process would be merely reversed at the DMV from what it is now, but hopefully the young individual will have some education on what organ donation is and the parents will have been educated as well. Now, if an individual does not register for their license at age 16 or 17, then they would be automatically registered as an organ donor at age 18, as an adult, and mailed information at such time in which they are informed they have been automatically registered, how to unregister if they choose, and information on organ donation. Before the age of 18 and if not already registered as an organ donor at age 16 or 17, the family would have the final say over their child’s organs. The process of opting-out would be made to be just as simple as the process of opting-in is now, by going online and expressing whether or not you wish to donate. This change of legislation is not meant to target or burden individuals who wish to opt-out, but is solely meant to help register more people who support organ donation but have not taken the time to register through the current opt-in system.

With education and awareness tied to the opt-out system and the successes observed by other countries that made the change, a real chance at increasing the number of organ donors and increasing the number of lives saved is possible in the U.S. It could happen, it can happen, it may just take some planning, extra resources, community involvement, and a little funding. But it is achievable.
Conclusion

Changing to an opt-out system in combination with adding education and awareness around organ donation could have a positive impact on increasing the number of organ donors in the U.S. Success of this transition would not only lead to more donors but would also result in more organ transplants and fewer people on the waiting list. Although technology and the medical field are quickly advancing with 3D printing of organs becoming more reliable and portions of cow and pig being utilized for smaller fixes, an organ transplant from another person provides real human tissues that can properly function within a person’s body.

In analyzing the opt-out system and implementing it into our legislation and schools, not all aspects of the policy change have been addressed. Perhaps one of the largest considerations that was not discussed is the financial burden that changing legislation would cause. Although changing the legislation would potentially take more time than money, mailing out information, creating commercials, providing materials for schools, and training teachers would be an investment in the organ donation process that our country has to be financially prepared to take on. However, I would hope the government would see the process as investing in people’s lives and investing in families instead of only seeing a financial strain.

Another limitation to the proposed opt-out system accompanied by education is the logistics of dying. As discussed in chapter 2, only 3 in 1,000 people die in such a way that allows for procurement of their organs. Thus, education about organ donation does not change the manner in which people die, but it would significantly increase the awareness and understanding of the organ donation process and potentially lead to an
increase in registered donors. Education in combination with an opt-out system allows for the potential to procure more organs if people did die in a way that allowed for their organs to be recovered as more people would perhaps choose to not unregister as a donor and instead feel confident in their knowledge of organ donation and their choice to be a registered donor.

Unfortunately, the legislative process can be a lengthy one. It takes time to write up a bill, propose it, vote on it, and approve it. Each step takes time and dedication which would cause the hopeful increase in registered donors to continue to be pushed off. However, changing the opt-in system to an opt-out system is only one step in the process of transition. In the meantime, individuals can create conversations with family, friends, and coworkers by educating themselves on the process and then educating others. Each person can ask others if they are registered as an organ donor, if they have considered registering, and what their thoughts are on the process of being an organ donor. By doing this, we can begin to break down the barriers of unawareness and lack of education by you yourselves being educators to those around you. You can show people how to register online and point them to resources. The largest influence on change that can be made while waiting for legislation happens with individuals having conversations. Be a voice and make that difference.

Thousands of lives could be saved and with the waiting list growing at a much faster rate than the donor list, action is needed sooner than later. In the U.S., we have the ability to make the change, to save more lives, give back time, and allow for more memories to be created by individuals waiting for an organ. The only question now is will we.
Epilogue

After performing the research for my thesis, I was able to fully grasp just how difficult legislative change can be. There are so many factors and values that have to be addressed in addition to cost and practicality. I wholeheartedly believe that the opt-out system in combination with an education program can be implemented into the U.S. with careful dedication of time and effort. My thesis has stretched my passion for the medical field and my desire to continue to do research on health care topics and to be a part of the change and advancements of the future.
References


