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THE ETHICS AND ECONOMICS OF KIDNEY DONATIONS AND TRANSPLANTATIONS

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ABSTRACT

With over 100,000 individuals waiting for a kidney transplant, and with over 1,000 individuals dying while waiting for a kidney, great and immediate attention must be paid to the field of organ donations and transplantations. The following thesis is a robust analysis of the major components affecting kidney transplantations in the United States. This thesis focuses on the ethics and economics of legislations as well as procedures to acquire and allocate a scarce medical resource. The literature review reveals shortcomings in each topic that can be remedied with recommendations that are dually supported by ethics and economics. One such recommendation is a required response system aimed to acquire more organs by respecting autonomy while reducing the burden to supply consent to donate organs post-mortem. An empirical analysis of data provided by the Department of Motor Vehicle (DMV) and Organ Procurement Organizations (OPOs) reveals an insignificant effect of a required response system on the procedure to acquire organs.

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Chapter 1

Introduction

The first-ever successful kidney transplant occurred in 1954 when a living donor, Ronald Herrick, donated a kidney to his identical twin brother Richard. Since that time, the shortage of kidneys needed for transplantations has been exacerbated because the demand for kidneys has greatly outpaced the supply of kidneys, compromising the lives of thousands of Americans every year. As of this writing, over 120,000 Americans are on the wait-list for an organ, with an overwhelming majority, over 100,000, waiting specifically for a kidney. Table 1 shows that the number of kidney transplants taking place in the U.S. has remained relatively stable while the number of candidates demanding a kidney has sharply increased (Organ Procurement and Transplant Network, 2016). However, the table additionally shows that the number of deaths attributed to waiting for kidneys, as opposed to death by old age or another illness, has been decreasing over the past decade. Although the numbers of deaths attributed to waiting for kidney has been decreasing, the number of people who die on the list still hovers around 4,000 deceased individuals every year. Nevertheless, without a significant change in the number of transplants over time, the larger decrease in the number of deaths over time must be attributable to a non-transplant reason such as increased life years on dialysis. As such, the annual shortage for kidneys exceeds 4,500 kidneys.

Table 1. Historical Donors, Wait-List, Deaths on List, and Shortage (Kidneys)

Year	Transplants	Candidates on wait-list	Change in wait-list	% Change in wait-list	Deaths on wait-list	Change in deaths on list	% Change in deaths on wait-list	Annual Shortage including deaths
2004	17,133	60,399	-----	-----	4,102	-----	-----	-----
2005	17,675	64,833	4,434	7.34%	4,242	140	3.41%	4,574
2006	18,342	69,602	4,769	7.36%	4,522	280	6.60%	5,049
2007	17,793	74,194	4,592	6.60%	4,549	27	0.60%	4,619
2008	17,638	78,262	4,068	5.48%	4,657	108	2.37%	4,176
2009	18,018	83,180	4,918	6.28%	4,692	35	0.75%	4,953
2010	18,046	87,757	4,577	5.50%	4,682	-10	-0.21%	4,567
2011	17,913	90,468	2,711	3.09%	4,786	104	2.22%	2,815
2012	17,610	95,022	4,554	5.03%	4,610	-176	-3.68%	4,378
2013	18,006	99,254	4,232	4.45%	4,568	-42	-0.91%	4,190
2014	18,099	101,915	2,661	2.68%	4,513	-55	-1.20%	2,606
%Change 2004-2014	5.64	68.74	-----	-----	-10.02	-139.29	-----	-43.03

Note: Reproduced from the Department of Health and Human Services (2016)¹

Figure 1 is a graphical depiction that is often used by the Organ Procurement and Transplant Network (OPTN) to overstate the scarcity of kidneys needed for transplants (Organ Procurement and Transplant Network, 2016). Namely, some individuals view that the greatly diverging gap between candidates on the wait-list (dashed blue lines) and the number of kidney transplants (solid green line) is indicative a scarcity of 83,816 kidneys (the difference between 101,915 candidates demanding kidneys and 18,099 kidneys supplied in the year 2014). What must be understood is that the size of the wait-list is a stock variable that accumulates from previous shortages. A stock variable is measurable at a given point in time similar to the money one has in a bank account at a given time. A shortage, on the other hand, is a flow variable that, in this context, represents the number of kidneys needed for a given year without the

¹ This work was supported in part by Health Resources and Services Administration contract 234-2005-37011C. The content is the responsibility of the authors alone and does not necessarily reflect the views or policies of the Department of Health and Human Services, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government.

accumulation of previous years. A flow variable is measured over a period of time similar to the Gross Domestic Product of a country for a year. As such, the annual kidney shortage is simply the sum of additions to the wait-list in a year plus the number of deaths in the same year that could have been delayed with a transplantation. Thus, there was a shortage of 2,606 kidneys in 2014. A surplus of 4,193 kidneys (averaged from the annual shortage including deaths) would be needed to maintain the wait-list at 101,000 candidates and avoid deaths caused by waiting. Even with these surplus of kidneys, a backlog of over 101,000 would exist. To alleviate this backlog would require a bare minimum of around 20,400 kidneys be transplanted every year over the course of five years (Kaserman & Barnett, 2002). Ideally, acquiring a greater the quantity of kidneys would reduce the wait-time for candidates on the wait-list and improve their lives.

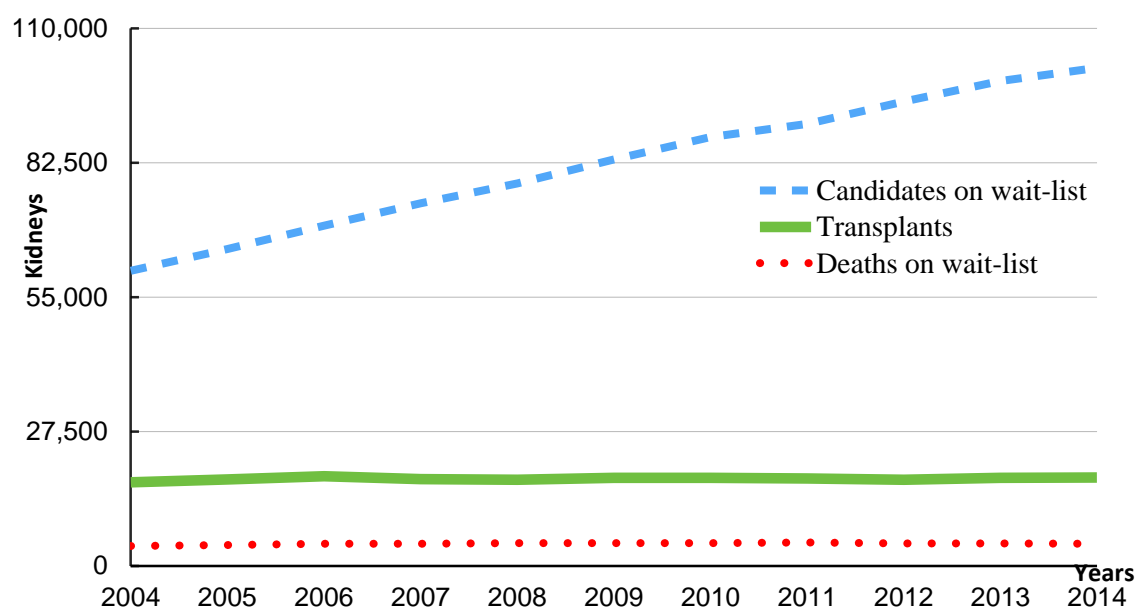


Figure 1. Wait-List, Transplants, and Deaths

Note: Reproduced from the Department of Health and Human Services (2016)

In the early years of organ transplantation, there was no official shortage for kidneys because transplants only occurred when there was a living donor, often a relative. As such, if one needed a kidney transplant, one would have to be admitted to a hospital with a willing donor accompanying them. Over time, innovations in technology and the invention of immunosuppressant drugs made it possible to utilize organs from deceased and unrelated donors. Additionally, with Medicare covering dialysis, patients with failing kidneys could receive dialysis treatment, extend their expected life years, and wait for a kidney to become available. Altogether, a shortage ensued because more End-stage-renal-disease (ESRD) patients were living and demanding unrelated kidneys from deceased donors (Kaserman & Barnett, 2002). To manage the demand, a wait-list was created and kidneys were allocated when one became available. Because kidneys from deceased donors were encountered too infrequently, the wait-list grew at a pace faster than supply and thousands of patients died every year waiting for a kidney. To address this deadly shortage, the U.S. enacted a multitude of legislations, policies, organizations, leaderships, mechanisms, and proposed solutions, all with varying degrees of success. The focus of this thesis is an ethics and economics based analysis of some of the U.S.'s major responses to the shortage of kidneys. The three sections of the thesis are: legislations governing kidney donations, mechanisms to acquire kidney donors, and the procedures to allocate kidneys.

Chapter 2 of this paper evaluates the ethics and economics of various major legislation that have impacted both deceased and living organ donors. Following the legislative evaluation, I propose recommendations and amendments that are ethically and economically sound to bolster the effectiveness of the original acts. Because the three acts I focus on do not differentiate among organs, their content is applicable to all organs and will be written about in that manner.

Chapter 3 assesses the mechanisms the U.S. has in place to acquire kidneys from both living and deceased donors. Because the general focus of this thesis is on kidney donations and transplantations, I focus on kidneys for the analysis of mechanisms in place to acquire living donors. However, because deceased donations often involve multiple organs, the deceased acquisition section will not be limited to kidneys and will be written in application to all organs. This section will also draw on international responses to the shortage to highlight the strengths and weaknesses of the current U.S. model. Consistent with Chapter 2, I propose recommendations to increase the supply of kidney donors; however distinct from Chapter 2, the recommendations in Chapter 3 will be data driven.

Chapter 4 of this thesis is an analysis of the current procedures and formula used to allocate kidneys in the U.S. Whereas the two former chapters incorporate both living and deceased aspects of donations, this section does not make such a distinction because all non-directed donated kidneys, regardless of source, are used uniformly in the formula for kidney allocation. In contrast to the previous sections, this chapter will not include recommendations but will instead raise concerns that ought to be addressed when deciding how to allocate kidneys.

Chapter 2

Legislation

Throughout the history of organ transplants, various government actions have both promoted and hindered the prospect of prolonging and improving life. It is apparent that many well-intended actions have had unintended consequences. Forthcoming are three major legislations that have profoundly impacted the field of organ donations and transplantations. The first two pieces of legislation, the Uniform Anatomical Gift Act (UAGA) and the Uniform Determination of Death Act (UDDA), govern donations from deceased donors while the last piece of legislation, the National Organ Transplant Act (NOTA), oversees donations from living donors. As such, any proposed recommendations in this thesis must work in accordance with the acts or provide substantial evidence to overturn or amend acts.

The Uniform Anatomical Gift Act (UAGA) of 1968

Prior to 1968, the laws governing organ donations varied greatly between states and some states even lacked regulations concerning organ donations. The lack of regulatory consistency throughout the nation created inefficiencies, confusions, and authoritative disputes between procurement agents and family members. To eliminate these inefficiencies and riled up sentiments, the Uniform Anatomical Gift Act (UAGA) was passed in 1968 with the dual goal of providing national consistency regarding donation regulations and facilitating the procurement of organs from deceased donors. The first goal was readily achieved because the UAGA was a federal decree that superseded the different state acts and held all states accountable to the same donation regulations. To achieve its second goal, the UAGA explicitly identified posthumous

sources of consent that could permit organ donations; such sources were categorized as either first-person or third-person consent. With regard to organ donations, posthumous consent is defined as the formal or informal documentation of the wishes made by the deceased while alive. The 1968 UAGA sought to identify such sources and to construct a hierarchical list of the sources by their authority over the donation decision. This hierarchy was created to streamline the decision making process.

The 1968 UAGA and its later amendments decreed the following first-person posthumous documentations as legally binding sources of donative consent: donor card, written directive, last will, driver's license, and donor registries. These sources may serve as direct reflections of the wishes of the deceased concerning organ donations. In the absence of first-person consent, the 1968 UAGA authorized and ranked six third-person survivors who may give consent to donate on behalf of the deceased. The 2009 Amendment expanded the list in order to widen the pool of survivors who may give donative consent and to expedite the procurement of viable organs from deceased donors (National Conference of Commissioners on Uniform State Laws, 2009). In order of priority, persons who may consent to donate organs on behalf of the deceased are:

1. the spouse of the decedent
2. adult children of the decedent
3. parents of the decedent
4. adult siblings of the decedent
5. adult grandchildren of the decedent
6. grandparents of the decedent
7. an adult who exhibited special care and concern for the decedent
8. the persons who were acting as the [guardians] of the person of the decedent at the time of death; and
9. any other person having the authority to dispose of the decedent's body².

² Criteria nine refers to executors of living wills or someone formally granted the power of attorney.

In sum, the UAGA indirectly prioritizes first-person consent because it authorizes the procurement agent to remove organs in the presence of first-person documentation of gift. This indirect prioritization became a direct prioritization when later amendments explicitly prohibited the wishes of the deceased from being overridden³. If and only if there is no first-person documentation of gift should the procurement agents proceed to elicit consent from a third-person source. Together, the consent of the third-person is secondary to the consent of the first-person because the procedure to procure organs commences, and subsequently ends, with first-person consent if such a document exists. The value of this act is that by prioritizing first-person consent, there is an increased efficiency at which organs can be procured because it limits the involvement of a third party (the kin). The UAGA intended to achieve its second goal to facilitate the ease at which consent can be acquired by ultimately crowning first-person documentation superior to the consent or objection of all other persons and by limiting the intermediary steps that need to be taken to acquire transplantable organs. Whether the commands of the act are ethically justifiable and economically efficient and effective is now the focus.

Ethical Analysis of UAGA

The Belmont Report (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1978) was published in light of the Tuskegee Syphilis Experiment that involved Caucasian scientists withholding curative treatments from a poorly informed group of African Americans infected with Syphilis for the purpose of research. In light

³ “An anatomical gift that is not revoked by the donor before death is irrevocable and does not require the consent or concurrence of any person after the donor's death” and, “a person other than the donor is barred from making, amending, or revoking an anatomical gift of a donor's body or part if the donor made an anatomical gift of the donor's body” (National Conference of Commissioners on Uniform State Laws, 2009, p.30).

of the inhumane abuse of a vulnerable group, the Belmont Report was published to set the guidelines for medically ethical research. The three main principles derived from the guidelines were justice, beneficence, and respect for persons. Because the Belmont Report governs human research, that specific report is not applicable to consent involving organ donations. However, the principles of the report, later conglomerated under the heading of Principlism, are applicable to the ethics of consenting to organ donations.

A year after the publication of the Belmont report, bioethicists Beauchamp and Childress (1979) spearheaded the principles of biomedical ethics. The overarching principles the two bioethicists developed were 1) justice, 2) beneficence, 3) non-maleficence, and 4) respect for autonomy. The authors did not intend to cement these principles as rules of conduct. Principles are flexible guidelines to be interpreted when drawing specific policies and decision making. Organ donations are within the realm of medical decisions and as such it is important to evaluate each principle concerning donations.

Justice refers to fairness in the sense that no one person is disproportionally promoted or harmed relative to a similarly situated person. The UAGA accomplished this principle of biomedical ethics by uniformly applying its commands throughout the country. The uniform component of the UAGA ensures that all deceased donors are held to the same level of respect pertaining to their posthumous wishes. Thus, justice is upheld because all deceased donors are similarly situated by the nature of their death and treated uniformly under the governance of the UAGA. Beneficence refers to the attempt to benefit or minimize the risk the patient is exposed to while non-maleficence demands that a practitioner does no harm to the patient. For example, a doctor prescribing that a patient undergoes chemotherapy even in the face of severe side effects is acting in beneficence if the doctor believes the benefit of the intervention outweighs the harm.

However, a doctor prescribing a diet of high-cholesterol food to a victim of a heart attack is violating the principle of non-maleficence because the doctor is exacerbating the harm to a patient. Neither beneficence nor non-maleficence are relevant to the UAGA because deceased donors bears no risk by the nature of the donors being deceased and incapable of being harmed any further.

Respect for autonomy is defined as the acceptance of a decision made by a non-manipulated and non-coerced individual. In medical ethics, respect for autonomy instructs the health professional to provide all the relevant information to a patient and to allow the patient to make a decision without undue influence. For example, if after a health professional provides all the options to manage a disease and a patient decides to forgo all curative treatments, the health professional must respect that decision even if the professional disagrees with the decision. It is ethically sound for a health professional to disagree but accept a decision because, ultimately, every individual has authority over themselves. Self-authority is a fundamental right that asserts no third party may alter or make decisions on behalf of an autonomous person without the consent of that person (Sneed, 2009). With regard to organ donations, so long as each individual who makes a decision to become a donor does so in an autonomous manner, that decision must be accepted. Violating an individual's autonomous decision regarding organ donations is a violation of biomedical ethics. The only caveat here is that the UAGA addresses deceased individuals while medical ethics typically concern living individuals. It is important to assess respect for autonomy in the context of death.

Under U.S. law, decisions of persons are respected even after death. When a last will or testament is drafted, the executor is legally obligated to carry out the terms of the will. Violating a last will can be met with legal penalties ranging from fines to incarceration. Thus, U.S. law

relating to wishes after death continue to uphold the ethical principle of respect for autonomy. Following this logic, when an autonomous individual decides to donate organs, that decision cannot be superseded even after death because the donative document is legally binding and comparable to the legitimacy of a living will as prescribed by the UAGA. Clearly, the UAGA in that aspect is upholding autonomy by prioritizing the decisions of the deceased even when the kin contest the deceased's decision. The priority of the wishes of the deceased is further bolstered by the fact that once deceased, the body does not become the property of the kin. In fact, the only legal right the kin have to the deceased is a quasi-property right granted by common law for burial purposes (Hartnett, 2010). Even these disposal rights are consistent with the UAGA, which states, "after removal of the part, custody of the remainder of the body vests in the surviving spouse, next of kin, or other persons under the obligation to dispose of the body" (National Conference of Commissioners on Uniform State Laws, 1968). These policies ensure that the kin have limited rights over the deceased and none of the limited rights allow legal ground for the kin to alter or override the decisions of the deceased if the decisions are documented. Again, the UAGA successfully reinforces respect for autonomy and upholds biomedical principles by prioritizing first-person consent over all other sources of consent even after death. Yet despite clear instructions by the UAGA to prohibit the wishes of the deceased from being superseded, hospitals have failed to abide by the act. It has been documented that even if a hospital has first-person documentation of consent, procurement agents will still request and follow-through on the wished of the next of kin, in complete contradiction to the laws prescribed by the UAGA (Overcast, 1984; Peters, 1986; May et al., 2000).

The main ethical consequence of the current practices is that the autonomy of the deceased is violated. This is a simple matter of the deceased having a legally binding document

that is unlawfully breached by the next of kin; it is analogous to the deceased having a last will allocating his/her wealth and the will being altered by the next of kin. Further, it contradicts the purpose of having posthumous decisions and sets dangerous precedents implying that documents and wishes are annulled after death. The reason procurement agents continue to accept the wishes of the third party in spite of the presence of first-person documentation is because hospitals are fearful of legal actions taken by the living relatives.

If the decision of the deceased is violated, the deceased cannot sue the hospital and there are no repercussions for the hospital. Controversially, if the deceased has documented proof of opposing organ donation, technically the hospital can still procure organs because of the powerlessness and the inability of the deceased to take legal actions against the hospital; the hospital knows that it faces zero liability for violating the non-gift wishes of the deceased. On the other hand, if the deceased has proof of supporting organ donation and the hospital does not respect the deceased's wish because of objections by the living kin, the deceased still cannot protest; again, the hospital faces zero liability for violating the positive-gift wishes of the deceased. In both cases, the hospital faces zero liability for violating the wishes of the deceased. But if the wishes of the living kin are not respected, not only can the kin sue the hospital, but they can spread their discontent to the community and impact the community's perception of the hospital; here, the hospital faces liabilities.

This reality was so well known that the 1987 UAGA Amendment was drafted to specifically to ease the fear of liability faced by hospitals for prioritizing first-person document of gift. The Amendment states that those who act in accordance with the UAGA, that is, prioritizing first-person consent, are legally protected and not liable for any civil or criminal prosecutions (National Conference of Commissioners on Uniform State Laws, 1987). Nearly

thirty years since the problem was addressed in the 1987 Amendment, the current practice is still that consent of the kin is sought and respected in substitution of first-person consent. When an Ohio Organ Procurement Organization (OPO) in 2013 discovered Elijah Smith's posthumous document of gift, they concluded that the document was enough evidence, as identified in the UAGA, to procure his organs. Mr. Smith was then put on life support to preserve his organs, but his family contested the gift and the OPO had to file an emergency case to get a court order granting them the authorization to extract the organs. In this specific case, the judge ruled in favor of the OPO because Mr. Smith's license, a legally binding document according to the UAGA, indicated that he wanted to donate his organs and his wishes are eminent as prescribed by the UAGA (McCleskey, 2013). Although the law protects hospitals when it prioritizes first-person document of gift, the hospital can still avoid the cost and time of litigation while preserving their reputation in the community if it respects the wishes of living kin instead of the deceased. Ultimately, the language, intentions, and measures the UAGA has in place to facilitate organ procurements are ethically sound, but adherence to act has been less than ideal due the fact that in practice, third-person consent often trumps first-person consent. It is then appropriate to evaluate how the UAGA authorizes third-party individuals who may represent the deceased.

In the hopes of consistently representing the wishes of the deceased, the UAGA prioritizes third-party individuals who may best represent and reflect the wishes of the deceased. Such a procedure in bioethics is known as substitute judgment. This bioethical procedure entails permitting a third-party individual to make decisions on behalf of an incapacitated individual that is consistent with what the incapacitated individual would have chosen for him/herself. It focuses on authentic values and preferences of the incapacitated in order to arrive at a decision they would have made for themselves (Sulmasy & Snyder, 2010). The idea of a surrogate decision

maker is that it is not necessary to know precisely what the incapacitated individual would have wanted in a specific situation. The substitute decision maker would be able to deduce what the incapacitated person would have wanted through understanding the incapacitated individual as a person of certain characteristics and behaviors.

Under the UAGA, first priority goes to spouses who are suspected to have an earnest and intimate understanding of how the deceased would want to be treated. Similarly, there is an underlying assumption that the spouse shares similar sentiment on a variety of topics including treatment after death, and that the spouse may have known their significant other for a longer time than an adult child and thus has more knowledge concerning the wishes of the partner. However, one could argue that the parents of the deceased child have known their deceased longer than anyone else on the list. Seeing as most children, who are by nature impressionable at their young age, grow up with the influences of their parents for 18 years, the parents may be most aware of the genuine sentiment of their deceased child. Moreover, because parents are believed to have the purest form of love toward their children, they may be best suited to make an unbiased decision (De Botton, 2006).

On the other hand, because of the implicit superiority of parents over their children, the adult child, when alive, may feel inclined to give an acceptable answer to the parent that is different from the honest answer. This is especially true for East Asian and African cultures where it is disrespectful to contest one's parents and superiors (Bankston & Hidalgo, 2006; Söng & Kim, 2009; Dixon et al., 2008). Thus, the parent may represent their child with a misrepresented belief of his/her child. Although parents heavily influence their children in early development, the influence wanes over time as does the communication between the two. Meanwhile, spouses tend to live together permanently and communicate more frequently and are

believed to retain the most present knowledge of the wishes of the deceased. Ultimately, the hierarchy is ethical because it seeks to give power to those who are able to best reflect the most to-date and non-coerced beliefs of the deceased.

In truth, though the language and intentions of the UAGA are ethically meritorious and geared toward respecting the autonomy of the deceased, the actual implementation of the act is often in violation of the ethical principle of respect for autonomy. Proceeding forward, it is important to examine the effectiveness of the UAGA in achieving its two goals to create a uniform procedure for procuring organs and to facilitate the ease at which organs are procured.

Economic Analysis of UAGA

Shalowitz et al. (2006) conducted a comprehensive and systematic literature review to determine that surrogate decision making is accurate 68% of the time. Granting that the accuracy rate is opportune, the rate is still not perfect. Without certainty or perfect information, there is room for violating the wishes of the deceased and creating the types of ambiguous inefficiencies that the UAGA sought to eliminate. To only source that will ever yield 100% accuracy is a first-person document of gift. This is the reason that the UAGA insisted on prioritizing the wishes of the deceased. In addition to identifying sources, in order to be able to respect the wishes of an incapacitated individual, the UAGA also contained a crucial component known as the required request provision.

According to this provision, upon admission, hospital personnel must inquire whether or not the patient has already made a decision about donating organs after death. If the patient has previously made a decision, the hospital must retain a copy of the document and file it with the

patient's medical records. If the patient had never made a decision, hospital personnel must inform the patient of the opportunity to donate. Once the option to donate has been presented, an answer must be acquired and included in the patient's records. This ensures that a document with clear reflections of the wishes of a patient is available. Additionally, the 1987 Amendment commands the following persons to make reasonable searches for documents of gift or revocation: law enforcement officer, fireman, paramedic, or other emergency rescuer finding an individual who is dead or near death, and the hospital upon the admission of the patient. In the event that the document is found after a patient has been transported to a hospital, the presence of the document must be made aware to the hospital. These procedures were put in place by the UAGA to guarantee certainty in a decision and streamline the efficiency of procuring organs.

Building on the UAGA's required request provision, in 1998, the Health Care Financing Administration (HCFA) passed a donor rule that required hospitals participating in Medicare to contact Organ Procurement Organizations (OPOs) when a patient's death is imminent or has already occurred. The OPO can then proceed to communicate the option to donate with the family. However, data on the role of required request in increasing the supply of kidneys suggests ineffectiveness of the provision.

The Department of Health and Human Services (HHS) (2000) conducted a survey to determine the effectiveness of the HCFA required request provision and determined that although there has been an uptake in the number of referrals to OPOs, most hospitals fail to notify the OPO of an imminent or recent death. This finding can be explained by the lack of incentive to follow either of the provisions. Namely, there is neither a reward for hospitals for abiding by the provisions nor a punishment for failing to adhere to the provisions. As such, it is inefficient to continue to require that hospitals waste time asking patients for an answer they do

not intend to respect nor contacting an OPO. Andersen and Fox (1988) examined the effectiveness of the required request provision on transplant centers in New York, California, and Oregon and concluded that although kidney donations increased in all three states, the increase cannot be solely explained by the required request provision. The authors showed that the documentation of request has been cumbersome to hospitals and an impediment to documenting the wishes of the deceased prior to death. Similar studies (Caplan & Welvang, 1989; Ross et al., 1990; Caplan & Virnig, 1992) have all corroborated the ineffectiveness of the required request provision. Thus research has shown that require request provisions of the UAGA and that of HFAC, which intended to create a mechanism to foster efficiency, has failed. The personnel in charge of abiding by the provisions have failed to align with the procedures of the provisions for the same reason many individuals do not donate organs; there is no self-interested reason to make the effort beyond altruism.

Another effort the UAGA undertook in 1987 to streamline donor registration was to eliminate the need for witnesses. The 1987 Amendment removed this provision in order to eliminate the obstacles an individual faces when registering to be an organ donor. The basic economic principle at work here is that if there are obstacles to supplying the good, there will be lower supply of a good. Similarly, requiring a witness to attend to a licensing event that may take several hours, or an attorneys office to sign a living will, may have been too much of a burden, thus individuals may have chosen not to donate. With the elimination of the witness provision, a hurdle to registering as a donor, an individual can register to be a donor without needing to take the time to involve the participation of a witness. The unintended consequence of this action was that the elimination of witnesses strained the capacity of kin to know about a donative intent unless there was direct communication about the decision. Even if potential donors casually

speaking about registering to be a donor, the memory of this conversation could potentially be lost over time. On the other hand, serving as a witness to the declaration of intent is a strong memory that may be recalled with immediacy. Since the elimination of the need for witnesses, communication between potential donors and their kin is crucial.

A survey of over 3,000 respondents by the Department of Health and Human Services (HHS) (2012) revealed that if the kin has knowledge of the decision of the deceased, the kin is significantly more in favor (96.7%) of aligning with that wish (Figure 2). If family members would prefer to respect the wishes of the deceased, then it is imperative that the kin know what those wishes are. Requiring witnesses to the donative decision may be one mode of making those wishes undeniably known. Of course, before reinstating such a policy, it is crucial to assess whether the dispersion of knowledge created by the witness requirement offsets the inconvenience of acquiring a witness. There is no current data on the effect of the required witnesses provision to the organ procurement rate. Nevertheless, this study highlights the importance of being aware of the wishes of the deceased either by document or informally.

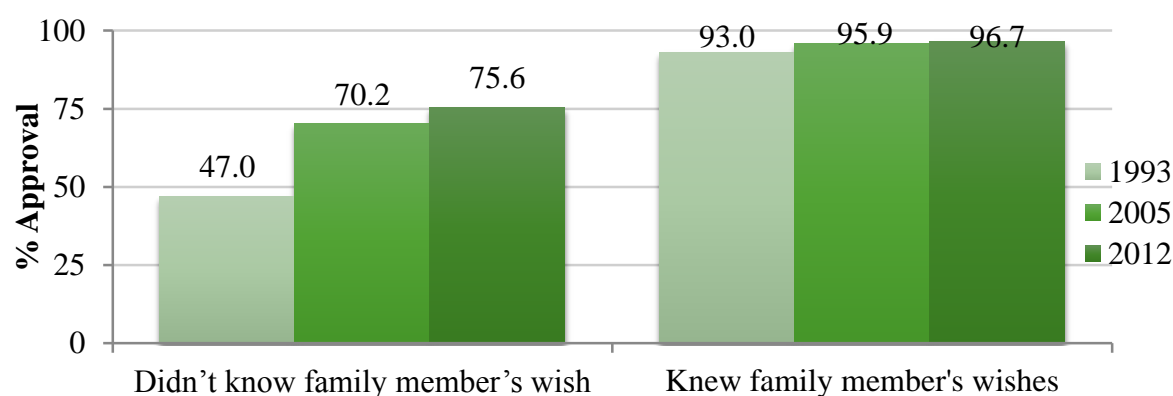


Figure 2. Likelihood of Donating Family Member's Organs When Wishes Are and Are Not Known 1993-2012

Note: Reproduced from the Department of Health and Human Services (2012)

Concerning the economic implication of the hierarchy of individuals who may give surrogate consent to donate, the structure of the list aims to maximize the efficiency and speed at which an individual could be located. Because time is of the essence to procure organs, and because consent must be obtained in the absence of a document of gift, spouses, who are likely to be at physical proximity to the deceased, are the easiest to contact and most likely to be present at the site and/or time of death. Of second priority is adult children who may be easier to contact than aged parents of the deceased adult. Conclusively, from an economic standpoint to maximize the supply of organs, it is justifiable to place spouses ahead of adult children, and adult children ahead of the parents of the deceased because that order reflects the lower cost at which the individuals can be contacted in the imminence of kidney deterioration.

Recommendations

The UAGA and its subsequent amendments have aimed to increase the supply of organs both with ethical merit and economic efficiency by 1) identifying all the sources that could give consent to donate, 2) prioritizing first-person consent and authorizing certain third-parties to hold more weight than others, and 3) mandating that hospital personnel inquire on the donating wishes of moribund patients. All three aims have failed at the hands of those responsible for executing the decrees of the UAGA. Frequently, hospital professionals disregard the priority of first-person consent even in the presence of documentation of gift and instead prioritize the wishes of the kin in outright violation of the UAGA. Further, the required request provisions have not been executed to its full potential because administrators of the responsibility do not have compelling incentives to make the effort.

Although the best remedy to the scarcity is to respect the wishes of the deceased when those wishes are known, many hospitals will not proceed with procuring organs without receiving approval from the next of kin. Thus, the second best remedy is to maximize the rate of consent of the kin. To do this requires a combination of incentivizing hospital personnel to request consent and to provide bereavement counseling to maximize the rate of family consent.

Subsection 3 of this chapter analyzes the National Organ Transplant Act (NOTA) of 1984 which outlaws the sale of organs. Consistent with NOTA, it is illegal to offer monetary incentives to the hospital to increase the number of donation requests made to families. That is not to say that hospitals do not earn a profit from transplants. A standard kidney transplant costs upward of \$260,000, all of which can be billed to insurers and patients (Bentley, 2014). If transplants are big business for transplant sites, then hospital personnel have the opportunity to increase profits by increasing procurement efforts which are associated with little cost but large payoffs. With the underwhelming steps personnel take to contact OPOs and routinely request donative wishes of the deceased, there is a deadweight loss from the as suboptimal acquisition of transplants as a result of low procurement rates. To incentivize hospitals to take greater efforts toward procurement, but still abide by NOTA, hospitals could be rewarded with recognition or certificates of excellence in transplants.

Birkmeyer et al. (2002) and Halm et al. (2002) have shown that hospitals with an abundance of surgical experience perform better and thus are likely to capture more recipients demanding surgery. With a focus on kidney transplants, Axelrod et al. (2004) also determined that transplant sites with few kidney transplant cases had significantly higher incidences of graft failures compared to site with high kidney transplant cases. If certain transplant sites are known to be of relatively lower quality, they will receive fewer referrals and thus even fewer

transplants. If hospital personnel make an effort to procure more organs with the foresight of gaining notoriety, then they can expect to perform more transplants and obtain notoriety that will lead to further increases in transplants; ultimately increasing profits through the quantity of transplants performed.

In most cases, when the family is presented a document of gift sourced from their deceased kin, the family is more likely to approve of the gift (Department of Health and Human Services, 2012). Assuming that the incentive works and that hospital personnel have documented consent from the required request efforts, the kin are likely to approve the donation once the document is provided as evidence for the deceased's wishes. Upon acquiring the family's consent, the procurement and transplant process can begin to coordinate.

To achieve the goals set by the UAGA requires the utmost effort to procure a document of gift in order to present definitive proof to the kin of the deceased's wish to donate his/her organs. Thus the certification acts as a signal that will lead to higher volumes of transplant referrals and more profitable business opportunity. These efforts are a Pareto improvement in that the deceased wishes are respected, the kin's wishes are accepted, hospitals benefit from high transplant volumes, and the recipient benefits from a kidney transplant.

Although the UAGA takes commendable steps to maximize donations from cadavers, it does not govern the declaration of death. Because most organs are sourced from cadavers, it is imperative to analyze the legislation that allows death to be declared and sanctions the UAGA: the Uniform Determination of Death Act (UDDA).

The Uniform Determination of Death Act (UDDA) of 1981

Dating back to 400 BCE, the long standing definition of death aligned with the Hippocratic humoral theory in which the flow of fluid is essential to life. If the heart ceased to circulate blood, the lungs would fail, and the individual would die. As such, the original definition of death was defined as the permanent cessation of circulatory and respiratory functions (Veatch, 2000). However, in the 1970s, improvements in technology blurred the line of death because machines were able to sustain a heartbeat independent of the body's ability to do the same. Although Harvard Ad Hoc Committee (1968) did not pursue to define death, their attempts to define an irreversible coma eventually led to the establishment of a definition of death. They agreed on the following four criteria to determine an irreversible coma:

1. Unreceptivity and Unresponsiveness - unawareness to externally applied stimuli.
2. No Movements or Breathing - lack of spontaneous muscular movements or respiration (observation period of at least one hour). If the patient is on a respirator, absence of breathing is determined by withdrawing the respirator for 3 minutes.
3. No Reflexes - lack of pupil dilation, swallowing, or yawning are evidence of the abolition of central nervous system activity. Lack of eye movement even when hit or turned, or ice water is placed in the ear. Lack of response to noxious stimuli; unelicitable tendon reflexes.
4. Flat Electroencephalogram⁴.

The Harvard committee's definition of irreversible coma served as the main reference point for the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1981) when they determined the definition of death to be either the "(1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem" (p.5) in the Uniform

⁴ The fourth requirement acts as supplementary evidence to the former three criteria.

Determination of Death Act (UDDA) of 1981. This new definition was additionally adopted by the American Bar Association (ABA) and the American Medical Association (AMA).

With regard to organs, most cadaveric organs are procured from a donor who dies in a hospital setting because organ procurement can begin immediately or shortly after depending on if the deceased's wishes are known. Cadaveric organs typically do not come from outside the hospital because the organs would be compromised by the time the body has been transported to the hospital and consent acquired. Concerning whether to utilize the cardiac or brain definitions of death in order to procure organs has been greatly debated and is worth consideration.

Ethical Analysis of UDDA

After the enactment of the UDDA, by and large, the majority of hospitals procure organs from donors after brain death (DBD) because ventilators can continue to keep the heart beating and prevent ischemia induced kidney deterioration (Steinbrook, 2007). OPOs can coordinate a kidney transplant while the deceased blood is kept in circulation. Although the brain definition of death is more popular, the cardiac definition of death has been given more consideration in the face of high demand for kidneys. The potential donors after cardiac death (DCD) have suffered from irreversible neurological injury and have been put on life-support. While brain-dead donors do not have brain function, by extension they do not have heart function, and thus are irrefutably dead under both criteria of death. The difference between brain-dead donors and heart-dead donors, and the controversy surrounding the inclusion of cardiac-dead donors, is that cardiac-dead donors are not dead according to the brain criteria of death; the heart dead patient may still have low levels of neurological activity and would not be considered brain dead (Veatch, 2000).

When the definition of brain death was determined in 1981, it was based on the empirical verifiability of brain activity. When the President's Commission attempted to define death, they did not imply that human beings are simply the sum of neurons and electrical signals. Rather than reducing a person to organic wiring, the death of a person was understood to be the absence of consciousness, emotions, memory, and/or cognitive abilities, all of which may be verified through scientific trial. But electroencephalograms (EEGs) do not have the ability to discern if neurological activity is representative of consciousness, emotions, or any other qualities attributable to humans. Even if a potential DCD has low levels of brain activity, that brain activity could be a signal of what is considered life. When the decision is made to withdraw life support, there is a waiting period of 2-5 minutes before death is declared. This time provides the opportunity to assess whether or not the patient can independently restore a heart beat. If there is no organic heart activity within that time frame, permanent cessation of circulatory function is determined and the patient is declared dead. It is worthwhile to note that procurement agents do not approach the kin about donation until after the kin have decided to withdraw life support. This procedure ethically abides by the donor rule that a practice is not undertaken to hasten death. However, if there is proof of brain activity that may represent life, and withdrawing life support leads to the cessation of brain activity, is it ethically permissible to "pull the plug"?

Consequentialism is a branch of moral philosophy that assess the rightfulness of an action by the effects the action produces (Fox et al., 2008). The Consequentialist answer relies on thinking through the dilemma chronologically. The patient was put on life support because the heart and respiratory system were on the verge of failing and compromising the brain. When the patient is on life support, the heart's natural ability to circulate blood has likely already failed and would have killed the person had it not been for the intervention of the machines. To a

Consequentialist, removing a patient from life support would not be murder because the act only allows a heart death that would have been inevitable without the intervention of life-support. Moreover, the intended purpose of medical technology is to improve life, not sustain a zero-sum game such as the cardiac-dead donor circumstance. It must be understood that keeping such a patient on life-support forever does not offer progress, it only creates a stalemate. Maintaining such a patient on life-support is a waste of valuable resources considering there is no foreseeable recovery.

Even if there are barely detectable neurological activities, the individual is essentially trapped in his/her own mind without the ability to engage. When a severely neurologically compromised patient is on life support, that patient does not have a trace of expressible autonomy. Similar to the UAGA granting the kin authority to make surrogate decisions on behalf of the deceased, most states have some form of health proxy legislation that bestow relevant authority with the legal responsibility of making decisions on behalf of an incapacitated patient such as a potential DCD. Historically, the kin's decision to withdraw life support is often based on the belief of poor prognosis, concern over suffering, and desire to provide a high quality of life, even if it means ending life (Keenan et al., 1997). This reasoning introduces another dimension necessary to decide whether DCD is an ethically acceptable criterion for obtaining organs: quality of life.

Hedonism is a branch of philosophy defended by Hedonists, such as ancient Greek philosophers Epicurus and Aristotle, who believed that happiness is the ultimate reach for human existence. Essentially, the theory defines happiness and pursuit of pleasure to be the pinnacle purpose of life. This theory of life is especially and historically relevant to American citizens, all of whom are here because "life, liberty, and the pursuit of happiness" are endowed unalienable

rights under the Declaration of Independence. Potential DCD patients will never have the opportunity to pursue happiness. If there is consciousness, very few would defend that a life confined to pure isolation, in this case confined to a brain, is a life worth living. Considering prisons capitalize on isolation to connote hardship, some could even argue that the isolation of DCD patients is equivalent to suffering. Notably, lessening emotional pain to provide a desired quality of life has been the dominate argument made in favor of euthanasia. This argument to allow an individual to end his/her own life in order to avoid suffering has been effective enough for the “right to die” legislature to be passed in five states and to be under review in 17 other states (Ollove, 2015). Euthanasia refers to the deliberate intention to end someone’s life by taking an active step to cease life. The distinction between euthanasia and the withdrawal of life-sustaining technology from DCD patients is that the latter allows a natural death to take place. Altogether, the predicted absence of recovery, the distinction between murder and withdrawing life-support, the power of the kin to act on behalf of the incapacitated, and the desire of the kin to provide a desired quality of life for their loved ones all illustrate the ethical permissibility of withdrawing life support and procuring organs from a heart-dead donor.

Besides the ethical justification of using DCD, there are utility benefits of the criteria. The Utilitarian branch of moral philosophy is founded on Hedonism. The founders of Utilitarianism, Jeremy Bentham and John Stuart Mill attempted to quantize Hedonism into hedonic calculus (Bentham & Mill, 1961). Thus Utilitarianism is a moral philosophy that aims to maximize utility, or happiness. The utilitarian logic is that if hospitals included donors after cardiac death in addition to brain-dead donors, there would be more cadaveric sources to procure organs from, thus there would be more organs available and ultimately fewer people on the wait-list. There are more people who benefit than there are people who are harmed because the

deceased can no longer be harmed and a single deceased donor could benefit up to six people on the wait-list.

Ultimately, in 2006, the United Network for Organ Sharing (UNOS) recognized the permissibility of the controlled heart death criteria at a conference on the viability of DCD (Bernat et al., 2006). With the acceptance of controlled cardiac deaths as a potential opportunity to procure organs, there has also been a push to use uncontrolled cardiac death. Uncontrolled cardiac deaths refer to patients who die outside of a hospital setting and never receive life sustaining intervention. At the site, if 30 minutes of cardiopulmonary resuscitation (CPR) does not restore autonomous circulation, the individual is declared dead. There is a rush to contact the kin and request consent to preserve organs for donation. Upon obtaining the consent, the individual is transported and receives continuous chest compressions and IV fluids to prevent ischemia. Once at the hospital, five minutes pass to assure the inability of the patient to self-restore circulation. Following the five minutes, the patient is put on mechanical ventilation to keep the blood circulating.

Opposition to utilizing kidneys from uncontrolled donations after circulatory determination of death (UDCDD) assert that the chest compressions used to preserve organs are overturning the cessation of the heart function. Supporters of UDCDD argue that circulation is not restored because without the continuous application of CPR, the individual will not independently restore circulation. Moreover, the manual maintenance of circulation by paramedics is well below the percussion pressure of a normal physiology needed for autonomous circulation. Secondly, the individual is still dead according to the UDDA because cardiac function is never restored even if blood is circulating (Munjal et al., 2013). For these reasons, New York City has justified the use of UDCDD in their transplant sites (Wall et al., 2011).

Economic Analysis of UDDA

Between 2002 and 2012, DCD transplants increased from 294 to 1,617 and now accounts for over 14.5% of all deceased donations (Matas et al., 2014). That still leaves the majority of transplants, around 85.5%, originating from brain dead donors. Without the inclusion of the brain dead criteria under the 1981 UDDA, it is more likely that current procurement rates would never have been achieved because of the uncertain conditions surrounding DCD procurements. The strength of the UDDA is that because it contains two sources of cadavers, there is an expanded pool to procure organs from. Because the use of brain dead donors has been successful, it is worthwhile to examine the potential of DCD in addition to DBD to mitigate the kidney scarcity.

Notably, Wisconsin's single site 29-year retrospective study revealed no significant difference in kidney graft survival, rejection rate, or surgical complication over the course of ten years (Bellingham et al., 2011). However, they did note that DCD graft functions were delayed compared to the DBD donors, 35.7% vs. 20.3%, respectively. Nevertheless, the ten-year post-transplant survival rate for DBD and DCD was comparable at 60.7% and 59.7%, respectively. Similar studies (Cooper et al., 2004; Doshi & Hunsicker, 2007; Joseph et al., 2015) have all corroborated the long-term equivalence of DCD and DBD. Realizing that the medical outcomes between the two sources are tantamount, it is necessary to determine whether DCD is monetarily worth the effort. If DCD is not cost effective, then it may be worthwhile to forego procuring organs from DCD patients and instead appropriate the human capital and funds to the more effective DBD procurement.

In a retrospective study examining Massachusetts transplant data between 1998 and 2005, Saidi et al., (2007) found that their focus hospital charged over \$83,000⁵ to transplant kidneys from DCD to a recipient while charging just over \$54,000 for the same procedure from a DBD kidney. The higher DCD charges arose from longer post-transplant stays (9.8 days vs 6.1 days) and increased requirement for post-transplant dialysis because of delayed graft functions associated with DCD kidneys. Despite higher costs associated with DCD relative to DBD, DCD transplants are still more cost effective than dialysis considering dialysis considering the \$83,000 DCD figure is a one time cost while dialysis costs \$85,000 every year (United States Renal Disease System, 2015).

The best estimation of the holistic long-term costs come from a Markov-based simulation found by Snyder et al. (2013). Their model aims to evaluate the cost and quality outcomes on the wait-list when hypothetical cohorts were exposed to either DBD kidneys or a combination of DBD and DCD kidneys. The model takes into account the source of cadaver kidney, direct cost of transplantation (procedure, materials, and length of stay), lost earning potential of recipient, out of hospital expenses, and immunosuppressive therapy. The first group of hypothetical recipients were exposed to only DBD donors while the second group was exposed to both DBD and DCD donors. The hypothetical recipients were exposed to probabilities of immediate or delayed graft function, or the need for a second transplant, or death. The four outcome metrics were graft success, complications, costs and Quality Life Adjusted Years (QALY) over ten years after the transplant.

The findings of the simulation revealed that a wait-list exposed only to DBD kidneys had 5.4 QALY; or, it costs over \$66,000/year to provide an acceptable quality of life for a potential

⁵ All figures here after have been adjusted for inflation.

recipient on the wait-list. Meanwhile, the wait-list group exposed to a pool of DBD and DCD kidneys had a higher QALY (6.0) equating to a nearly \$57,000/year to provide an acceptable quality of life for someone on the wait-list. This finding asserts that including DCD in the mix of deceased donors saves over \$10,000 per case than a scenario with the exclusive use of DBD. Together, the Wisconsin, Massachusetts, and simulated study show that including DCD kidneys is more cost-effective than allowing patients to continue with costlier dialysis or exclusively using DBD.

Of additional interest is the effect of utilizing uncontrolled donors after cardiac death (UDCDD). Although millions of Americans die every year and even with a majority of Americans having denoted an interest in becoming an organ donor once deceased, many potential deceased donors are underutilized. Some cannot donate because age has compromised the quality of the kidney and others die in non-hospital settings which also allows deterioration to compromise kidneys before consent can be obtained. Both Spain (Sanchez-Fructuoso et al., 2006) and France (Fieux et al., 2009) have experienced notable success controlling the wait-list with the use of uncontrolled donors after cardiac determination of death (UDCDD). With the success of utilizing UDCDD in Spain and France, the Institute of Medicine (IOM) noted that utilizing UDCDD has the potential to offer over 20,000 kidneys every year in the U.S. (Childress et al., 2006). A single site evaluation of graft outcomes from controlled and uncontrolled DCD sources between 1989-1993 in Pittsburgh revealed no discernible outcome difference between the two sources (Casavilla et al., 1995). Similarly, Washington D.C.'s experience with UDCDD showed the potential of UDCDD kidneys to supply more kidneys without the cost of poor outcomes. More recently, a retrospective comparison of uncontrolled and controlled DCD kidney transplants between 1995 and 2005 revealed that there was no substantial difference in outcome

between the two sources (Gagandeep et al., 2006). The studies still hinge on control in the sense that the deaths occur in a trauma setting rather than non-hospital settings. Although most deaths still occur in a medical setting, likely because of terminal illnesses, the U.S. has seen home and nursing-home deaths increasing over the years. In order to maximize the number of deceased donors acquired requires establishing a procedure to capture potential donors who die outside of a hospital setting (Health, United States, 2010).

Leading the effort to utilize non-hospital deceased donors is New York City. Between 2007 and 2010, a coalition of law experts, bioethicists, transplant experts, and community representatives met to create a mechanism to procure organs from non-hospital UDCDD individuals. The premise of their proposal is that witnesses must be present at the setting and time of death to attest to the time of death to ensure that ischemia did not take hold for over 120 minutes. Once Emergency Medical Technicians (EMT) are at the scene, they are to perform resuscitation for 30 minutes. If autonomous circulation is not restored, death is declared and the nearest Organ Procurement Organization (OPO) is contacted to acquire consent for organ donations. Once the consent is obtained, OPO licensed vehicles must transport the deceased to the hospital. Meanwhile, chest compressions are reinstated during the transport to the hospital where the deceased is attached to a mechanical ventilator until the transplant is commenced (Wall et al., 2011).

There are several economic variables that are taken into consideration to offset the cost of the proposed New York City system. First is the need for near perfect information availability among witnesses at the scene of the incident. Without knowing how long an individual has been unconscious, EMTs are unable to determine whether the individual is even capable of donating viable kidneys. Next, the EMT must find identification that the OPO could use to determine

whether the deceased registered to be an organ donor. The OPO must also have appropriate information to contact the kin in order to obtain additional consent. All of this information must be acted upon within two hours before preservative attempts are to be made. Organ Preservation Unit (OPU) must have their own vehicles and preservation specialists to transport the deceased individual to the hospital. This ensures that the opportunity cost of employing an EMT service is low in the event that there is an emergency elsewhere. Although the proposed system is ethically sound and community approved, the financial feasibility of the program is uncertain. Because the program is resource intensive, the success of the program hinges on the economies of scale provided by high donor registrations. The effectiveness of New York City's program, once it is published, will provide invaluable lessons for other states.

Recommendations

Ultimately, the pinnacle achievement of the UDDA is that it allows more sources of deceased donors. With the moral justification of brain dead donors and both controlled and uncontrolled cardiac dead donors for transplants, it is then imperative to pave the way to maximize procurement of cardiac dead donor. Considering the Massachusetts experience entailed higher costs for cardiac sources, one recommendation would be to provide a higher reimbursement for hospitals that extract organs from cardiac dead donors. Currently, all kidney transplants fall under the same Diagnostic-Related Group (DRG) despite the fact that cardiac transplants cost more to a hospital. As such, hospitals are essentially punished for attempting to help alleviate the kidney scarcity by using donors justified by the UDDA. Considering the outcomes of cardiac and brain dead donors are equivalent and that both cadaveric sources are

less costly than dialysis, it is cost effective to appropriate dialysis funding to deceased cardiac procurement efforts. If it is difficult to maintain a procurement system outside of the hospital, it is advisable that efforts are allotted to procuring uncontrolled cardiac dead patients from the emergency or trauma departments.

Despite the bulk of kidneys originating from deceased donors, there are still living donors to consider. Living donors were not officially addressed until 1984 with the next significant piece of legislation creating the governing bodies of transplantations and cementing the scarcity of organs.

The National Organ Transplant Act of (NOTA) of 1984

Many of the administrative aspects of organ donations and transplants were established in 1984 through the National Organ Transplant Act (NOTA). The act authorized the U.S. Department of Health and Human Services (HHS) to oversee all aspects of organ donations and transplantations. In 1986, HHS created the United Network for Organ Sharing (UNOS) to oversee the Organ Procurement and Transplantation Network (OPTN) and Organ Procurement Organizations (OPOs).

The various responsibilities of UNOS include establishing an efficient organ sharing system, maintaining a historical database of all transplants that have occurred in the U.S., managing the national transplant waiting list, creating allocation procedures, monitoring organ matches to ensure organ allocation policies are followed, and educating the public about organ donations and transplantations (United Network for Organ Sharing, 2016). Under the umbrella of UNOS, the OPTN is responsible for increasing efficiency and equity in organ allocation and

increasing the supply of donated organs. The 58 OPOs throughout the country are responsible for increasing the number of registered donors and coordinating the donation process once it begins. OPO representatives are also the ones who approach families in hospitals about the opportunity to donate their kin's organs after death.

One of the biggest impacts of NOTA was the explicit outlaw of the sale of organs. This provision came to fruition in 1984, one year after the revelation that Dr. H. Barry Jacobs, a Virginia physician, had been purchasing organs from donors in third world countries (Sullivan, 1983). His actions were deemed so horrendous and untenable that the following year, all forms of sales were prohibited by NOTA. The act prohibits all "valuable consideration" extending not only to direct exchange of money for organs, but also incentives such as charitable contribution on behalf of an organ donor or partial coverage of funeral costs of the donor (Legal Information Institute, 1984).

On the grounds that NOTA authorizes the principal actors in all decisions related to organ donations and transplantations, and on the grounds that many believe NOTA heightened the organ scarcity, it is crucial to analyze the commandments of such an overarching piece of legislation.

Ethical Analysis of NOTA

If the power to immediately save thousands of lives now and in the future are endowed upon a single entity, surely the composition of that entity must carefully balance public sentiment, efficiency, and morals. One association to UNOS is referred to as the "God Committee." This group dates back to the 1960s when seven individuals in Seattle had to decide

who could receive access to the limited dialysis sessions available at that time. The group often chose recipients on the basis of resemblance: for example, an educated middle class white working man or a respectable church going white mother (Fox et al., 2008). To prevent such extreme biases from occurring, NOTA demands that the UNOS board must have $\frac{1}{3}$ of the members disassociated with organ transplantation or procurement. In compliance, the UNOS board is half composed of physicians and transplant surgeons, while the other half is comprised of donor family representatives, attorneys, and philosophers. Besides the governing body of UNOS, NOTA also requires that every OPO throughout the U.S. have public representatives on its board of directors (Veatch, 2000). This specific requirement is ethically sound because it ensures that there are various perspectives representing the different stakeholders and that no one group of individuals is unfairly discriminated against. Moreover, because OPOs are spread throughout the country, requiring representatives of the public ensures that relevant population concerns are addressed and that geographic constraints are taken into consideration. In Chapter 4 it will become clear that there are certain locations in the U.S. with clear racial disparities caused in part by geography. Mandating that the OPO board have public representatives assures that those with the largest stakes, for example African Americans in organ scarce areas, have a voice in how organs are acquired and allocated fairly. In practice, it is naïve to claim that UNOS and OPOs are entirely impervious to biases. Nonetheless, because UNOS strives for a balance between efficiency and equity, there will always be some tradeoff that causes inefficiencies and inequities regardless of the composition of the governing bodies.

One considerable inefficiency, and undisputedly the most controversial aspect of NOTA, is the outlaw of the commercialization of organs. This prohibition of “valuable consideration” extends to both living and deceased donors. That is, neither living nor deceased donors may be

rewarded with any form of financial benefit. To analyze the merit of this provision requires analysis of benefit, autonomy, paternalism, and respect for persons.

With the current gift and altruism based organ acquisition system, the recipient of a donation benefits from improved and prolonged quality life while the donor, deceased or alive, receives the internal and nonmaterial satisfaction of helping someone (referred to as the warm-glow effect in economics literature). Because the majority of individuals do not willingly choose to incur more harm than benefits to themselves, it is reasonable to interpret that living donors donate because they assess the benefit of the warm-glow as being greater than the cost of donating. If these living donors did not believe the benefit of the warm glow to offset the cost of donating, then they would not donate. That same reasoning or sentiment is not shared among the majority of American, or really the majority of citizens in any country; that is precisely why every country in the world with the means to organize kidney transplants has a scarcity of kidneys (Shimazono, 2007). Costs associated with live kidney transplants can include irreversible complications during the operation, the need for dialysis or transplant in the future because dependence on a single kidney, and/or lost wages during the three-to-four-week recovery period, and other tangible and psychic costs. If the scarcity can be explained partly by the fact that most living donors do not measure the warm-glow benefit of donation to be higher than the cost of donation, then providing a reason for living donors to weigh the benefits of donation to be greater than the cost of donating may be one solution to the scarcity; i.e, allowing valuable consideration for organs.

Models of compensating differentials in labor markets show that occupations with more risk and of less desirability are compensated more (Pouliakas & Theodossiou, 2013). With regard to organs, living donors bear all the risk in donating while deceased donors do not. As

such, living donors are the target for a compensatory system precisely to offset the risk and apprehension of donating. Second, compensation supporters do not defend the mechanism in which the organ recipient buys the organ directly from the seller. To assure non-coercion, market proponents support the idea that the government (UNOS or the OPOs) purchase the organ and distributes the organ to the best matched candidate (Satel, 2009). This guarantees an equitable system in which affluence does not buy life. More importantly, it ensures that potential sellers are entirely aware of the risks associated with donations and are not misinformed by biased and self-interested recipients.

The primary support for the compensation of organ sellers is voiced by Utilitarians who find ethical merit in a marketplace considering both parties gain and are better off from the exchange (similar to the Pareto improvement achieved when one honors a deceased individual's wish to donate organs). This Utilitarian way of thinking permeated into modern bioethics where health professionals are held accountable to maximize the well-being of their patients (referred to as beneficence from the earlier account of Principlism in the UAGA). With a compensated system, the recipient of the sale benefits the same as before while the seller now gains a monetary benefit while also retaining the warm-glow effect of helping someone live. Thus, with a compensation system, the benefit of donating has the potential to be greater than the cost of donating and more people would find it reasonable to donate, leading to a reduction in the shortage. To a Utilitarian, conclusively, a compensation system could maximize utility for both parties and thus would be ethically justifiable. Different from Utilitarians who are in favor of maximizing utility, Libertarians favor a compensation-based system on the basis of maximizing autonomy.

Locke's (1952) exploration into laws of nature serves as the seed for Libertarianism. In his *Second Treatise*, Locke notes that individuals own themselves as property. This led to the underlying principle of Libertarianism in that people have certain rights over themselves and that it is unethical to impede on a person's freedom to do what they please. Similar to the bioethical principle of beneficence stemming from Utilitarianism, the bioethics principle of respect for autonomy stems from Libertarianism. This principle was included in the ethical analysis of the UAGA where it was deemed unethical whenever the kin's decision overruled the wishes of the deceased. Similarly, the Libertarian view holds that because individuals have the ultimate right over themselves and their bodies, they have the right to do as they please with their body, including the sale of it. The caveat is that individual liberties must not impede the liberties of others. This restriction is why yelling "fire" at a theater and making death threats, for example, are not protected by the freedom of speech. With regard to organs, so long as the sale of one's body does not impede another person's freedom, Libertarians support the commercialization of body parts. NOTA's prohibition of valuable consideration, to a Libertarian, is unjustifiable on two counts: invasion of autonomy and undue paternalism.

Frankfurt (1971) has clearly articulated autonomy to mean self-governance reflecting personal preferences and desires. If it is the preferred choice for an individual to sell an organ in order to obtain a higher benefit, then the prohibition of organ sale is a restriction of autonomy. A popular argument against compensating organs is that it will coerce the poor by compelling the disadvantaged to sell an organ that he/she would prefer not to (constrained autonomy) (Arnold et al., 2002; Matas et al., 2008). To a Libertarian, prohibiting a medium to escape poverty is a further restriction of autonomy. In fact, creating a barrier to selling an organ through a safe medium opens the door to much worse mediums to escape poverty such as black markets

for organs. Images of the wealthy preying on the desperation of the poor is associated with the black markets namely because that image is accurate.

Wealthy recipients throughout the world do in fact purchase the rights to human organs from third world citizens. This market exists notably in India and an abundance of literature has expounded on the deplorable and horrid treatment of sellers in third world black markets (Sehgal et al., 2002; Jha, 2004; Scheper-Hughes, 2004). These desperate third world individuals resort to the black market because they have nowhere else to turn. Moreover, because exchanges are hosted directly between the wealthy recipient and desperate seller, there are prolific accounts of buyer failing to uphold promises and payments to the seller. However, the fraud and deceptions associated with black markets are precluded with a legal, regulated, and above-ground markets where the buyer is the government.

Iran is the only country in the world that allows a legal living market for organs. The Iranian government established a legal marketplace for the sale of organs in the 1980s and Iran has reaped the full benefit of the marketplace because it is the only country to come close to full eradication of their kidney wait-list⁶. To achieve this feat, the recipient's insurance pays 90% of the entire cost of the transplant while the government pays the remaining 10% (around \$1,200 for a kidney) and provides one year of health insurance that covers conditions related to the surgery (Mahdavi-Mazdeh, 2012). The recipient additionally pays a negotiated amount between \$2,300 and 4,500 (Ghahramani et al., 2012). In total, a living seller can expect to be compensated upwards of \$3,500 for a kidney. A surveys of Iranian kidney sellers have highlighted that because over 60% of sellers were living below the poverty line, the majority of sellers were motivated by their economic standing. Nevertheless, over 90% were satisfied with their decision

⁶ There are still those who cannot afford a living donor and must wait for a deceased donor.

and a marketplace where both parties gain may be feasible in other countries, including the U.S. (Malakoutian et al., 2007). A legal organ market would promote autonomy and be utilized by those who believe selling their organ is the first-best accessible option relative to all other options they have. Lastly, Libertarians would argue that the authorities behind NOTA were acting out of paternalism where the authorities felt inclined to protect the disadvantaged from accessing an option that the authorities did not approve of.

This paternalistic logic is weak considering most people make sacrifices to obtain something they consider to offset the sacrifice. The poor drop out of school to obtain multiple or undesirable jobs out of necessity for immediate income, keep the heat low during winters to control cost, consume without satiation, and sacrifice overall luxury and leisure for work to sustain basic life (Devine et al., 2006). Similarly, even though middle-class Americans regularly sacrifice preferable leisure for labor, no one denounces such sacrifices. There is additionally the sweatshop argument. A majority of Americans purchase goods produced in sweatshops while fully cognizant of the poor treatment of workers. The economics of a sweatshop argument is very similar to the valuable consideration argument for organs: “subjects are indeed choosing employment opportunities that improve their wellbeing and capabilities” and that sweatshops are a necessary evil to prosperity afforded by the best alternative (Skarbek et al., 2012). If both of these scenarios of sacrifice and utilizing those of economic disadvantage are permissible, then allowing compensation for organ sellers should be permissible on the same grounds.

Moreover, if Deontologists argue that dire economic conditions erode autonomy, by extension, they have to concede that when a parent of a moribund child donates an organ to that child, then that donation ought to be barred due to manipulated autonomy as a result of affected psyche. Often, family members donate organs to one another because they operate under the fear

of losing a loved one. Likewise, the impoverished may sell a kidney out of fear of not being able to pay for a loved one's medical care for example. The family donor and kidney seller are both operating under less than ideal emotional states so it is unreasonable to outlaw only the sale of organs when the premise of donating to a family member is identical to the premise of selling a kidney to provide for a family. On the extreme side of the argument, despite euthanasia having a negative connotation, five states currently allow physician assisted suicide because by the mere fact that because every individual has a right to life, every individual also has the right to death. These individuals choose to end their lives often because they want to avoid suffering in the terminal stages of life. Similarly, those who choose to sell their organs do so to avoid worse prospects of life such as not being able to feed their children, pay rent, or pay for a loved one's medical care. If it is acceptable to allow someone to redeem their right to die, then equivalently it should be acceptable to allow someone to freely forfeit a part of themselves. Altogether, Libertarians argue that it is not the responsibility of anyone to limit another's exercise of liberty. Perhaps the repugnance concerning the sale of organs is rooted in the fear that commercializing humans leads to the devaluation of humans.

Assuming that it is permissible to allow an individual to sell an organ because the individual owns the right to do with his/her body as he/she pleases, what prevents an individual from selling a heart? That is, is it permissible to allow a purchaser (whether the government or insurer) to kill someone by buying a life-essential organ? Because five states currently allow euthanasia, patient-chosen death in the face of terminal illness already seems acceptable in some areas of the U.S. Libertarians would answer in the affirmative, yet it *feels* wrong. Bioethicists refers to this concept as the "wisdom of repugnance" (Kass, 1997).

The theory holds that intuitive response to a situation should be objective evidence for assigning a value to the situation. This repugnance acts as a signal whenever reason cannot articulate opposition to a situation. Organ sales are considered repugnant transactions because they are emotionally repulsive to members of the society who consider the act to diminish human dignity. This repugnance is the same reason that the consumption of dog and horse meat California, and indentured servitude throughout the U.S. are explicitly outlawed (Roth, 2006). The idea of compensation for organs feels wrong precisely because someone's life should not be purchasable. The entire foundation of equity crumbles once the idea of purchasing humans is introduced because it suggests that some humans are worth more than others. An entire branch of econometrics is devoted to calculating the value of a statistical life (VSL). VSL refers to the value placed given a marginal change in the likelihood of death. Labor, environmental, and health markets are often used to estimate a VSL range between \$4 and 9 million (Viscusi et al., 2003). But such estimates are not indicative of the actual value of life when death is certain. For the same reason, life insurance, which relies on risk of death, is not an equivalent comparison to payment for certain death resulting for the choice to sell a vital organ.

The value of a human can never be calculated in any way because value is subjective. The value of a parent/guardian to a child, regardless of the wealth or societal contributions of the parent, is immeasurable. However, that same parent may be worth \$10 an hour to an employer. That same parent may be worth a million dollars to a billionaire hedge fund CEO who needs a kidney to live. Although the Libertarian and Utilitarian defense in favor of organ commercialization is attractive, a market is ultimately indefensible because their same arguments do not hold for vital organs. Conclusively, the contributors to NOTA maintained human dignity for all by valuable consideration for organs. Nevertheless, it is possible to align with the

principles of NOTA while also compensating donors. This matter is discussed later in the *Recommendations* subsection.

Economic Analysis of NOTA

Society's desire to protect human dignity is even evident in legal goods market. In a typical goods market, when faced with high demand for a product, sellers may increase the price of a good without facing any backlash. However, in the event of a natural disaster or emergency, although there may be a high demand for emergency goods such as medical products, reconstructive equipment, or food staples, sellers are prevented from increasing their prices (price gouging) because doing so undermines respect for human necessity. Concerning organs, organ sales transacted between individuals is considered a negative externality. Negative externalities are defined as costs absorbed by a third-party when an individual engages in a private transaction or behavior. For example, when an individual decides against receiving a flu shot, society bears a cost as well as the individual if the individual catches and spreads the flu. In the context of organs, although the private individual benefits from the sale of a kidney, society bears the repugnant cost of the transaction. To control such undesirable behaviors, the government typically fines the behavior, for example fining per unit of pollutant, or completely outlaws the behavior, for example making it illegal to murder someone. NOTA is an example of a complete outlaw because it prohibits all behaviors related to monetizing human organs. Without NOTA, each valuable transaction for kidneys would be a negative consumption externality because society would bear the cost of the transaction. NOTA declared such behaviors to be a public nuisance and reflects the irritant with a price ceiling set at \$0, effectively

averting the nuisance and exacerbating the shortage. Figure 3 depicts the theory of repugnance with the use of externalities. Where as q_{pvt}^* is the optimal quantity of production for private marginal cost (MCpvt) and marginal benefit (MB), because society bears a higher cost marginal curve (MCsoc) from the repugnance, only a lower quantity (q) is supplied. Repugnance creates a deadweight loss because potential transactions are forgone and the scarcity is increased.

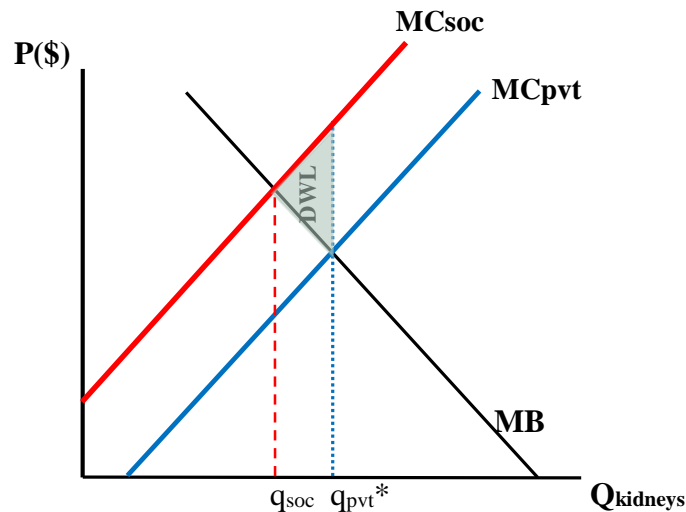


Figure 3. Negative Externality and Dead-Weight Loss (DWL)

Another economic component of NOTA is the creation of a governing body regarding all matters on organ donations and transplantation. Essentially, a non-profit monopsony and monopoly were established because only one entity in all of the U.S. can acquire and distribute organs (at a price of \$0) and that is UNOS. When an organ becomes available, it goes into the possession of the OPO which then determines the best recipient to give the organ to. Although monopsonies typically suffer deadweight loss resulting from an upward sloping marginal cost curve, OPOs are not expected to face the issue because OPOs pay the same price (\$0) for all organs donated. It retains a flat supply curve similar to a competitive market. A single seller and buyer was necessary to ensure that there was uniformity in the manner organs are acquired and

allocated. Having a single entity acquire and furnish extremely valuable goods such as organs for transplantations safeguards fair acquisition of donors and that recipients are not unfairly taking advantage of donors in the manner than is often found in black markets for organs.

A cursory evaluation of a living market for kidney sellers would first take into consideration a reservation level. First there would be minimum level of payment to blanket the risks involved with donating. The payments for quality would simply add on this minimum level of payment. Drawing from the Becker and Elias model, this minimum value has to take into consideration the risk of donating, the lost income during the rehabilitation stages, and the risk of lower quality of life (Becket & Elias, 2007).

Currently a living altruistic donor only receives coverage for the costs associated with the actual transplant and follow up procedures. Donors do not receive compensation for lost income during the rehabilitation period. For there to be a fair market, there has to be a guarantee of at least breaking even. Many people choose to forgo donations because the cost of donating (loss of income and risk of reduced quality of life) is greater than the benefit (warm-glow). A minimal level of compensation would begin with the reservation price that offsets the cost of giving up a kidney. This reservation price would take into consideration the risk of undergoing the surgery, the loss of income, and the risk of reduced quality of life post-sale:

$$Y = r_1Harm + \beta_1Income + \beta_2Quality \quad (1)$$

The estimated risk of surgery related death is estimated to be 0.03% (Bia et al., 1995). To calculate the value of losing life requires evaluating the statistical value of life. The Department of Transportation (2016) estimated that the statistical value of a life to be \$9.4 million. The expected recovery time for a donor is between four to six weeks. Using the more conservative figure of six weeks, means a full year's income is reduced by 11.5% assuming one works all 52

weeks in a year. The average income of an American was \$54,000 in 2013 (DeNavas-Walt et al., 2014). There is no exact mechanism to calculate the reductions in quality of life following a kidney donation. To that extend, Becker and Elias arbitrarily used \$7,500 for the quality of life. Adjusted for inflation, that value would now be around \$8,600. Messersmith et al. (2014) published a survey of 2,455 living donors and came to the conclusion that 84% were satisfied with their lives post-donation. If their findings are generalizable to the population as a whole, it is reasonable to suggest that there is an insignificant reduction in life quality following a kidney donation. Evidence from the survey support the use of Becker and Elias' \$8,600 for quality of life. Taking these values into consideration yields an average reservation price of nearly \$19,000. This is the amount of compensation necessary to breakeven between the costs and benefits of a living kidney sale. Even though there is no profit to be made at this level, this is where cost equals benefit and would capture those who would donate as long as cost is not greater than the benefit.

Figure 4 depicts the theoretical decrease in the shortage once compensation of \$19,000 is taken into consideration. The starting price of a kidney transplant prior to compensation is around \$260,000 (Bentley, 2014). The compensation for sellers raises the price of a kidney transplant to \$279,000. There after, supply is expected to increase because of the additional payments for changes in income. This increase in supply is associated with an increase in quantity supplied which reduces the shortage of kidneys needs for transplants. The supply curve eventually becomes rigid because compensation is unlikely to incentivize someone who does not need compensation to better their life. Nevertheless, such a sale is currently and will likely in the future be prohibited for the ethical reasons aforementioned.

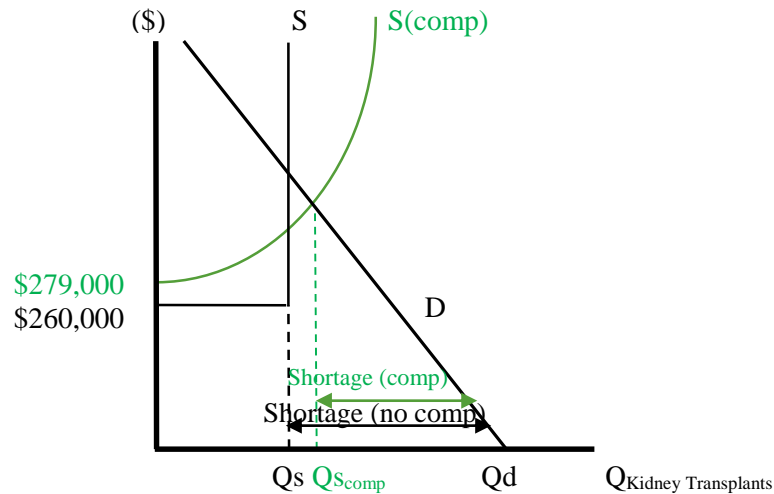


Figure 4. Shortage with/out Living Compensation

Recommendations

Although NOTA is ethically sound in that it protects human dignity, the annual death of thousands exacerbated by NOTA cannot be ignored. Moreover, if NOTA bans valuable consideration for organs to protect human dignity, then surely NOTA does not apply once a person is deceased when there is no dignity to violate, harm to incur, nor coercion to be induced. One novel proposal by Pennsylvania in 2000 was to pay a portion of the funeral expenses of a deceased donor. If organs are procured from a deceased donor, the state proposed to approach the survivors and offer to pay between \$400-4,000 toward the funeral expenses. The Ethics Committee of the American Society of Transplant Surgeons ultimately reached the conclusion that a small financial token of gratitude toward funeral expenses that Pennsylvania was proposing does not violate human dignity (Arnold et al., 2002). Although the Pennsylvania proposal was never actualized due to a fear of violating NOTA, compensation toward funeral

expenses ought to be reconsidered. There would be two ways to compensate post-mortem donations.

One way is a sort of contract in which an individual could sign up to be a donor and denote on a document of gift that he/she want to redeem the funeral compensation. Upon death, the document could be provided to the surviving kin as proof of positive or negative gift and indication of whether or not the deceased individual wanted to redeem the funeral compensation. Alternatively, if a living individual had never denoted a desire for funeral compensation, or the document of gift cannot be found, theory of equity requires that the compensation option ought to be presented to the surviving kin. Those who would redeem the option are still the same income constrained cohort that would gain from living sales. But as long as the death was not inflicted in order to rapidly acquire the payment, there is no ground to believe that there is a person to take advantage of. Additionally, not only would it incentivize those who were unwilling to donate for purely altruistic reasons but it would inevitably stimulate a system that would pursue to capture as many donors as possible inside and outside a hospital setting in order to redeem the compensation the sellers signed up for. This post-mortem payment system is ethically sound considering it neither takes advantage of the desperation of individuals nor objectifies humans as simple means to an end.

Without an empirical foundation, the ethics committee then evaluated deceased donor compensation found that an acceptable level of compensation would be between \$800 and \$4,500. This range is reasonable considering the average funeral expense is between \$6,000 and \$10,000 (Ellig, 2015). The amount paid to deceased donors has to be significantly less than for living donors because the deceased donors do not incur the harm or lost wages that living donors incur. More specifically, the funeral compensation must be below \$13,000 because that is the

non-wage component of the Becker and Elias model. If post-mortem compensation is substantial, exceeding \$10,000, the system becomes financially unfeasible because there would be a surge of demand for the benefit from the survivors who have zero costs to incur but 100% of the benefit to redeem. A more detailed analysis of how a post-mortem compensation would be undertaken is discussed in Chapter 3.

Conclusion

It is apparent that there needs to be a better implementation of the Uniform Anatomical Gift Act (UAGA) and more accountability on those who are to execute the provisions of the UAGA. The act was established to promote organ donations and respect the wishes of the deceased. For several psychic and logistic reasons, the intended effects of the act have not been fruitful. Until there are incentives to follow the procedures set forth by the UAGA or punishment for failing to follow the UAGA, procurement agents will continue to seek consent from families and will perpetuate the widening gap between those who need organs and those who are willing and able to donate organs. To yield the fruits of the act requires a balance of procurement agents increasing their efforts to obtain first-person gift documentation and present the document evidence to the kin for final approval. Increasing such efforts will require non-monetary incentives that still allow transplant sites to achieve more profits from more transplants. The inclusion of the two definitions for determining death by the Uniform Determination of Death Act (UDDA) was essential to the progress of organs transplants thus far. Without UDDA, there would undoubtedly be a larger shortage because hospitals would be constrained to a very controversial and unpredictable mode of death, cardiac, to acquire organs. Nevertheless,

implementation of UDDA can still be improved if resources were funneled to procure organs from both controlled and uncontrolled cardiac dead donors. Lastly, the National Organ Transplant Act (NOTA) created a governing body that involves nearly every stakeholder in organ donations and transplantation to ensure that all perspectives are represented. NOTA bans the live sale of organs to protect equity and protect human dignity, however, NOTA should be modified to provide post-mortem compensation in order to capture more organs while retaining human dignity.

With these legislations in mind, it is now appropriate to examine just how organs, specifically kidneys, are acquired in the United States and how current mechanisms can be altered to maximize organ acquisition.

Chapter 3

Acquisition

Different countries have implemented different acquisition mechanisms to increase the supply of organs with varying results. With the exception of one country, Iran, all other countries with the means to host an organ transplant system rely entirely on the altruistic donations of its citizens. Although most countries rely on altruism, there are two mechanisms to obtain altruistic donations: direct consent (opt-in) and presumed consent (opt-out). The tradeoff for sole reliance on altruism is thousands of patients dying on the wait-list. This dilemma introduces the need for an additional mechanism to acquire donors. A funeral compensation system in accordance with the National Organ Transplant Act (NOTA) may be a feasible option to delay the deaths of thousands every year.

Economists often believe that if the world is left to a free market, the problems of scarcities will disappear. They are not naïve enough to believe that free markets are by any means just. Taking cues from Keynesian theories of economics, three countries have at one time legalized a government controlled marketplace for organs. Iran still has a legal marketplace while India and the Philippines have retracted their once legal marketplace. If NOTA is modified to give financial consideration for organs acquired from deceased individuals, it is valuable to assess the success and failures of the Iranian live organ sale market to evaluate compensation for deceased donors in the U.S. The following section analyzes the ethics and economics of the opt-in/out systems and a possible compensatory system for acquiring organs from the deceased.

Opt-in vs Opt-out

The United States and nearly two dozen countries⁷ operate under an opt-in system that requires individuals to take an active step to approve being a donor. The default assumption under an opt-in system is that individuals do not want to be organ donors after death. If the individual desires to be an organ donor, the individual would have to take initiative and actively sign up to be a donor. In the U.S., an individual could become a donor by denoting a check-mark on the option to be a donor on their driver's license application, registering at their state organ registry, or indicating it on a last will. If a deceased individual does not have any sort of documentation of gift, the Organ Procurement Organization (OPO) assumes that the individual did not want to be a donor. At that point, the only legal option, permitted by the Uniform Anatomical Gift Act (UAGA), to obtain the organs of the deceased individual is if the kin give consent on the deceased's behalf. As studies in Chapter 2 suggest, the implementation of the UAGA has been ineffective and costly to those on the wait-list for an organ. Some countries avoid the shortcomings of the UAGA by operating under an opt-out system.

Most notably Spain and a different set of two dozen countries⁸ operate under an opt-out system, also known as presumed consent, that requires individuals to take an active step to oppose being a donor. In stark contrast to the opt-in system, the default assumption under the opt-out system is that individuals want to be organ donors after death. Analogously, if the

⁷ Opt-in: Australia, Brazil, Canada, Cuba, Denmark, Estonia, Germany, Guatemala, Hong Kong, Iceland, India, Ireland, Israel, Japan, Kuwait, Lebanon, Lithuania, Malaysia, Malta, Mexico, the Netherlands, New Zealand, the Philippines, Puerto Rico, Romania, Saudi Arabia, South Africa, South Korea, Switzerland, Taiwan, Thailand, the United Kingdom, and Venezuela (Rosenblum et al., 2012).

⁸ Opt-out: Argentina, Armenia, Austria, Belarus, Belgium, Bulgaria, Chile, Columbia, Costa Rica, Croatia, Czech Republic, Ecuador, Finland, France, Greece, Hungary, Italy, Latvia, Luxembourg, Norway, Panama, Paraguay, Poland, Portugal, Russia, Singapore, Slovak Republic, Slovenia, Sweden, Tunisia, and Turkey (Rosenblum et al., 2012).

individual does not want to be an organ donor, the individual would have to take initiative and actively sign out of being a donor. For example, the individual could mark “no” for the donation option on the driver’s license application or denote the opposition on the last will. If a deceased individual does not have any sort of documentation of gift, the procuring agent technically has full discretion to assume the individual wanted to be an organ donor and to proceed with procuring the viable organs. In reality, there are two opt-out options. In “hard” opt-out countries (Belgium, Finland, Singapore and Sweden), it is acceptable to positively assume of the donation and collect organs without consulting with the kin. In “soft” opt-out countries, even in the absence of documentation, procurement does not take place without the consent of the kin (Rosenblum et al., 2012). Since 2005, as Figure 5 depicts, the American majority (51%) has shifted in support of an opt-out system (Department of Health and Human Services, 2012). With a majority of American now in favor of a presumed consent system, it is important to assess the ethical merit and potential economic benefit of an opt-out system.

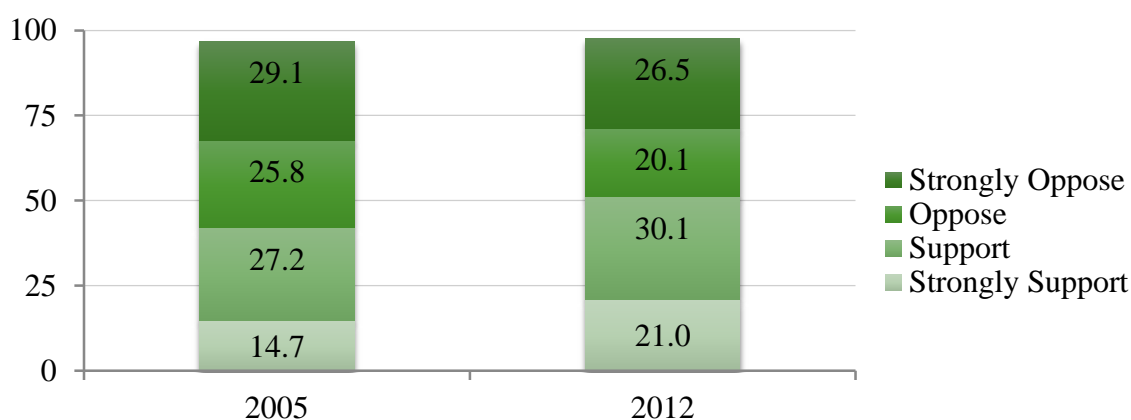


Figure 5. Support for Presumed Consent

Note: Reproduced from the Department of Health and Human Services (2012)

Ethics of Opt-in vs Opt-out

The ethical justification for the opt-out system can be summarized as facilitating the wishes of the majority which allows thousands to be saved. In other words, the system puts the burden on a few to maximize the benefit of the many and accept the benefit of the many at the harm and cost of the few. This train of logic is a sub-branch of Consequentialism called Utilitarianism. Utilitarianism, founded by Jeremy Bentham and John Stuart Mill, assesses the rightfulness of an action by the quantity of benefit or malice the action produces (Stein, 2002). Bentham's form of Utilitarianism aims to maximize "good" as defined as happiness (hedonism) (Bentham & Mill, 1961). As such, Utilitarians would endorse an opt-out system because it maximizes utility for two parties. The first is the individuals on the wait-list because with an opt-out system, the pool of possible donors is much larger so the chances of receiving an allocation is larger. The second party that benefits is the donors themselves because they can obtain their wish, to have their organ donated after death, without any effort.

Where opt-out falls short of ethical justification is that it compromises an individual's right to be the ultimate owner of his/her own body and undermines the "informed" part of consent. Presumed consent does not technically take away the right to one's body because the option to opt-out still exists. However, the burden has been shifted to take action to defend the right. The nature of inalienable rights is that it is guaranteed to all regardless of circumstances. As such, inalienable rights such as the right to life and the right to one's own body should not necessitate that work be put into them to preserve the right. Moreover, with a presumed consent system, it becomes much easier to take advantage of those who were incapable, unable or unaware to oppose donating. The Belmont Report concerning consent requires the agent to be fully knowledgeable of all factors affecting the agent. With a presumed consent system, there is

also a misplaced presumption that all agents are aware of their options when that presumption has no ground. As bioethicist Robert Veatch bluntly states, “To presume consent is to make an empirical claim [...] that people would consent to a policy of taking organs without explicit permission” (Caplan & Coelho, 1998, p.176). That empirical claim is unsubstantiated considering only 60% of Americans have noted their desire to donate (Department of Health and Human Services, 2012). Presuming consent would mean the system procured an organ from an unwilling donor 40% of the time, assuming they were unaware of the ability to opt-out. That margin of error is far too large to presume accurate consent rates. Such an opt-out system would lead to the transfer of power of self from the individual over to the state.

Concerning informed consent, the population least likely to support organ donations are the least educated (Department of Health and Human Services, 2012). In an opt-out system, the least educated would be unfairly held accountable to seek the means to oppose post-mortem organ salvaging. Ultimately, the ethical downfall of the opt-out system is that the burden to preserve a right ought not be shifted to an individual when those rights are morally guaranteed. It is by this same method that society does not require an individual to consent to life saving treatments in an emergency room when foregoing treatment maybe more cost-effective. Only in the presence of a Do Not Resuscitate (DNR) order or an Advance Directive (AD) instructing to forego medical intervention can a hospital withhold treatment. The near universally held belief is that individuals hold the right to life and that resources ought to be devoted to secure the life. Likewise, because there is near consensus concerning an individual’s rights over his/her body, all resources and protocols must assume the individual retains ownership of the body. The burden needs to be on the state to prove otherwise. Even with the assumption that an opt-out system is ethical, it is necessary to asses whether or not it will produce the fruits it has boasted to produce.

Economics of Opt-in vs Opt-out

In a randomized control trial, Johnson and Goldstein (2003) assessed the impact of default assumptions on the rate of deceased donations. In three stages, participants were asked to note their donation choice given three scenarios: 1) the opt-in scenario with a negative assumption default, 2) the opt-out scenario with a positive assumption default, and 3) control group with no default. The first phase of the experiment showed significant differences because of the default. Specifically, that the opt-out scenario, where the default assumption is a positive assumption, had twice the donation rate of the opt-in scenario. This small scale experiment suggests that countries with an opt-in system and negative assumption like the United States will have fewer potential donors registering than countries with an opt-out system like Spain. In fact, when the researchers compared the cross-country consent rate in the second stage of their study, the data strongly mirrored their control trial. Figure 6 shows consent rates often exceeded 90% in the opt-out countries (in green) while opt-in countries (in red) reached a ceiling at 28%. Their findings confirm the claim that opt-out systems are significantly better at registering donors than opt-in systems. Once the difference in registration rates was determined, it was necessary to evaluate whether the higher observed registration rates in opt-out countries translated to higher transplant rates.

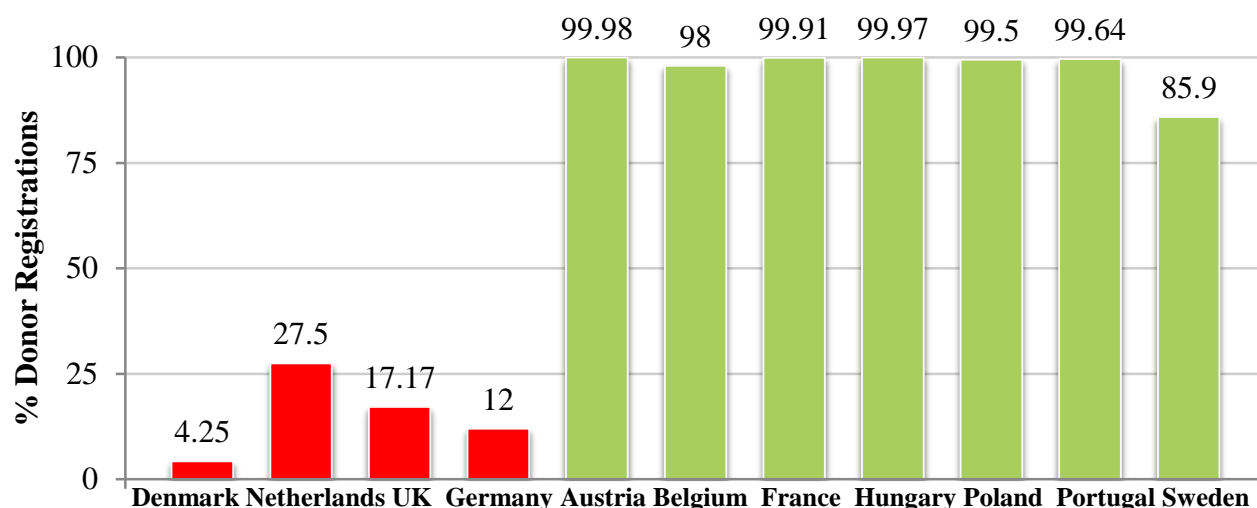


Figure 6. Effective Consent Rates, by Country

Note: Reproduced from Johnson and Goldstein (2003)

In a panel study, Shepherd et al. (2014) collected 13 years' worth of data from 48 countries to calculate the effect of the default assumption on transplant rates. To effectively determine the impact of legislation, they controlled for road traffic accident mortality, Gross Domestic Product (GDP), the number of hospitals beds, religion (specifically Catholicism), legal system, and philanthropic propensity. They concluded that deceased donor rates were higher in opt-out countries than opt-in systems (14.42% vs 9.98%, respectively). In contrast, the rate of living donations was higher in opt-in systems than opt-out (9.36% vs 5.49%, respectively). Nevertheless, the total number of transplants that took place over the course of 13 years was still higher in the opt-out countries (28.32% vs 22.43%). These findings have been similar to those that been found in earlier reports (Abadie & Gay, 2006; Horvat et al., 2010). Although data suggest that the opt-out system captures more registrants and actualized donors, the effect of the switch from one system to another must be given consideration.

In 2012, nearly 95% of American approved of donating their organs after death, but the difference between their intentions and their behavior is significant because only 60% of Americans were registered to be organ donors during time of the survey (Department of Health and Human Services, 2012). This is perhaps because it is too costly to register as an organ donor in an opt-in system. The cost is that the potential donor be aware of their option to donate and where they can reflect their donation wishes. The benefit of the opt-out system is that it effectively and efficiently reflects the intention of the majority and eliminates the cost of taking initiative and taking action. Simply, it gives the individual what he/she wants without the individual having to do anything to make their wish known. In fact, this is one of the principles dictating the elasticity of supply. The easier it is to supply an item, supply should increase. Although the majority of Americans support organ donations, it is unclear whether introducing a presumed consent system to the U.S. will create a crowding-out effect. With the assumption of positive gift, those who were unsure may move to denote opposition to gift because of an intrusive assumption. To evaluate this possibility, it is helpful to consider how other countries have responded to the switch.

When the United Kingdom (UK) was considering a switch to an opt-out system, Rithalia et al. (2009) conducted a systematic review to predict whether the switch would benefit or harm the current donor rates of the UK. Their systematic review of similar countries revealed that when three countries (Austria, Belgium, and Singapore) made the switch, there was an increase in organ donation rates in all three countries. Austria's deceased donation rate increased from 4.6% to 10.1% after the presumed consent legislation passed. Similarly, Belgium witnessed an increase in deceased donation rate from 18.9% to 41.3% and Singapore too had an increase in donation rates from 4.7% to 31.3%. Together, three countries saw an increase in transplant rates

following the switch to an opt-out system. This finding partially refutes the crowding-out effect argument in the sense that it showed the magnitude of transplant rates was larger than the crowd-out rate. It ought to be noted that because this specific systematic review obtained its results from observational studies, it is not possible to draw a causal relationship between presumed consent legislation and the increase in deceased donor rates. Additionally, the study did not take into consideration other non-legislative changes that may have affected the donation rates. Noteworthy is that Wales commenced a presumed consent system in December of 2015. In future studies, Wales will add to the data on the effect of the switchover and provide insight on the viability of the switch in the United States.

One country that did not reap the benefits of the opt-out system is Brazil. In 1998 Brazil made the initial switch to an opt-out system, two years later Brazil reverted to the opt-in system after facing tremendous public opposition to the presumed consent system. There is no way to assess the impact of the switch because Brazil began collecting data in 1997. Despite the lack of data, there seems to be a consensus among the professional community that the donor rates plummeted after the switch because the donor rate in 1998 was the lowest, at 2.6%. Neto et al. (2012) compared donation rates in 1998 (opt-out) to donation rates in 2000 (opt-in) and calculated that reverting back to an opt-in system was met with a 5.4% increase in donation rates.

No prediction can be drawn concerning the crowding-out effect in the U.S. because there are no studies showing the absence or presence of a crowding-out effect after the switch to an opt-out system. What is clear is that there are more underlying differences between the two mechanism than the superficial difference in defaults. Because so many opt-out countries still require permission from the kin, it cannot be that legislation alone explains the difference in donations. Spain is often cited for the viability of the opt-out system because it leads the world in

the number of total donations. Shepherd et al. (2014) excluded Spain from their analysis and found that the difference in donation rates still favored opt-out systems which allowed them to defend the idea that opt-out legislations are superior to opt-in legislation. However, Deffains & Ythier (2010) citing Spain, have suggested that the switch in legislation is not a strong causal link because Spain's dominance in donations occurred 10 years after presumed consent passed. A consideration to be mindful of when comparing the two donation systems is the exceptionality of the Spanish model. Besides the soft opt-out system that Spain operates with, they also have a multilayered and multi-sited coordination system that maximizes the efficiency at which donors are identified and organs are procured. cursory analysis of worldwide donations per million indicate that four of the top five leading countries operate under an opt-out system while 5th place U.S. operates under an opt-in system (International Registry on Organ Donation and Transplantation, 2014). This suggests that there is more to deceased donation rates than changing the assumptions. Moreover, that data do not take into consideration variables such as transportation which significantly affects the transplant rates in the U.S. considering the large surface area inhibits kidney transportation.

The fact that opt-out countries still require kin consent the same way the U.S. does is indicative of a confounding variable affecting the higher donation rates in those opt-out countries. Moreover, it is unclear how the switch, if it were to happen, would affect the crowd-out rates in the U.S. What is clear, however, is that the system falls short of bioethics and thus should not be implemented in the U.S. Although the American opt-in system is not without flaw, the opt-in system is more ethical than the opt-out system because it requires explicit consent concerning what the state does to an individual's body. Additionally, because the American opt-in system is able to compete with Spain's opt-out donation rates, it is more likely that

modifications to an already ethical system is the key to transforming registrations into transplantations. A widely recommended modification to improve the opt-in system is a supplementary step known as required response.

Required Response

A shortcoming of the opt-in system is that it does not provide the explicit opportunity for people to make their decision. That is, it burdens people to be aware that they can make a donative decision at their Department of Motor Vehicles (DMV) or online on a state registry website. An opt-in system supplemented by a required response provision would operate as such: citizens would be required to make a decision on whether or not they want their organs donated after death. This request can be made on an income tax returns, which virtually all American are required to complete annually, or at the DMV, where most people currently register to be donors (Department of Health and Human Services, 2012). In order to have ethical merit, information on the deceased donations must be supplied with the decision form in order to maintain “informed” consent. The individual always retains the power to change their decision at any time. The default assumption would still be the same as that of the opt-in system; without a document of consent, the procurement agent is to presume that the deceased did not want to be an organ donor. The difference and benefit of the required response supplement is that there is certainty that an individual has made a decision concerning the matter and all the procurement agent needs to do is look for the source of decision. This document was a key recommendation in Chapter 2 because such a document would strongly persuade the kin to consent to the organ

donation. Together, the required response system would blatantly provide information on the opportunity to register to be a donor and reduce the burden of supplying consent.

Ethics of Required Response

A required response system has the ethical benefits of allowing people the opportunity to fulfill their desire and to maximize autonomy. The justification for the opt-out system was that the majority of citizens wanted to be organ donors and the country reduced the burden of fulfilling that wish by assuming consent, thus satisfying the wishes of the majority. Similarly, requiring a response allows people the opportunity to fulfill their desire to donate organs once deceased but with direct consent rather than guesswork. Unlike the unethical manner in which the opt-out system sacrifices the right of a few for the convenience of the majority, required response would be ethical because no one group is more burdened than another concerning their wishes. Comparable to the economic justification of the opt-out system, the required response system still reduces the burden of needing to know that donation is possible at the DMV or online because the question will be presented at the forefront. A required response system would also strengthen the commands of the UAGA because the procurement agent would have certain information on locating a document of consent and be able to provide evidence for the surviving kin to consent to the donation.

Moreover, because the decision is made while the individual is competent and in a relaxed setting, the decision that the individual makes is more likely to be clear and representative of their true intentions. If the decision is noted on an annual income tax return, the ethical benefit is even greater because the decision is more accurate whereas there are several

years between licenses renewals. Ultimately, regardless of the medium used to acquire consent, the decision is left entirely to the patron thus sustaining the ethical principles of autonomy and respect for persons.

On the other hand, a required response system does pose the opportunity for social coercion. There could be pressure at the DMV to give a socially acceptable answer to the donor question. It is comparable to a grocery store cashier asking a customer if he/she would like to make a charitable contribution before the final transaction and for the customer to possibly feel inclined to be charitable so as to not draw negative judgment. This social coercion is a cost that may impede registrations. Because this social coercion ceases to exist on an income tax return form, the tax return form may perhaps be the most appropriate medium to require a response. Nevertheless, considering thousands of individuals die every year, this minor intrusion of privacy may be permissible if it captures the thousands more who are willing to donate. Because of the benefits of the required response system is that it reduces the burden to supply registration, there is an expectation of an increase in supply of registrants. An assessment of that economic expectation follows.

Economics of Required Response

Obtaining information about donations and knowing where one can donate is a barrier to registering. Required response eliminates that barrier, which causes supply to become relatively more elastic. That is, because an obstacle ceases to exist, suppliers, in this instance eligible donors, are more easily able to supply themselves. If it becomes easier for individuals to register

as donors, there will be an expanded pool of potential donors which will facilitate the ease at which organs for transplants can be acquired.

Currently some states utilize a paper driver's license application where patrons answer questions on paper and hand the completed application to the DMV clerk for processing. This paper application can be thought of as an opt-in system because the patron has the ability to check the "donor" box, but if it is left unanswered, the clerk is to assume that the patron did not want to be a donor. The patron could have intentionally or mistakenly skipped the question on the application. If it was unintentionally left unanswered, then there is a potential donor who is lost because of simple paperwork.

Alternatively, some states process driver's license applications verbally instead of through paper. That is, the clerk reads the questions aloud and the patron gives a verbal response. This system is indirectly a required response because it eliminates the opportunity for the question to be left unanswered and requires the patron to verbally respond. This system would capture those who intend to donate by explicitly highlighting the opportunity to donate.

This difference in processing a driver's licenses presents a novel opportunity to compare the effects of a required response opt-in system to the basic opt-in system. I hypothesize that states with verbal applications would have higher donor registration rates than states with paper applications because the verbal application requires an answer and captures all positive responses. Because organs are transported across state boundaries, it is impossible to know whether verbal states correlate with more transplants. However, with more registered donors and donor indications on ID cards, the procurement agents would have more evidence to contact families and gain consent (as examined in Chapter 2). Thus, there would be more transplants from donors of verbal application states and an overall reduction of the wait-list because of the

verbal states. To prove this empirically, I contacted each state's Department of Transportation (or the state equivalent of a DMV) and 58 OPOs to obtain data on whether the verbal or paper processes correlated with higher donor registration rates.

Methodology

I contacted the central Department of Transportation of each state to first identify whether the state DMVs process driver's license applications verbally or through paper. 40 of the 50 states and D.C. responded with their procedure (Appendix 1 Table 1). Upon identifying states as either paper (opt-in) or verbal (opt-in + required response), I obtained the number of new non-commercial licenses issued in the state for every year between 2004-2015 and the number of donors from the count of new licenses per year. That is, of the new licenses issued every year, how many of those first time license holders indicated their desire to be donors. The data were constrained to new licenses to avoid double counting and to avoid minors who would need a parent's signature to become a donor. Together, this data allows for examination of registration rates and control to the size of the driving population for the states.

I also contacted the 58 OPOs around the country to obtain data on the annual number of new donor registrants for their respective areas for every year between 2004-2015 and of that count, how many came from driver's licenses. Requesting such data enables the confirmation of the accuracy of the data obtained from the DMVs. OPOs representing eleven states responded with data. Corroborating the data from the DMVs to the data from the OPOs furnished a total of eight states for the data analysis. The data and information provided by the DMVs and OPOs totaled to represent eight states. I used STATA to run a repeated measures ANOVA test to

determine whether or not there was a significant mean difference between the two groups (verbal and paper states). ANOVA compares the difference between groups over time based on differences in treatments. In this contest, the treatment is the difference in methods, verbal or paper.

Results

Table 2 shows that the ANOVA test of eight states between 2011 and 2008 revealed an insignificant effect of the method on the differences in donor registration rates. This results essentially shows that the method used to register donors does not affect registration rates. Without differences between the two treatments, there was no additional need to assess the movement of the method. That is, to determine whether the verbal increased or decreased registrations.

Table 2. Results

Model	Sum of squares	df	Mean Square	F	Sig
Regression	7.324e ⁰⁹	3	9.273e ¹⁰	2.12	.1337
Residual	2.075e ¹⁰	18	1.153e ⁹		
Total	6.480e ¹¹	31	2.090e ¹⁰		

Limitations

There are several limitations to this study. First on the part of the DMVs is the small sample size of the study. This occurred largely because of the lack of responses with data. Even with the inclusion of states that responded, there were inconsistencies with that data given due to

different definitions of “new licenses” and because data were confused in the process of transitioning to a new records keeping system. Resource constraints made it prohibitive for the participating DMVs to match registrants to their age, sex, and wealth. As such controls for certain variables could not be included.

Discussion

Given the limitations, the results show no differences in donor registration rates depending on the procedure used to acquire consent from DMV patrons. This is not to say that a larger study involving more states with more accurate data will similarly fail to show no differences. Additional research is required to determine, first, whether there are differences between the two methods. If there is, more research is needed to assess whether it is important to first assess whether different procedures to register donors exist. If such differences exist, it is important to assess whether the verbal methods yield higher registration rates or if it does the opposite. In the event that paper states have higher registration rates, it is likely that the verbal system is too intrusive and should not be applied nation wide.

Compensated Marketplace

For over a decade, the demand for kidneys has greatly exceeded the supply of kidneys and created a deadly shortage. The popular economic catch-all solution for any shortage is a free market. Allowing a free market for kidneys would mean kidneys would be priced above the current price ceiling of \$0 and buyers and sellers are free to determine an efficient price. Because paying living organs is neither ethically nor legally permissible, it may be more feasible to

modify the compensation ban in the National Organ Transplant Act (NOTA) and pay a portion of the funeral expenses of deceased donors (introduced in Chapter 2).

To determine whether a deceased marketplace above the price of zero for kidneys would succeed in the U.S., it is crucial to understand how the determinants of demand and supply play in favor of a compensated system. Specifically, the ability of the market to eliminate the kidney scarcity relies on a relatively inelastic demand for kidneys and a relatively elastic supply of kidneys. If these determinants of demand and supply hold true, it is reasonable to expect a compensated system to succeed in the U.S.

Inelasticity of Demand

On the demand side, those who need kidneys are relatively inelastic, meaning they are not strongly influenced by fluctuations in prices. Kidney transplants are desirable almost regardless of price because the only alternative to a kidney transplant is dialysis, and dialysis is far from a perfect substitute. Dialysis patients live for an average of five years while kidney transplant patients live for an average of ten years (Vollmer et al., 1983; Oniscu et al., 2004; Beth Israel Deaconess Medical Center, 2012; Bueti et al., 2014; Santos et al., 2015). Not only are transplants associated with comparative longevity, they are also associated with providing a higher quality of life.

Depending on how poorly functioning one's kidneys are, a patient visits a clinic about 2-4 times a week, is pricked with a needle in the vein, waits 2-4 hours for the blood to be drawn, cleaned, and returned to the body. As an individual's kidney inevitably deteriorates, the dialysis visits become more frequent, and the toll on the individual becomes increasingly devastating.

Dialysis also creates a cycle of disutility because of the high opportunity cost of routine dialysis. 2-4 hours 2-4 times a week is 4-16 hours of the week that an individual is away from work and missing out on income while still having expenses. Because kidneys only deteriorate while under dialysis, a patient can expect longer visits and increasing loss in income as time proceeds. As prolonged dialysis whittles away at income, individuals also lose the ability to maintain their intended lifestyles and their health which deepens the hole dialysis creates. In contrast, a kidney transplant is a single 2-4 hour operation followed by diminishing postoperative visits and increasing freedom and control over life. Consequently, because dialysis leaves people worse off, *ceteris paribus*, patients would prefer transplants to dialysis because transplants provide longer life spans and higher quality of life compared to dialysis. Besides the patients, insurers, who also comprise demand, would prefer transplants compared to dialysis.

Dialysis is covered by Medicare, Medicaid, and most other insurers under the End-Stage-Renal Disease Program (ESRD). Although the ESRD population comprised only 1% of the total Medicare population in 2012, the ESRD population disproportionally accounted for 6.5% of Medicare's total spending in 2012. ESRD patients incur six times the cost of the average non-ESRD beneficiary (\$79,000 vs \$11,000) (Medicare Payment Advisory Commission, 2014).

The 2015 United States Renal Data System (USRDS) Annual Report reveals that the ESRD program costs Medicare around \$31 billion in 2013. Figure 7 shows that dialysis per patient per year costs nearly \$85,000 while kidney transplants costs nearly \$30,000 per patient per year (United States Renal Data System, 2015). Although a transplant is costlier in the first year (resulting from the surgery), the \$30,000 figure is achieved when the costs are averaged out over the lifetime of the transplant. Considering there were a total of 466,461 ESRD patients undergoing dialysis in 2013, savings would exceed \$25 billion a year if all the dialysis patients

received a kidney transplant. If looking at demand through the eyes of insurers, the significant savings of transplants makes the good more attractive than dialysis. If payments for funerals ever come into fruition, insurers will have \$25 billion worth of reasons to be willing to pay for the funeral costs.

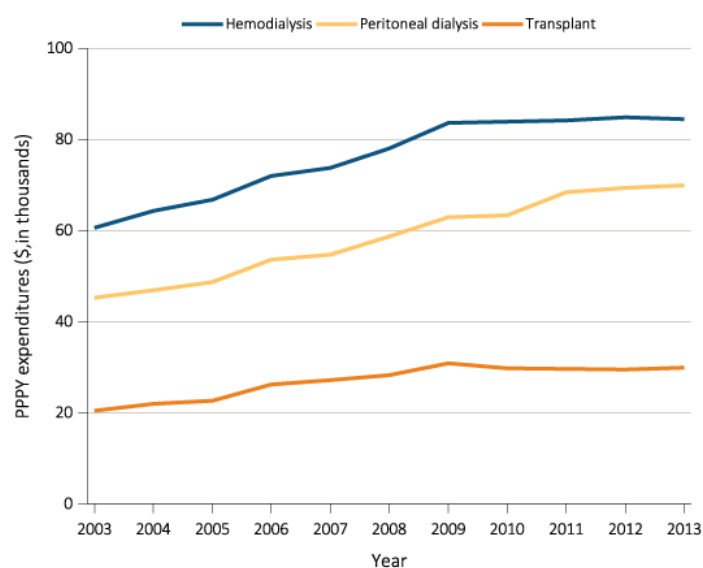


Figure 7. Total Medicare ESRD Expenditures per Person per year, by Modality

In conclusion, the data show that transplants increase life years and improve quality of life. Although dialysis is a substitute for transplants, is it not preferable to transplants. As such, even if the price went above the current price of zero, patients on the wait-list are not going to withdraw from the wait-list because they value their lives above a price of zero. Moreover, because transplants on average cost \$55,000 less than dialysis, insurers should prefer transplants to dialysis. Conclusively, patients and payers, both comprising the demand side of the market, gain more from transplants which makes the demand for organs relatively inelastic.

The reason it is important that demand be relatively inelastic is because the patients on the wait-list will likely need to pay a portion of the funds used for the supplier's funeral expenses. The deceased donor payment scheme will likely involve the recipients' insurance

paying into a pot that will be used to pay for the funeral expenses of the deceased donor. If demand is relatively inelastic, then the recipients will not forego transplants simply because of the added charge. Moreover, insurers will assess the savings of \$275,000 (per patient, per year) to be enough reason to contribute to the funeral expenses. As such there should be no difficulty in collecting sufficient funds needed to entice suppliers. However, the willingness to pay for transplants hinges on the expense of supplying kidneys for transplantations.

Elasticity of Supply

Distinct from a relatively inelastic demand for kidneys, it is often thought that the supply curve should be relatively elastic, subject to significant changes in prices, if there are incentives in addition to the warm-glow effect. A longitudinal survey revealed that the public has increasingly, over time, endorsed some form of financial compensation. Figure 8 shows a 46% increase in the number of people supporting organ compensation between 1993 and 2012 (Department of Health and Human Services, 2012). However, the same Figure shows a crowding-out effect because there was an increase in the number of people who would be less likely donate once compensation is introduced (8.9% to 9.5%). This section examines both the hypothesized supply elasticity and the crowding-out effect after introducing a price greater than zero to an originally altruistic market.

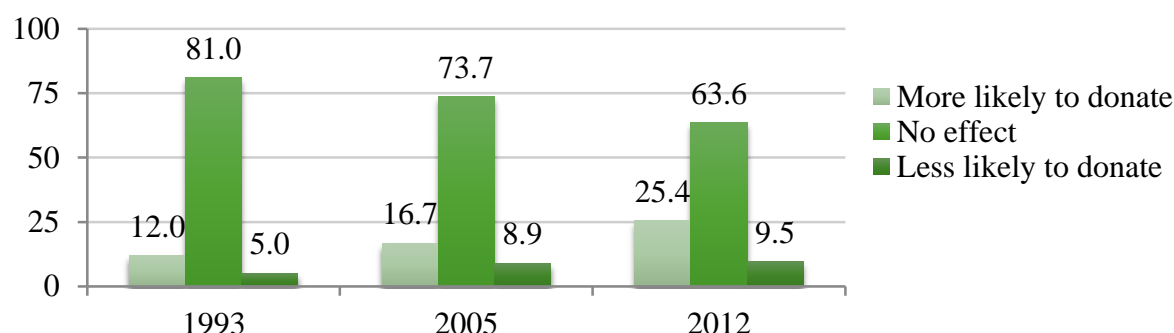


Figure 8. Financial Incentives and Own Organ Donation, 1993-2012

Note: Reproduced from the Department of Health and Human Services (2012)

Currently there is no empirical work measuring the elasticity of the supply for kidneys because no valuable consideration for organs has ever legally existed in the U.S. However, studying the elasticity of other medically scarce goods provides an informative basis for assessing the elasticity of the supply of kidneys. There is only one compensated good that is similar to a kidney: reproductive eggs.

Conceding that selling reproductive eggs does not affect the functions of the body as significantly as renouncing a kidney, the two products still have many similarities that offer valuable basis for comparison. Whereas other donated bodily goods such as blood, plasma, sperm, and bone marrow are renewable, eggs and kidneys have a finite quantity and require surgery to obtain the goods. It can be argued that the sale of eggs is even more burdensome than donating kidneys because women have to endure daily injections of hormones in preparation for the sale. Most countries have banned the compensation of egg donations in parallel to the ban of compensation for kidneys. However, compensating egg donations is legal in the U.S. and is regulated at the state level: essentially a free market. Because of the medical similarities between eggs and kidneys, and because the sale of eggs is legal in the U.S., studying the market effects on the egg market is the most comparable good the U.S. has to understand how a market for kidneys

would work. As such, it is invaluable to examine how compensation for live egg sales affects the supply of eggs to understand how compensation for funerals may affect the supply of kidneys in the U.S.

Kenney and McGowan (2010) conducted an interview of 80 women who have donated their eggs and came to a conclusion that 58.8% of the donors identified remuneration as a significant motivator in their decision to donate. Other similar studies have found that more than half the egg donors are financially motivated (Kalfoglou and Gittelsohn, 2000; Partrick et al., 2001). When several clinics in New York City increased compensation by nearly \$3,000 1998, Lindheim et al. (2001) examined differences in motivations for the groups of women who donated before and after the increase in compensation. The authors concluded that women who donated after compensation increased were more motivated by finances than the women who donated prior to the price change. These studies suggest that donor actions are subject to changes in financial incentives. The same could possibly be said for kidneys; offering a financial incentive greater than zero is likely to cause an uptake in living individuals who would seek to profit from selling organs after death.

Egg sharing allows women who sell their eggs to be subsidized for their own fertilization treatments. When Belgium began providing full-reimbursement for in-vitro fertilization (IVF) in 2003, the number of egg sharers dropped by 70%. Although this was an observational study, it does give weight to the theory that the original intention to be an egg seller was to be able to afford IVF treatments (Pennings & Devroey, 2006). Whereas women endured surgery and gave up an organic part of themselves so that they could afford a service (IVF), by extension, it is not unreasonable to suggest that people would endure surgery and give up a different organic part of themselves, a kidney, in order to afford something they deem is worth giving up a kidney for.

With regard to organs, because the surgery would take place after the end of life, there should be even less resistance to agreeing to supplying organs, i.e., a relatively elastic supply curve.

An interesting aspect of supply worth considering is the possibility of the crowding-out effect. The crowding-out effect occurs when introducing compensation to an altruistic market causes those who are willing to donate for free to withdraw from donating. This is noticeable in Figure 8 where there has been a 15.5% increase in the number of people who would explicitly not donate if payment was introduced.

By far the most cited account of the crowding-out effect occurred in the field of blood donations. Most notably, Titmuss (1970) revealed that the monetization of blood donations in the U.S. reduced the overall supply of blood donations. In his work, Titmuss compared growth rate of altruistic blood donations in the United Kingdom (UK) to the growth rate of compensated blood donations in the United States. Whereas the rate of donations was increasing annually in the UK, there was a decline in annual blood donations in the U.S. despite the monetary incentive to donate blood. Titmuss's findings were never directly verified until Mellström and Johannesson (2008) conducted a randomized control trial in which different groups were exposed to financial incentives for donating blood. The results they achieved showed that female college students were significantly less likely to donate blood when payment was involved. However, once men were taken into account, there was no crowding-out effect following the introduction of monetary incentives. The authors interpreted the findings to suggest women are more concerned with the social status of being altruistic and thus are more averse to payment. The caveat to their findings is that the experiment was conducted in Sweden and thus may not be wholly generalizable to the U.S. population. Regardless, the findings are valuable to understand plausible attitudes toward "donating" organs for compensation. There have been several studies

outside the scope of blood that have suggested introducing payment to donations crowd-out people who are otherwise willing to donate for free (Freeman & the National Bureau of Economic Research, 1996; Gneezy & Rustichini, 2000a; Gneezy & Rustichini, 2000b; Falk & Szech, 2013).

However, Lacetera et al. (2012) conducted a two-year long field study in the U.S. where blood drives provided non-monetary rewards. Two sites acted as controls with no incentives, one site had a \$5 gift card incentive, and the last site had a \$20 gift card incentive. The authors show that the \$5 site had an average of 6.5 units collected while the same site without the incentive had an average of 3.7 units collected. For the \$20 site, turnout and units collected tripled compared to the historical data from the same site. Both results were statistically significant, thus their conclusion was that non-monetary incentives did not cause a crowding-out but in fact increased the total supply of blood. Similarly, Deck and Kimbrough (2013) conducted an experiment designed to imitate compensated organ donation and assess the role of economic incentives on pro-social behavior. Participants were endowed with different assets that lost value over at each round of the experiment. The participant could then choose to trade their non-valuable assets for compensation. This is the equivalent of a deceased donor trading in their no longer valuable kidneys for compensation such as funeral expenses. The control group with no payoff market traded their assets at a significantly lower rate than the experimental group with a market payoff. Together, these two recently conducted randomized control trials in the U.S. lead to the conclusions that a significant crowding-out effect may not be expected to occur once payment is introduced for organs. A relatively elastic supply of reproductive eggs can be extended to a relatively elastic supply of kidneys. The reason that supply must be relatively elastic is because it would 1) provide more suppliers, and 2) provide more suppliers at a lower

cost than if the supply was relatively elastic. With the expectation that a large crowd-out effect will not occur, the viability of compensation increasing supply of kidney donors is reasonable.

In conclusion, the relatively inelasticity of demand makes it feasible to acquire the funds necessary to incentivize donors. Likewise, the comparability between reproductive eggs and kidneys reveals the feasibility of post-mortem compensation for kidneys. Because deceased donors face fewer risks comparative to the benefit, and because studies reveal minimal crowding-out effects of introducing compensation to a altruistic market, supply is expected to be relatively inelastic. Together, the contrasting elasticities of demand and supply support the feasibility of funding funeral expenses of donors.

Conclusion

Because opt-out countries must still acquire consent from the kin in a similar manner as the U.S. opt-in system, the difference in transplant rates cannot solely be a result of the difference in default assumptions. Moreover, because the opt-out system is not ethically sound, the U.S. should maintain an opt-in system. A modification to the opt-in system, known as required response, is thought to reduce the burden of supplying registration and thus is expected to yield more donors. The empirical analysis of DMV and donor registry data did not reveal a significant effect of required response. However, the limitations of the analysis simply require more research to definitively disprove the effects of required response on donor registration.

Another proposal to increase supply of kidneys is to pay a portion of the funeral expense of a deceased donor. This post-mortem compensatory system is likely to be feasible because supply is thought to be relatively elastic while demand for transplants is probably relatively

inelastic. As such, incentivizing registrations and requiring patients and insurers to pay for the funeral funds will unlikely to be major obstacle. Once kidneys are obtained, the next step is to allocate a scarce medical good.

Chapter 4

Allocation

Over 100,000 people are currently on the wait-list for a kidney. It is difficult to imagine the scale of that number but even more difficult to imagine the physical and emotional pain of waiting. As previously mentioned, it is not uncommon for a patient to wait five years to receive an organ, all the while accumulating fear and hopelessness everyday on the list, frequenting the hospital more, missing out on milestones such as watching a child graduate or getting married, or playing with grandchildren, and losing the simplest forms of independence such as walking untethered to an IV drip. The shortage reduces candidates from living to simply surviving.

Whenever there is a shortage of a good, especially a life-saving good, that good has to be allocated efficiently and equitably. In an ordinary market, the allocation is dependent on purchasing power and desirability of the good. Whoever wants the good and has the means and willingness to match the sticker price can obtain the good. However, for organs, the National Organ Transplant Act (NOTA) authorizes a monopsony, the United Network for Organ Sharing (UNOS), to determine how organs are distributed. Because the allocation of organs is specific to the organ type, this section will limit its scope to kidney allocation to retain consistency in this paper and because the kidney allocation formula is the most widely used and applicable to the largest population of the wait-list.

It would be careless to say the UNOS approach is without errors. The UNOS board tries to make the best decision with the inputs they have. Naturally when it comes to stakes of life and death, there are many interwoven factors to be taken into consideration and some factors are arguably given more weight to than others. The first portion is an analysis of being added to the wait-list for a kidney followed by an analysis of receiving a kidney.

Enlisting on the Wait-List

Unless a patient has found a donor who is willing to direct the donation to a specific recipient, the first step of receiving a kidney is to join the wait-list. Registering for the wait-list is fairly straightforward; it requires a referral from a doctor who could attest to the deterioration of the kidney that is projected to fail. However, even with a referral, patients can be excluded from the list if they meet the criteria of exclusion in their choice of transplant site.

Ethics of Exclusion

Though each transplant site has its own criteria, common reasons that patients are excluded from the list are if they are active alcohol or drug abusers, have uncontrolled/untreated psychiatric conditions (depression, bipolar disorder, etc.), are regularly noncompliant with medical treatment (failure to follow a dialysis schedule or failure to attend doctor's visits), or have other illnesses (cancer, artery disease, HIV, etc.) that may compromise a successful transplant. This section will focus on the exclusion of alcoholics and the noncompliant because those two qualifications are more within an individual's control whereas psychiatric and physical illnesses are not.

The transplant site's decision to exclude drug and alcohol abusers is based on Consequentialist and Utilitarian logic. Consequentialism is a theory of moral philosophy that is impersonal and driven by methodology; in the face of a moral decision, one would evaluate all the options on the merit of the consequences each produces, and select the option that produces the best consequences (Frey, 2004). Consequentialist argue that the abuser's inability to withdraw from addictive substances will result in wasting a scarce organ, i.e., the consequence of

allowing an addict to receive a kidney is the creation of an endless cycle in which the addicted recipient will need another new kidney once the transplanted kidney has deteriorated from habitual substance abuse. The Utilitarian argument becomes relevant toward the latter part of the cycle. Utilitarianism is a type of Consequentialism that assigns the hedonic principle of happiness to “better consequences.” The moral agent should select the option that maximizes utility or happiness. Because both Utilitarianism and Consequentialism are impersonal, they share the Egalitarian principle of treating all similarly situated individuals equally. This methodology (of assessing options by the benefits they produce, and by holding all similarly situated individuals equally) gives rise to the argument that individuals have a moral responsibility to prioritize the alternative that saves the most lives (Savulescu, 1998). If all lives are equal, then saving the group with most lives produces the most utility.

Consequentialist and Utilitarian theories have tangible evidence concerning other scarce medical resources such as vaccines. Fearing an influenza pandemic, the National Vaccine Advisory Committee (NVAC) put forth a procedure to maximize the distribution of the vaccine. The committee placed vaccine workers and health-care providers at the top of the list because their survival ensures that the vaccines continue to become available for others (Emanuel & Wertheimer, 2006). In the context of organs, the endless retransplant cycle could have been prevented if the kidney was allocated to someone who could abstain from substances that expedite kidney deterioration. The non-addict would use the kidney to permanently stay off the wait-list and allow opportunities for other individuals on the wait-list to receive a kidney and increase the new recipient’s utility. Ultimately the utility of many are maximized when the kidney is given to one who can stay off the list.

The rebuttal to both a Consequentialist and Utilitarian would come from a Deontologist.

The school of Deontology demands principles, not consequences, ought to determine the moral pursuit of a decision. Moral dilemmas ought to be evaluated by the actions themselves, not the consequences they produce. Kant (2002), the founder of Deontology, bundled the principles guiding moral decisions under the name of “categorical imperative” because the principles should hold in all similar categories of circumstances. In it were ideas such as abiding by universal maxims and treating humans as ends rather than means. The strength of Categorical Imperatives became very evident in a thought experiment involving a fat man, and five would-be victims on the tracks of a runaway trolley. Utilitarianism suggests that a moral agent should sacrifice and push the fat man onto the tracks in order to save five lives because that option produces the most utility. Deontology suggests to allow the trolley to barrel toward the five individuals because sacrificing the fat man (using a human as a tool) violates the moral principle against violating someone’s right to live (universal maxim).

As such, by excluding someone from the list, that individual is not given the same opportunity to live as another similarly situated person. This exclusion ultimately violates equity. Moreover, excluding someone from the list a decision is made to shorten that person’s life. This active decision is in fact allowing someone to die. Knowing that without access to a kidney the individual is going to die sooner rather than later, the end result, motivation, and intent are all the same: death. Causing death is a violation of the universal maxim against violating another’s right to live. In bioethics specifically, it is irresponsible to abandon someone in need when relevant actors have the power to help. The exclusion of addicts clearly violates the Hippocratic Oath to “do no harm” and the principle of non-maleficence by withholding medical treatment that is beneficial to an individual (Beauchamp & Childress, 1979). It simply reduces down to the matter

that the decision to exclude someone from the wait-list is causing their death when that death could have been delayed.

Lastly, there is also the argument that the current practice of excluding addicts, especially alcohol addicts, is blind to confounding variables such as the predisposition to alcohol abuse. There is a tendency to punish those who choose to practice behaviors, such as gluttonous consumption of alcohol, that lead to their predicament. The sentiment is that an individual should not be given a scarce resource because they are the cause of their own organ failure (Baron, 1998). That sentiment is a blind attribute casted over all substance abusers. However, registration on the wait-list neither distinguishes nor punishes with exclusion genetic vs self-induced diabetics, which are significant contributors to kidney failure. Why is there a blind assumption that all alcoholics brought their predicament upon themselves? Those who are predisposed to consume alcohol due to their environments should not be categorized with those who chose actions that led to a path of alcoholism. Similarly, they should not be penalized for having a trait beyond their control. Because alcoholism is not a genetic marker, it is not possible to discern predisposed vs self-induced alcoholism. And although there are genetic markers for diabetes, genetic and self-induced diabetics are not discriminated against, then it is only fair to not discriminate between predisposed and self-induced alcoholics.

Another group commonly excluded from the wait-list is the noncompliant. Lack of compliance can come from failing to follow dietary requirements (avoid high-cholesterol foods, eat more vegetables), physical requirements (exercise more), or medical requirements (go to the doctor every month and take over a dozen different daily medication). These requirements are made to ensure successful transplants and graft success. Compliance is necessary because even after receiving an organ, there are strict post-operative procedures that must be followed to

safeguard that the organ is not rejected. These procedures can range from regularly taking immunosuppressive drugs to attending routine physician and lab visits. If a patient has a history of not following directions, there is a Consequentialist fear that their non-compliant nature will run its course to the detriment of the transplanted organ and that another transplantation would be necessary; here, the Utilitarian argument, waste of a scarce resource and prolongation of suffering for others on the list, is relevant. This is the same logic utilized to exclude a non-compliant person is identical to that used to exclude substance abusers. Because I have taken opposition to the exclusion of addicts, I appropriately oppose the exclusion of the non-compliant. I argue that the grounds used to exclude non-compliant recipients is more unethical than the exclusion of substance addicts. Often, those who are noncompliant are not in positions to be compliant. For example, two general requirements of compliance include regular doctor visits and healthy eating. Those two requirements on the surface appear manageable, however, one must be aware of which group predominately needs kidneys: people far below the average income level (Furth et al., 2000).

Healthcare is a unique good because unlike nearly all other ordinary goods -- and although healthcare has not been declared a human right -- it is illegal to turn someone away from emergency medical care due to their inability to pay (Fell, 1994). Presently, the exclusion of non-compliant individuals does not make a distinction between those who are unwilling and unable to be compliant. To restrict someone to dialysis rather than providing the benefits of a kidney transplant simply because their economic conditions prevent them from being compliant is unequivocally wrong because such a system mistakenly treats unequal individuals equally. Similar to how the exclusion of substance abusers blindly grouped the genetically predisposed with those who are not genetically predisposed to substances, excluding the non-compliant

blindly groups the income constrained to those who are not income constrained. The two cohorts are inherently different and their differences should be a consideration in deciding to proceed with treatment.

Lack of disposable income will hinder an individual's ability to adhere to medical guidelines and is inadvertently used as an argument by the transplant site against enlisting the individual on the transplant waiting-list. Thus, to require medical compliance as a prerequisite for a transplant is insidious because it indirectly requires the recipient to be wealthy enough to afford pre- and post-transplant medical care. Keith et al. (2008) found that transplant candidates with only Medicare coverage are 78% less likely to be listed on a transplant waiting list than those insured privately that because private insurance is more generous in payment. To this extent, if it is illegal to deny medical care due to an inability to pay for that care, then it ought to be illegal to discriminate against those who cannot be compliant due to constraints such as economic impoverishment. Moreover, because it can sensibly be assumed that ESRD individuals want to be compliant with the aim to not harm themselves, it is only reasonable to conclude that lack of compliance, accidental or intended, is committed out of either ignorance or inability to be compliant, neither of which ought to disqualify someone from bettering their life through a kidney transplant. The following subsection provides an overview of how exclusion of substance abusers and the noncompliant affect the economics of kidney transplants.

Economics of Exclusion

Active substance abusers and historically noncompliant patients are excluded from registering on the kidney wait-list out of fear that their tendencies will negatively affect the

outcome of graft success and waste a scarce medical good. This fear is not unfounded. Because narcotics' effect on kidneys is so thoroughly known in the medical community, there have not been many opportunities to assess kidney transplant outcomes in substance abusers. Lentine et al. (2015) conducted a retrospective study in Missouri to assess the effect of pre-transplant substance abuse on graft outcomes. Abusers were identified with opioid analgesic fill rates. The authors concluded that high levels of prescription narcotics prior to a kidney transplant increased the risk of kidney transplant complications by 2-4 times compared to non-abusers. The lack of studies on the effects of substance abuse prior to a transplant is in itself telling of the resistance to allow substance abusers to compromise the wait-list. Ultimately, this one study alongside the medical consensus on drug addiction attest to the fact that transplant sites exclude substance abusers for the sake of strengthening the efficiency of allocating a scarce resource.

In contrast to the absence of extensive studies examining the effects of prior substance addictions, there are an abundance of studies assessing the effects of medical non-adherence in kidney transplant recipients. A comprehensive literature review of non-compliance suggests that there is a positive relationship between non-compliance and graft failure in that non-compliance compromises the success of a transplant (Laederach-Hofmann & Bunzel, 2000). More recently, a retrospective cohort study examining the cost of non-compliance in kidney transplants estimated that persistent non-compliance was associated with \$36,000 higher medical costs after three years compared to highly compliant recipients (Pinsky et al., 2009). These costs are incurred when the non-compliant patient is admitted to the hospital and undergoes anti-rejection therapies. On the subject of costs, it would be ill-conceived to not examine the economic circumstances that affect the ability to afford and be compliant with medical directives.

Figure 9 shows that the two leading causes of end-stage-renal-disease (ESRD) are diabetes and hypertension (United States Renal Data System. 2015). Incidence and management of both of these diseases are directly and inversely correlated with wealth. Those who are in the higher socioeconomic strata experience fewer incidences of diabetes (Braveman et al., 2010; Krishnan et al., 2010) and hypertension (Zhang et al., 2006; Kaplan et al., 2010) and are more apt through wealth or education to manage the disease (Currie & The National Bureau of Economic Research, 2008; Ettner et al., 2009). There are a few explanations for such a correlation between income and health. First, because individuals in low economic standing have weaker purchasing power relative to higher socioeconomic individuals, they are less able to purchase food that promote health. Not only are they less able to afford health foods, they have less access to it, a phenomena known as “food deserts.” Bader et al. (2010) examined the relationship between New York City neighborhood environments and disparities in food access. Notably, they found that low-income tracts experienced lower vehicle ownership and access to public transportation, and increased exposure to crimes, both of which impede access to food. The authors also noted that crime in the area was a significant factor in whether or not individuals make the effort to obtain healthy food. Although the authors did not test it, it is reasonable to suggest that crime may also deter exercising outside. Abraham (1993) noted in her anecdotal study of a single Chicago family that crime in the area deterred the family from journeying outside unless it was absolutely necessary. Lastly, low income also constrains the ability to regularly attend medical check-ups because once one’s sick-leave is exhausted, taking time off from work to go to doctors has a higher opportunity cost compared to a high-income individual because it is withheld money that is more necessary for their household

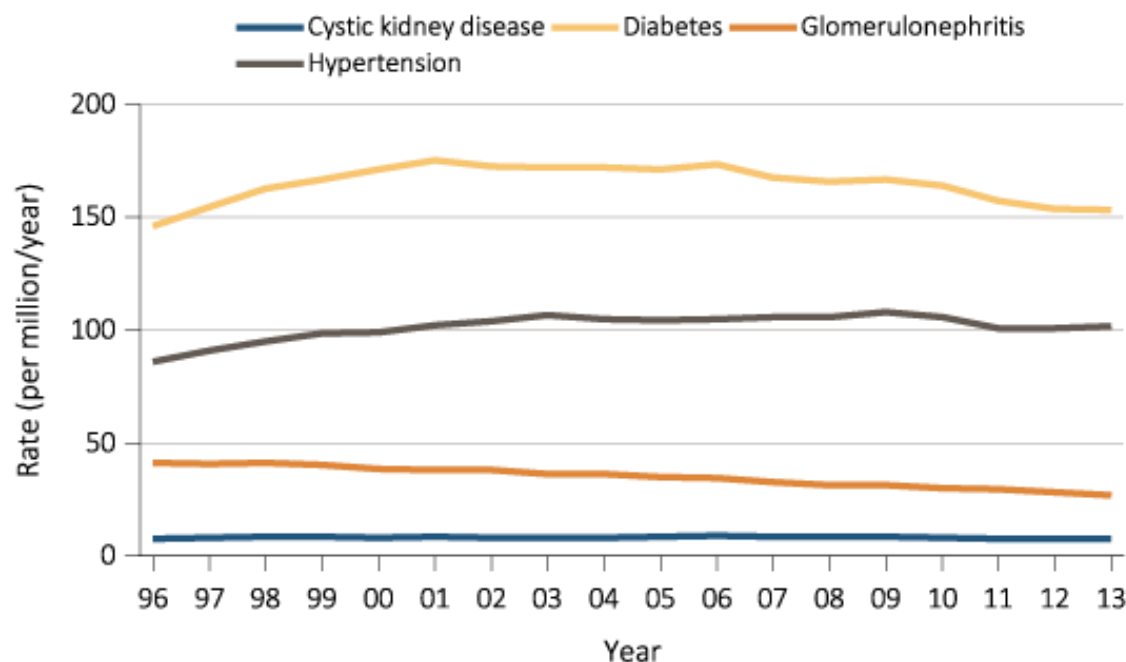


Figure 9. Trends in Adjusted* ESRD Incidence Rate (per million/year), by Primary Cause of ESRD, in the U.S. Population, 1996-2013

Examining compliance specifically in kidney transplants, Swanson et al. (1991) conducted a survey assessing the role of socioeconomic status (SES) factors in post-operative compliance. The results of the study showed that those with lower SES were significantly less compliant. A strong component of SES-related compliance is income because it influences the ability to follow a regimen. After a transplant, the recipient must take immunosuppressant drugs for the rest of that patient's life. If a patient is a low-SES patient, the ability to continuously take the drugs is undercut. If the patient cannot afford the drugs necessary to inhibit an immune attack against the transplanted organ, then the transplanted organ is compromised and the patient will need to re-enroll in dialysis or receive another transplant. Woodward et al. (2001) conducted a retrospective cohort study to examine the effect of Medicare extending immunosuppressant drug coverage from one to three years on the graft success of both high- and low-income recipients.

At the baseline, prior to the extended coverage, low-income individuals had a 40% higher risk of graft loss than the matched high-income individuals once the coverage year ended. Once Medicare began covering the medication for three years after the transplant, the risk ratios were equivalent between both income groups, leading to the conclusion that income and ability to pay for immunosuppressant medication is a deciding factor in whether or not a transplant is successful. In 2000, Medicare began to provide lifetime immunosuppressant drug coverage decidedly because the ability to pay affects whether or not the wait-list becomes longer or shorter. In a follow-up study, Woodward et al. (2008) examined the graft success between high and low income groups once lifetime coverage commenced. Again they discovered that prior income-related disparities in graft survival disappeared once the drugs were indefinitely covered by Medicare. Racial disparities in tandem to income have also been studied. Patzer et al. (2009) found that as neighborhood poverty increased, the likelihood of wait-listing decreased for blacks compared to whites in all the income levels. In the poorest neighborhoods, blacks were 57% less likely to be waitlisted, and thus less likely to receive a kidney, than whites in the same neighborhood. Together, these studies show that the population that needs kidney transplants the most are lower and middle-class individuals who are significantly wealth constrained and discriminated against. When transplant sites require compliance, the site must first consider the ability of an individual to afford compliance.

Recommendations

As studies have shown, substance abusers and the medically noncompliant are excluded from the wait-list purely for the sake of averting re-transplants and maximizing the number of

potential gains. Gains are maximized when the kidney is allocated to patients who can manage the health of the kidney and remain off of the wait-list in order to allow others a chance to receive a kidney. Nevertheless, it is unethical to exclude such groups because of the evidence that such exclusions are biased in favor of the wealthy and unforgiving toward those who begin with a disadvantage.

Concerning drug and alcohol abusers, there is no denying that their behavior is harmful for themselves and others on the wait-list because of the prolonged wait caused by more people on the list. There is a negative production externality because the inclusion of risky patients creates the burden of waiting longer for others on the wait-list. Many transplant sites do permit substance abusers on the wait-list after six months of rehabilitation but even that provision is not enough. In a perfect world, a drug addict would be able to detect organ deterioration early and start to become sober before the need to get on the list. In reality, it is not realistic to suggest substance abusers attend regular check-ups. The same abusers are likely to avoid such check-ups for the variety of reasons detailed by the aforementioned studies (lack of insurance, affordability, inconvenience, fear of legal punishment, etc.). It is more likely that irreversible kidney deterioration has taken place by the time a substance abuser recognizes a problem. The six-month rehabilitation period may even exacerbate the condition and decrease the likelihood of graft success. Rather, the appropriate practice would be to allow an addict on the wait-list, allow the addict to become sober while on the list, and necessitate that if an organ is received, continued drug/alcohol consumption is absolutely prohibited; so much so that if the transplanted organ is compromised due to resumed addictive behavior, re-transplantation will be a bigger hurdle than the first time (possibly a deduction in priority). This would balance equity with efficiency by creating a path for substance abusers to critically use a transplanted kidney.

Though allowing addicts on the list can cause a longer wait for others on the list, it is trade-off worth pursuing because a longer wait is still a better option than complete abandonment and death when that death could be delayed. If UNOS is attempting to be equitable in their distribution of a scarce good, Egalitarian theory of equity requires everyone in equally situated positions be given equal opportunities at life.

Pertaining to the non-compliant, not only should they be allowed on the wait-list, but the directions given to them ought to be consistent with what is within their reach. If compliance is thought in terms of supply, flattening hurdles to compliance is a method to induce more supply of compliance. This partly requires financial support through insurance so that drugs and transportation are affordable. If taking time off of work is too costly, perhaps innovations in home health monitoring systems is a method to provide convenience to disadvantaged individuals. In 2013, a novel approach to support compliance, mHealth, was assessed in a randomized controlled trial in South Carolina. The system marries an electronic medication tray, a wireless BP monitor, and a smartphone to remind users to take the appropriate drugs and to self-monitor blood pressure every three days. The standard control group had to independently remember to take the drugs and visit a clinic to have their blood pressure measured. The trial revealed that the intervention group utilizing mHealth had a significantly higher adherence rate than the standard control group (McGillcuddy et al., 2013). Innovations like these not only help monitor diabetes and hypertension as leading causes of ESRD, but they also limit the hurdles the disadvantaged already face. Innovations such as mHealth ultimately allow fairer treatments of different groups and make transplants more efficient and equitable with the inclusion of those who were once excluded. To avert accidental non-adherence, all transplant recipients must receive information relaying the importance of compliance. Excluding non-compliant patients

wrongfully combines those who are unwilling to be compliant and those who are unable to be compliant. Insofar as ethics, it is ethically unforgivable to exclude someone from life. The recommendation would be to allow noncompliant people to get on the list and ensure medical restrictions are met to their competencies. If the transplanted organ fails due to non-compliance even after adjusting to their situation, consider reducing priority as a punishment during the re-transplantation evaluation. In conclusion, the most ethical stance is to hold the right to life for everyone without exclusions: anything less would be unethical.

Receiving a Kidney

When the United Network for Organ Sharing (UNOS) creates a procedure to allocate kidneys, they attempt to balance efficiency and equity. Because the supply of kidneys is low compared to demand, there is a strong inclination to assure that the good is used in the most beneficial way. However, “benefit” is a conundrum. Sometimes it is beneficial to give the kidney to the youngest candidate who may extract the most life years from the kidney. At the same time, this allocation may be unfair considering the younger candidates tend to have more time to wait while the older candidates do not. Other times it may be beneficial to give it to the person who is suffering the most because they stand to gain the most in respite; but despite having the most to gain, the patients in urgent need are also the riskiest to transplant.

In Chapter 2, I noted the widespread criticisms of the “God Committee” for being unfair. To avoid hypocrisy, this subsection will analyze the ethics and economics of the formula used to allocate kidneys instead of providing recommendations. I additionally raise questions and concerns that UNOS ought to consider when deciding how to allocate a life saving good.

Current Allocation Procedure

In December of 2014, UNOS implemented a new kidney allocation system (KAS). Prior to the change, only wait-list candidates were given a “score” denoting their position on the wait-list. KAS also gave kidney donors a “score” to identify the quality of the donated kidney. The intention was to use both scores to efficiently match donors to recipients.

The recipient's score, called the “Kidney Donor Profile Index” (KDPI), is a 0-100 percentage value indicating how likely a kidney is expected to fail relative to all other donated kidneys. The factors of the donor that are taken into consideration are the age, height, weight, ethnicity, diabetic status, level of blood pressure, life status (deceased or living), cause and type of death (brain or heart), level of kidney function, and Hepatitis C exposure. The healthier and younger a donor is, the lower the KDPI score is (Table 3) (Kidney Donor Profile index (KDPI) Guide for Clinicians: How to Interpret and Discuss KDPI with Patients, 2014). For example, if a kidney is sourced from a living, young, and health donor, the kidney is likely to score below 20% which means the kidney is likely to function longer than 80% of other donated kidneys.

Table 3. How Much Difference in Expected Longevity Exists Between Low, Medium, and High KDPI Kidneys?

KDPI score	Expected years of function
<20%	11.5 years
21-85%	9 years
>85%	5.5 years

The recipient score, called the “Expected Post Transplant Survival” (EPTS), is a 0-100 percent value indicating how long a transplanted kidney will last in the recipient compared to

other possible recipients on the list. Candidates with EPTS scores lower than 20% are expected to derive more years of function from a transplanted kidney than other candidates. That is, the group with a 20% upper bound stand to gain more years from the transplant. The factors of the recipient that are taken into consideration to calculate the EPTS score are age, diabetes status, prior donations, and time on dialysis, Equation 2 (Kidney Donor Profile index (KDPI) Guide for Clinicians: How to Interpret and Discuss KDPI with Patients, 2014). The binary indicator is 1 if true for diabetes, prior transplant, and years on dialysis.

$$\begin{aligned}
 \text{Raw EPTS} = & \\
 & 0.047 * \text{MAX}(\text{Age} - 25, 0) + \\
 & 0.015 * \text{Diabetes} * \text{MAX}(\text{Age} - 25, 0) + \\
 & 0.398 * \text{Prior Solid Organ Transplant} + \\
 & -0.237 * \text{Diabetes} * \text{Prior Solid Organ Transplant} + \\
 & 0.315 * \log(\text{Years on Dialysis} + 1) + \\
 & -0.099 * \text{Diabetes} * \log(\text{Years on Dialysis} + 1) + \\
 & 0.130 * (\text{Years on Dialysis} = 0) + \\
 & -0.348 * \text{Diabetes} * (\text{Years on Dialysis} = 0) + \\
 & 1.262 * \text{Diabetes}
 \end{aligned}$$

Under the new system, high quality kidneys with a KDPI score of less than 20% are matched with candidates with EPTS scores also below 20%, meaning excellent kidneys are matched to recipients who can extract the most years from the high functioning kidney. If a kidney has a KDPI score greater than 20%, then there is no match to an EPTS score. Instead, kidneys with a KDPI score greater than 20% are made available to any candidate with the highest points, regardless of EPTS score. Additional points outside the EPTS scores take into consideration blood type, Calculated Panel Reactive Antibody (CPRA) level, and compatible Human Leukocyte Antigen (HLA) (Table 4) (OPTN Policies, 2016).

Table 4. Points Allocation

If the candidate is:	And the following allocation sequence is used:	Then the candidate receives this many points:
Registered for transplant and meets the qualifying criteria described in <i>Policy 8.4: Waiting Time</i>	8.5H, 8.5I, 8.5J, or 8.5K	1/365 points for each day since the qualifying criteria in <i>Policy 8.4: Waiting Time</i>
Aged 0-10 at time of match and a 0-ABDR mismatch with the donor	8.5H, 8.5I, or 8.5J	4 Points
Aged 11-17 at the time of match and a 0-ABDR mismatch with the donor	8.5H, 8.5I, or 8.5J	3 Points
Aged 0-10 at time of match and donors has a KDPI score <35%	8.5H, 8.5I	1 Point
A Prior Living Donor	8.5H, 8.5I, or 8.5J	4 Points
Sensitized (CPRA at least 20%)	8.5H, 8.5I, or 8.5J	See Table 8-2: Points for CPRA
A single HLA-DR mismatch with the donor*	8.5H, 8.5I, or 8.5J	1 Point
A zero HLA-DR mismatch with the donor*	8.5H, 8.5I, or 8.5J	2 Points

*Donors with only one antigen identified at an HLA locus (A, B, and DR) are presumed “homozygous” at that locus.

Note: Reproduced from OPTN (2016)

Not listed above, but also taken into consideration, are urgency and geography. Because the criteria listed above are included in the formula to measure the medical success of a transplant (CPRA and HLA), this paper will only focus on the non-medical aspects of the formula: urgency, waiting time and geography.

Ethics of Urgency

Despite a patient having more points, the Organ Procurement Transplant Network (OPTN) grants physicians the right⁹ to move a patient up the list due to medical urgency even if

⁹ Policy 8.2.A (OPTN Policies, 2016)

that patient does not sum up the most points. A kidney is allocated to a patient in urgent care even in spite of poor HLA matching¹⁰. The logic of prioritizing those in the most precarious situations is that it delays a more immediate death that would have occurred without intervention. There are three schools of ethics that all endorse the prioritization of urgency: moral egalitarianism, utilitarianism, and Rawlsian theory of justice.

Moral Egalitarians argue that justice requires equality including equal opportunities (Stein, 2002). To understand why Egalitarians would argue in favor of prioritizing urgency, it is useful to examine a hypothetical example. Suppose there are two similar patients (same geography, age, blood type, CPRA level, HLA mismatch, neither are prior donors) with failing kidneys named Alex and Blake. Out of the entire wait-list for kidneys in Maryland, Alex accumulates the most points (a hypothetical ten points) and is on top of the list in Maryland to receive a kidney. Meanwhile Blake accumulates fewer points (a hypothetical seven points). Both Alex and Blake have a life prognosis of three years without a transplant. Suppose suddenly that Blake suffers from a fall and injures a kidney so that it functions significantly worse than before the fall. Blake is now expected to live only a few weeks without a transplant. In this scenario, even though Alex has more points, the next available kidney will be given to Blake because without an immediate intervention, Blake will die because of the omission of care. Moreover, if the kidney is given to Alex instead of Blake, the probability of Blake receiving another suitable kidney becomes grimmer because the condition will continue to deteriorate. Alex can afford to wait longer while Blake cannot, meaning Blake has a reduced opportunity at prolonging life. In

¹⁰ Antigens are genetic proteins that identify cells in one's body and signals the intrusion of non-self cells such as viruses and bacteria. Although there are several different types of antigens throughout the body, there are six that are relevant to transplants. A perfectly matched donated kidney is called a "zero-mismatch" and is indicative of strong graft success (Konvalinka & Tinckam, 2015).

the event that two individuals are not equal, such as Alex and Blake after the fall, Egalitarians would seek to balance the imbalance by providing additional support to the more disadvantaged. Prioritizing urgency is promoted by Egalitarians because it levels the playing field and allows equal opportunity to prolong life.

Rawlsian theory of justice (Rawls, 2005) would also align with the UNOS urgency criteria. Rawls's veil of ignorance posits that a group of people who are unaware of their identities (sex, race, education, wealth, etc.) establish the rules of their society. Being mindful of structural violence, it could very well be that someone with a lack of medical or educative resources has been put in a position in which they could not get ahead of their illness by registering on the wait-list as soon as eligible and is now in emergency need for help. For such scenarios, it is not that the urgent have a higher right to life, rather they have a higher claim to opportunity because they began on an uneven level of opportunity. Because each individual behind the veil is unaware of their position in society or the degree of structural violence, each individual would be mindful to establish rules that aid the worst off in the event that one of rules maker is the worst off. Essentially, Rawls's veil mirrors the golden rule: treat others the way one would want to be treated.

Utilitarian support for the criteria is based on the argument that there is more utility to be derived by prioritizing urgency. When two individuals have different levels of hunger, mildly hungry and extremely starving, food offers more satiety to the starving individual than the mildly hungry individual. This is analogous to the idea that a dollar is worth more to a poor man than to a billionaire. In economics, this progression of gains is subject to diminishing marginal utility. According to the theory, the first unit of utility carries more weight than each proceeding unit of

utility. For kidneys, the patients in the direst circumstances could benefit the most from a transplant because that individual is saved from the grip of death.

Arguments against prioritizing urgency are delivered by Consequentialists. The scarce kidneys could be more efficiently utilized if they were given to those who could permanently stay off the wait-list (Stein, 2002). Their argument is that if the kidney is given to the worst off, the worst off may still need urgent care or another transplant because of the severity of the condition. If the kidney was instead given to a relatively healthy patient (low EPTS score) who could best utilize the kidney, then others on the wait-list are provided the opportunity to receive a kidney without the interference of an urgent patient needing a re-transplant. Besides the ethical implications of prioritizing those in urgent need, it is important to evaluate whether kidneys allocated out of urgency are inefficient allocations.

Economics of Urgency

The impact of diminishing marginal utility in kidney transplants is unknown because there is inadequate research on the subject. No studies in the U.S. have compared the financial or outcome effect of transplanting urgent patients versus non-urgent patients. Several other countries, notably Portugal (Costa et al., 2003), Netherlands (De Meester et al., 2000), Turkey (Celebi et al., 2015), and Germany (Kleinert et al., 2013), have examined the success of urgent kidney transplantations. All concluded that although emergency transplants offered a few additional years of life, the success rates of the graft were disappointing. The sentiment is that because the urgency to the situation requires almost precipitous allocation of a donated kidney to the person in most need, the medical compatibility of the donor and recipient is given a blind

eye. Whereas efficiency requires the fewest HLA mismatches to ensure long-term graft success, urgent patients are given kidneys with less than ideal HLA mismatches which ultimately an inefficient use of a scarce good.

Even if there were U.S. data, rather than anecdotes, showing that allocating kidneys to the emergency cases is extremely inefficient, it is unlikely the UNOS would overturn the urgency clause for the simple reason that the clause prevents an immediate death from occurring. This resource intense effort has been coined the rescue rule by McKie and Richardson (2003). Society tends to disregard cost-effectiveness and allocative efficiency when a life is in danger. This is why governments utilize extensive resources even in the low-probability event of finding survivors after a plane disappears. Cost-effectiveness is an opportunity cost that is pushed into the background in the face of urgency.

With or without ethical merit, the urgency clause does cheat individuals who have been passed over in order to meet emergency needs. To balance this effect of the urgency clause, UNOS rewards patience.

Ethics of Waiting-Time & Geography

Waiting time for adults is based on either the earliest time since the kidney(s) filtered less than 20ml/min or the time since registering as an End Stage Renal Disease (ESRD) patient. Medically, a time variable shows the progression of kidney deterioration; the longer a patient has been on the wait-list, the worse the kidney is, the better a prognosis can be made of transplant viability. The time variable also rewards patients because the longer one waits, the more points

one accumulates, and the better chance one has at receiving a kidney. However, the time variable is dependent on geography.

As the allocation procedure stands, kidneys are initially distributed to local candidates in one of the 58 Donor Service Areas (DSAs). If there are no suitable candidates in the DSA, candidates in the nearby regions will be considered. Lastly, if a viable recipient cannot be found regionally, the kidney becomes available nationally. For example, examining Figure 10, if a kidney in Texas becomes available but cannot be matched with a recipient in the state of Texas, the kidney will be made available to Tennessee because it is within Texas' region (#4). If a suitable recipient cannot be found in Tennessee, the scope extends to any of regional stages (3, 5, and 8). If those states fail to provide a recipient, the kidney becomes available nationally (Organ Procurement and Transplant Network, 2016).

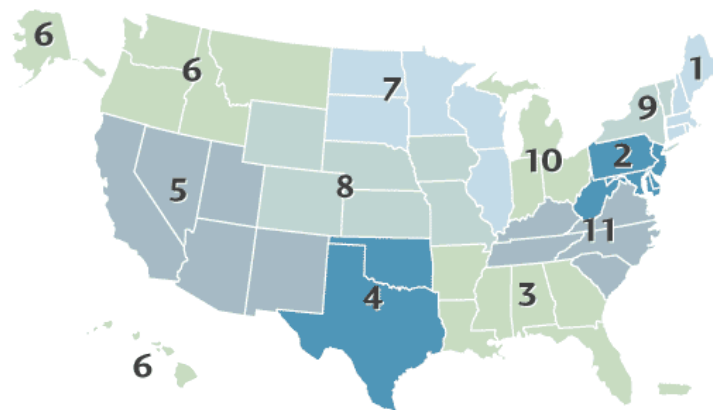


Figure 10. Organ Distribution Regions

Because allocation begins locally, wait-time is directly correlated with where one registers to wait for a kidney. That is, if a patient registers at a transplant center with a high ESRD density, the patient is more likely to wait longer for a donated kidney than someone who registers on the wait-list in a low ESRD area in a different part of the country.

Using locally donated kidneys for local registrants on the wait-list induces feelings of community and social responsibility because there is a tendency to believe that those who are the closest to U.S. physically are at the forefront of our thoughts. Oppenheimer and Olivola (2011) note that kin selection theory in biology suggests relatedness is a significant factor in the decision to be altruistic. Because kin selection is overgeneralized, physical and social distance act as substitutes. Rachlin and Jones (2008) empirically determined that distance and altruism are negatively correlated: as social distance increases, altruism decreases. Social distance then begins with relatives, followed by friends, followed by colleagues, and then acquaintances, all of who are related by some sort of physical distance. Here, a Hobbesian argument can be made in favor of the social contract.

There is evidence of social contracts simply due to the fact that most communities are not grappled in an internal war that Hobbes (1651) called a “State of Nature.” In a State of Nature, there is a constant state of war because every individual is selfishly driven to benefit themselves even at the expense of others. Thus, there is violence, theft, falsities, and deceit. However, individuals eventually realize that alliances to secure protection serve as peaceful mediums to secure benefits for each member. In fact, this was alluded to in Plato’s *Republic*, 380BCE, by Socrates who drew the analogy that even thieves must be honest with each other in order to achieve the goal of stealing (Plato & Richards, 1966). Ultimately, a civil society forms because members agree to operate under the same laws (a contract) where each member is protected from the harms of fellow members. This contract is coupled with the inclination to believe that members owe more to fellow members on the micro level than on the macro level; that neighbors owe more to fellow neighbors than they owe to fellow statesmen, than to fellow countrymen, than to fellow cosmopolitans. As such, Hobbes’s social contract diminishes with distance

because the contributions of an individual at a macro scale does not have the same magnitude of effect as contributions on the micro scale. This can be explained very simply by stating that people of a community have had a more direct effect on each other than people at a distance. Neighbors owe more to each other than to someone in a different community because members of the same community have directly contributed to the effects of the community. For example, if it is assumed that all neighbors in the community have paid local taxes, then each neighbor has provided direct and local benefits such as schools, public transportation, and emergency first responder services. If it is assumed that every citizen in the U.S. pays federal taxes, the benefits of those taxes may not directly affect everyone in the U.S.; for example, a multi-state highway that someone in a rural area may never use. Likewise, statesmen and countrymen believe they owe more to their states and country than citizens of another state or country because there are fewer direct effects with distance. And once there is an established contract to reciprocate a benefit, this becomes a Deontological argument.

To provide an analogy of how Deontologists are bound by obligations, Timmermann (2005) draws a hypothetical scenario involving two people named Andrew and Charlotte who need to be rescued. The only difference between the two is that Charlotte furnished a favor to the rescuer in a prior time and as such the rescuer has more of a duty, even an obligation, to save Charlotte. Duties of gratitude even obligate one to honor one's parents because they are the direct causation of one's existence (Kant, 2002). According to Spinoza et al. (1982), moral aptitude is inscribed in humans by the laws of nature that govern human emotions such as gratitude which Spinoza defined as “the desire whereby we endeavor to benefit one who has bestowed a benefit on us” (p.149). Consequently, Timmermann’s analogy extends to the geographical component of kidney allocation because the donor of a DSA has likely been more affected by the contributions

of those on the wait-list for the area than of individuals on the wait-list of other DSAs. This results in the duty to provide the kidney to those in the local area in order to reciprocate a benefit.

This has been evident in the adoption of fluorescent light bulbs in communities. A field experiment assessing the impact of social pressure on the decision to purchase fluorescent light bulbs revealed that when members of a community were notified of their neighbors' energy output, they tended to purchase fluorescent light bulbs. Thus, the social pressure acted as an extensive margin in which the agent decided to enter the market (List & Herberich et al., 2010). Similarly, when donors are aware of the impact of their community members, there is social pressure to enter the donor pool with the intention to provide organs to community members.

Beyond the idea that there is a need to reciprocate a benefit, the idea that one group deserves more attention because of membership to that group deserves a cautious evaluation. Such feelings of membership is similar to categories of elitism such as racism, sexism, and classism, all which ultimately resulted in slavery, centuries of oppression, the Holocaust and genocides, and chronic violence toward a dissimilar group. In fact, fearing such elitism, donors are not permitted to direct their organs to a constrained group of people such recipients of a specific race, sex, or religion (Veatch, 2000).

Although the scarcity of kidneys is evident throughout the country, there are certain parts of the U.S., such as region five, that suffer more severely from the scarcity of donations (Davis et al., 2014b). Because those areas are underserved, more people on those DSA wait-lists will die than other parts of the U.S. simply because they see lower donor rates. Moreover, because underserved areas have longer wait times, the full benefit of a kidney transplant cannot be met because longer waits are associated with worse graft outcomes (Meier-Kriesche et al., 2000). Egalitarians would assert that equals deserve equal treatment and that the worst off deserve

priority. As such, Egalitarians would object that a relatively healthy recipient ought to receive a kidney on the basis of residence when the donated kidney could have gone to a recipient will suffer the harms of wait-time simply because he/she lives in an underserved area (Stein, 2002). This disparity has been verified and has been shown to be worsening through the years, growing from a range of 3.26 in 2000 to 4.72 years in 2009. This disparity has especially been prevalent in the West and Southeast regions of America and in areas with high black and low education populations (Davis et al., 2014a).

It appears that the geographic component of allocating kidneys has given rise to a discord within the school of Deontology. On one hand, there is a moral duty to reciprocate gratitude toward those who have benefited an agent so it is morally correct to allocate the kidney to local community members who are implicitly bounded by a social contract. On the other hand, there is a moral duty to care for those who, all else equal, are the worst off, therefore it is morally correct to allocate kidneys to those who are in most need regardless of location. To resolve this internal conflict requires a broader perspective. It is defensible that members of a community have more of a duty to one another than to non-immediate community members. However, it is also undeniable that a contract exists among statesmen and countrymen. The existence of a national contract, even in the face of diminished strength, coupled with the duty to serve those most in need would result in a stronger argument for national allocation instead of local allocation.

In fact, Utilitarian ethics leans toward a national allocation as well. Unlike Deontologists who believe people are of different moral standing, Utilitarian ethics tend to treat people in an egalitarian manner. Because everyone counts as “one,” the group with more people are given extra weight by the fact that there are more “ones” to account for. To this effect, Utilitarians would argue that if everyone is worthy of life, then attention ought to be given to those who

stand to gain the most from the rescue: those in the most desperate positions. This argument requires that kidney allocation begins nationally rather than locally.

In 1998, the U.S. Department of Health and Human Services (HHS) called on UNOS to make efforts to alleviate the blatant geographic disparities (Federal Register, 1998). HHS demanded that UNOS create a solution that would balance efficiency and equity so that organs are allocated on the basis of objective priority criteria and not on the basis of accidents of geography. Many studies have since looked into the regional inequalities of kidney allocations.

Economics of Waiting-Time & Geography

One well known study by Mathur et al. (2010) calculated the effect of supply and demand for kidneys among different regions of the U.S. The study revealed that areas with high ESRD incidence have 2% higher wait-listing rate and 37% lower transplant rate compared to low ESRD incidence areas. Residing in an area with a high demand for kidneys reduced access to a live saving medical good. These results likely occur because of the high competition for the kidney among potential recipients. Additionally, because high ESRD area yielded longer wait-times, the registrants on the wait-list would continue to become sicker because long wait-times are associated with worsening of condition and thus a lower rate of graft success. The researchers calculated that the relative risk of dying prior to receiving a transplant for low and high ESRD density areas was 1.34 and 2.23 respectively. The authors additionally found that the high ESRD incidence areas were predominately composed of minorities such as African Americans and Native Americans. Similar to how income is an indirect prerequisite to registering on the wait-list for a kidney, income seems to play a direct role in attaining a kidney. Axelrod et al. (2010)

discovered that those in higher socioeconomic-status (SES) strata were able to increase their likelihood of receiving an organ by 74% because they had the means to enlist at multiple DSAs.

Exacerbating the racial disparities is the fact that there are more Caucasian donors than any other race. Because white donors are genetically more similar to white recipients on the wait-list, white kidneys tend to go to genetically compatible white recipients (Diethelm et al., 1993). Besides improving efforts to increase the number of non-Caucasian donors in order to better suit the needs of non-Caucasian wait-list recipients, UNOS can make an effort to reduce racial disparities by modifying the geographic component of allocation. As alluded to in the ethics of geographic allocation, one modification would be to commence the allocation at the national level. Though UNOS uses deterioration as an argument for efficiency, it may be efficient to allocate kidneys nationally rather than locally.

HLA matching refers to immunological compatibility for which kidneys means the immune system of the recipient matches the immune system of the kidney donor and thus the recipient will not reject the donated kidney. HLA matching is a key component that determines the long-term success of a transplantation because it determines whether the host body will accept a kidney and how well the foreign organ will be accepted. On one side of the geographic efficiency argument is that local allocation qualifies the effect of deterioration. On the other side of the geographic efficiency argument is that if kidney allocation was formulated nationally from the start, there would be a higher chance of finding better HLA matches that would ultimately offer significant benefit to the recipient because the kidney is likely to be accepted without the host's immune system attacking. As such, the patient could more efficiently use the kidney and stay off the list longer. Moreover, because the kidney is distributed nationally, it has the additionally potential to reduce regional inequalities.

In a unique cost analysis of HLA matching, Schnitzler et al. (1999) revealed that when two hypothetical zero-HLA mismatch patients are differentiated only by the locale of residency, the recipient closest to where the kidney was donated incurred expenses of more than \$6,000 less than the more distant recipient over the course of three years. The higher expense of transplanting the distant recipient stemmed from the cost of transporting the kidney as well as preserving the kidney for a longer period of time. Although the researchers found that local allocation yielded the largest savings, national allocation with the intent to minimize HLA mismatches would still save over \$4,700 per transplant. Their simulations did not take into account points assigned for wait-time, or prior transplant, or CPRA sensitivity. If the other factors were taken into consideration, then there is a greater potential to reduce regional inequalities because those who have been waiting for a longer period of time due to low regional donor rates would be underscored through their wait-time points. Despite the costlier scheme of allocation based on a national scale, the larger scale is still cost effective and beneficial in the sense that it would maximize HLA matches and reduce inequalities by giving the kidney to those who are medically viable and have accumulated the wait-time points.

UNOS identified four metrics to evaluate the severity of geographic disparities: waiting time, transplant rates, pre-transplant mortality, and quality of the donated kidney. When these metrics were compared between local and regional distribution levels, it was revealed that three of the four metrics, waiting time, transplant rates, and quality of donated kidneys, have worsened over time, suggesting that HHS' final rule has had no discernible impact on geographic disparities. For example, prior to the 1998 final rule, the average wait-time between DSAs was 2.10 years. When this metric was evaluated for 2009, the wait-time disparity between DSAs grew to 3.50 years. Likewise, regional disparities in wait-time increased from 2.74 in 1998 to

5.08 in 2009 (Davis et al., 2014a). The findings are not surprising because there is no record of UNOS making any effort to mitigate the disparity. UNOS ought to undertake an effort to address the disparity in order to avoid harming patients on the wait-list.

Conclusion

Concerning enlistment on the wait-list, UNOS ought to allow, with constraints, substance abusers and the non-compliant on the wait-list because doing so would expand the pool of candidates with higher HLA matches (which have been determined to be cost-effective) and because doing so would uphold the most fundamental ethical principle of delaying death when the means to do so are accessible. With regard to allocating kidneys once on the wait-list, it is likely that UNOS will continue to retain the urgency clause in order to delay immediate deaths. With the abundant data existing on geographic disparities caused by local allocation, UNOS ought to consider changing the allocation procedure to mitigate geographic disparities that have lead to some groups unfairly waiting longer for kidneys simply by the accident of where they reside.

Chapter 5

Conclusion

Until the scarcity ceases to exist, there must be a justifiable way to manage the acquisition and allocation of a highly valuable resource. Concerning bodies of legislation, it is clear that the well intended goals of the Uniform Anatomical Gift Act (UAGA) have not come to fruition due to the blatant violation of prioritizing first person consent. Without a foreseeable change in the desire of health professionals to obtain and prioritize the consent of the kin, the best method to achieve the goals of the UAGA is to maximize the consent of the kin. A large survey conducted by the Department of Health and Human Services (HHS) (2012) showed that the kin are significantly likely to align with the wishes of the deceased if the wishes are known. One mechanism to incentivize health professionals to obtain first-person document of gift is to provide a certification of excellence for sites that perform successful transplants. With a goal of attaining the certification, health professionals are expected to increase their effort to obtain a first-person document of gift in order to help the kin give the final permission to donate the deceased's organs.

Concerning acquisition of consent, the U.S. ought to continue with an opt-in system rather than converting to an opt-out system. Although the literature review supports the opt-out system because of the higher donation rates, the literature review also suggests that there are more contributing variables than a simple assumption. Although the empirical analysis of DMV data did not produce evidence to support a required response system, further research is needed to completely eliminate the benefits of a required response system.

The Uniform Determination of Death Act (UDDA) has greatly contributed to the acquisition of deceased donors by including cessation of brain function as a criteria of death. This inclusion has allowed the procurement of many organs due to the ability to control for loss of circulation. Without the ability to control for blood circulation, the integrity of organs would be compromised. Nevertheless, because UDDA has additionally included the cardiac criteria of death, that criteria can be more advantageously used to acquire donors from uncontrolled settings such as outside of the hospital. Both controlled and uncontrolled cardiac criteria of death have been shown to be comparable in outcomes and more cost effective than dialysis. Thus, an effort ought to be made to create a mechanism to capture donors after cardiac death (DCD). Together, both definitions prescribed by UDDA would expand the pool of donors and allow a better chance for those on the wait-list to obtain an organ.

The National Organ Transplant Act (NOTA) has ordained monopsony and monopoly power to a single entity, the United Network for Organ Sharing (UNOS), in order to provide consistency to a matter concerning life and death. Additionally, NOTA has banned all valuable consideration for organs. The ethical analysis of NOTA defends the prohibition of sale for living donors because such a compensation system violates human dignity and suggests some lives are more valuable than others. However, NOTA can be modified to allow compensation post-mortem because it would not violate dignity nor create a slippery slope for causing death. A recommended post-mortem compensatory system is toward a fixed portion of the deceased donor's funeral expense. The payment structure would hinge on persons the wait-list contributing to a reserve for funeral expenses. Because the patients on the wait-list and the insurers (demand portion) are relatively inelastic, there should be little difficulty in obtaining the money necessary to fund the funeral expenses. Because donors (supply portion) are expected to

be relatively elastic, the costs associated with enticing donors should be lower than if supply were relatively more inelastic. The funeral expenses would be below the compensation proposed by Becker and Elias (2008) for living donors because the deceased donors do not bare the risk of death nor loss in income. As such, the funeral expenses should range between \$800-\$4,500 as proposed by the Ethics Committee of the American Society of Transplant Surgeons (Arnold et al., 2002).

Lastly, with respect to receiving a kidney, it is clear that current UNOS practices are strongly aligned with Utilitarian and Consequentialist ethics. This affinity is evident with the exclusion of patients based on objectionable behavior such as substance abuse and non-adherence to medical regimen. This act of exclusion is unethical because it violates the bioethical principle of non-maleficence, to do no harm. With regard to receiving a kidney once registered on the wait-list, it is clear that UNOS tries to balance efficiency with equity. Equity is upheld when patients with urgent needs are prioritized even if such an allocation is an inefficient use of a scarce resource. At the same time, efficiency is upheld when allocating kidneys by distance in order to reduce deterioration. However, such a geographically based allocation procedure has created geographic disparities in which some are unfairly constrained to wait longer simply by the accident of residence. UNOS ought to consider the viability of a national scale for allocation in order to reduce disparities and to possibly better biological compatibility between the donor and recipient.

Appendix A

Table 5. Study States

Paper States	Verbal States	No response
1. Alaska*	Colorado	Alabama
2. Arizona	Delaware*	Arkansas
3. Connecticut	Florida*	California
4. Georgia	Idaho	Louisiana
5. Hawaii	Illinois	Mississippi
6. Kentucky*	Indiana*	Montana
7. Maine*	Iowa*	New Hampshire
8. Massachusetts	Kansas	North Carolina
9. Minnesota	Maryland	Oklahoma
10. Nebraska	Michigan	Pennsylvania
11. Nevada	Missouri*	South Carolina
12. New Jersey	Ohio	
13. New Mexico	Texas	
14. New York	Vermont	
15. North Dakota	Washington	
16. Oregon	Washington D.C.	
17. Rhode Island		
18. South Dakota		
19. Tennessee		
20. Utah		
21. Virginia		
22. West Virginia		
23. Wisconsin		
24. Wyoming		

*Included in data analysis

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ACADEMIC VITA LASANTHI FERNANDO

Objective

To obtain a position that will provide me the skills and opportunities to alleviate the scarcity of organs needed for transplantations.

Education

The Pennsylvania State University	University Park, PA
<i>Schreyer Honors Student and Paterno Fellows</i>	May 2016
Bachelor of Science in Economics	
Bachelor of Arts in Philosophy	
Minor in Bioethics and Medical Humanities	
Minor in Business in the Liberal Arts	
<u>Achievements:</u> Honors Thesis - <i>The Ethics and Economics for Organ Donations and Transplantations</i> , Marshall for the College of the Liberal Arts	

Relevant Experiences

Schreyer & Radboud Health Care Think Tank	Netherlands & USA
<i>Researcher</i>	August 2015 - Present

- Collaborated with Dutch students from Radboud University to write a comparative report on early implementation of palliative care.
- Conducted empirical research on early palliative care in nursing homes.
- The report and recommendations are to be published and presented to the Dutch Ministry of Health.

Capitol Associates Inc.	Arlington, VA
<i>Legislative Intern</i>	May 2015 - July 2015

- Tracked, researched, and analyzed policies and legislations relevant to healthcare.
- Attended Congressional hearings on healthcare topics and effectively relayed the developments.

Department of Economics	University Park, PA
<i>Head Grader for ECON315: Labor Economics</i>	January 2015 - Present

- Graded all in-class assignments for over 160 students and proctored exams.
- Managed six other graders to grade out-of-class assignments.

Global Human Rights Brigade	Panama City, Panama
<i>Volunteer</i>	March 2013

- Worked with Panamanian lawyers to provide pro-bono legal consulting to neglected families in remote communities.
- Lead educational workshops tailored to the community on various topics: the land titling process, government institutions, family law, property rights, business rights, conflict resolution, etc.

Employment Experience

HUB Information Desk

Desk Attendant

University Park, PA

August 2013 - present

- Worked 12-15 hours a week throughout the academic year.
- Effectively communicated information to students, faculty, and visitors on all Penn State matters.

Skills

Technology: Microsoft Office Suites, Apple iWork, The R Project Statistical Computing, STATA

Language: Spanish - proficient written and read, basic spoken.