REFORMING THE U.S. ORGAN DONATION SYSTEM: POLICY INSIGHTS FROM THE EXPERIENCE IN OTHER COUNTRIES

Josephine Kershaw  
Ph.D., Associate Professor  
Health Care Management, College of Business  
The University of Findlay

Lori Nunemaker  
M.B.A.-Health Care Management Candidate  
The University of Findlay

Maria Hinds  
J.D., OTR/L, Associate Professor  
School of Allied Health Sciences  
Florida A&M University

Joseph DeCosta  
B.S. Nuclear Medicine Technology Candidate  
The University of Findlay

ABSTRACT

As the second decade of the 21st century begins, for 110,000 people in the United States are on a waiting list, that is, they are candidates hoping to receive a life-saving organ donation (HRSA, 2010). According to national data from the Organ Procurement and Transplantation Network, less than 30,000 transplants – a fraction of the waiting list – were performed in 2010, illustrating the large gap between the demand and the supply of organs. This gap continues to increase annually, leading to thousands of potentially avoidable deaths each year. Although the United States leads the world in biomedical advances, it has struggled to narrow the organ transplant gap. Policy insights can be learned about how to alleviate this problem by considering factors that contribute to the success and failure of organ donation programs in other countries. For example, the organ donation programs in Spain and Iran have managed to decrease the organ shortage and, consequently, shorten their transplant waiting list. On the other hand, some countries have lower rates of organ donations among their populations than the United States. In this article, organ donation programs in selected countries in Europe, Asia, and Australia are explored. Drawing on these international experiences, possible courses of action will be discussed for policymakers to consider in reforming the U.S. organ donation system.

The Present Crisis

Each day, 18 people die in the United States because the life-saving organs they need are not available and, every 11 minutes, another name is added to the national organ transplant waiting list (NFT, 2011). As of the end of May 2011, the waiting list totaled 111,480 people, according to the continually updated ticker on the United Network for Organ Sharing’s website (UNOS, 2011). The Organ Procurement and Transplantation Network (OPTN) operated by UNOS under contract with the federal Health Resources and Services Administration reported that 24,604 deceased donor transplants, a fraction of the number on the waiting list, were performed in 2010 (OPTN, 2011). There are several reasons for the shortage of organs. On the demand side of the equation, technological advancements have made such complex medical procedures possible and longer lifespans have led to a significant rise in the demand for organs. On the supply side, the present system has failed to motivate most Americans to register as donors, thus resulting in a demand that has greatly exceeded supply. Transplant waiting lists have been expanding, not only in the United States, but also around the world.

Many of the debates regarding the harvesting of cadaver organs for patients on transplant waiting lists have centered around the legal and moral definition of life and death, because a donor must be declared dead before any organs can be harvested. Drawing the line between life and death (i.e., where the donor...
is dead but the organs are not) requires an expansion of the
definition of death from that of the natural cessation of vital
heart and brain functions (Tabarrok, 2010). There has been no
consensus on the diagnostic criteria for brain death. Various
neurological criteria for the diagnosis of brain death are used,
such that a person could be diagnosed as brain dead according
to one criterion and not be diagnosed as brain dead according
to another (Shewmon, 1998; Haupt & Rudolf, 1999; Wijdicks,
2001; McCarthy, 2002).

Even though organ transplant waiting lists are growing, the
number of patients waiting, and how long they will wait, will vary by organ type as may be seen in Table 1.

<table>
<thead>
<tr>
<th>Organ</th>
<th>Waiting list candidates</th>
<th>Median time to transplant (days)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kidney</td>
<td>88,943</td>
<td>1,269</td>
</tr>
<tr>
<td>Liver</td>
<td>16,228</td>
<td>296</td>
</tr>
<tr>
<td>Heart</td>
<td>3,164</td>
<td>131</td>
</tr>
<tr>
<td>Lung</td>
<td>1,755</td>
<td>200</td>
</tr>
<tr>
<td>Pancreas</td>
<td>1,363</td>
<td>356</td>
</tr>
</tbody>
</table>

Table 1. U.S. Organ Transplant Waiting List: Candidates and Waiting Time by Organ Type

Overview of Organ Donation in Other Countries

To gain policy insights from the experience of other countries, this article begins with the organ donation systems in two
countries, Australia and the United Kingdom, which have recently implemented reforms. Next, the successful organ
donation initiatives adopted by the European countries of
Austria, and Spain are discussed and followed by the organ
donation programs in the autocratic Asian countries of China
and Iran.

Australia. Lagging noticeably behind other countries, Australia has an organ transplant rate of only 10.8 transplants per million
people. In 2009, the Australian government allocated $151 million over four years to reform the country’s organ donation system and increase public awareness of this pressing issue. (Medicare Australia, 2009). The goal was to encourage residents not only to register to become donors, but also to discuss their wishes with their families. Although this was a step in the right direction, it remains to be seen if this campaign will be enough to increase the supply of donated organs and keep patients from waiting years for a needed transplant.

United Kingdom. Like its former island colony, Australia, the United Kingdom has relatively low organ donation rates,
with only 22 to 32% of residents across the United Kingdom registered as donors (NHS, 2009). Less than one half (41%) of these residents have discussed the issue of transplantation with their family, while 58% have not (Europeans and Organ Donation, 2007). In the United Kingdom, the conversion rate, or percentage of potential donors who donate organs upon their death, is approximately 50%. At present, efforts are underway to reform the organ donation system in the United Kingdom. Among the many projects is the doubling of the number of transplant coordinators, who receive specialized training on how to counsel families about the ethical and emotional issues related to donation of their relative’s organs. To identify potential donors, the coordinators also work closely with doctors in intensive care units. Moreover, in the United Kingdom, a policy change to an “opt-out” system is being considered.

Austria. In contrast, Austria has one of the highest donation rates in the world, with 27.2 donors per million people. Less
than a decade ago, Austria’s rate was only 4.6; but, through implementation of their “no-give no-take” system, Austria is quickly reducing their organ shortage (Rithalia et al., 2009). Austria has closed this gap with an opt-in mechanism, such
that citizens who do not opt-in as organ donors are moved to the bottom of the list in the event they need a transplant. For Austrians, this opt-in system has been a successful motivator to increase organ donation rates.

Spain. Unlike most countries, Spain has had great success in raising organ donor rates, leading the world with 34 deceased donors per million people coupled with a conversion rate of 80-85% (Council of Europe, 2010). Although Spain has not entirely eliminated the waiting list for organs, it has reduced the number of candidates to a few hundreds. One of the main factors behind Spain’s organ donation success is the use of an opt-out system of presumed consent. Under the opt-out system, it is automatically assumed that everyone is a donor unless they specifically designate themselves as unwilling to donate their organs. Because no additional steps need to be taken to be considered a donor on the individual’s part, the pool of available donors increased significantly in the opt-out system. Also, in 1989, Spain established a nationwide transplant coordination network that streamlined the process for coordinators and doctors to identify potential donors. Spain’s growth in organ donation rates may be further due to the use of an expansive legal definition of death, such that patients can be pronounced dead sooner when the organs are more likely to be viable (Wong, 2009).

China. Standing out among the nations of the world in its source of transplantable organs is China, which uses the organs of executed prisoners. In 1984, a Chinese rule ushered in the harvesting of organs from those who were sentenced to death, if the prisoner “volunteered,” if the family consented, or if no one claimed the body (Kram, 2001). According to a 2010 Xinhua News Agency article, China’s 164 hospitals that are authorized to perform transplant surgeries relied on death-row inmates as the source of organs for 65% of organs donated. Although the Chinese Ministry of Health initiated a pilot program in 2010 to establish a donor registry, formal waiting list, and voluntary donation, progress has been gradual with 60 transplants performed in the pilot compared to the estimated 8,000 that were done that year in China (Alcorn, 2011). As in other economically disadvantaged countries, for example, India and the Philippines, China has a thriving black market in organ trafficking where illegal transplants are performed on those who pay the purchase price (BBC News, 2009).

Iran. Although current data on Iranian organ donation rates is unavailable, Iran is the only country to completely eliminate its waiting list for kidneys (the organ most commonly transplanted) by providing monetary payments to organ donors. The shortage was eliminated in only 11 years after implementation of a legalized payment system instituted by the government in 1988 (Ghods & Shekoufeh, 2006). In Iran, the donor receives remuneration from both the government and the recipient. A payment of $1,200 along with a year of health insurance coverage comes from the government and the amount is supplemented by compensation from the organ recipient or, in cases of impoverished recipients, from one of several charitable organizations (Howley, 2008). This complementary structure of government, recipient, and charitable payments aims to assure access to treatment for poor as well as wealthy organ transplant candidates.

Options for Reforming the U.S. System

Across the world, countries have tried various methods to alleviate the organ supply deficit for their citizens. The options following are presented as possibilities for the U.S. to consider in its quest to decrease the growing gap between the demand and supply of transplantable organs. However, the success or failure of these methods may be rooted in societal norms and cultural acceptability.

Incentives. One alternative is to offer incentives for enrolling as a donor. A negative incentive would be a “no-give no-take” system similar to that in Israel and the bottom of the list system in Austria. Positive monetary incentives, such as payment of funeral expenses for deceased donors and health insurance, tax credits, and life insurance for living donors, were proposed in 2009 by Senator Arlen Specter (Tabarrok, 2010). Additionally, incentives for living donors should not be overlooked, because organs from a living donor rather than a cadaver have generally lower rejection rates, and the donor and recipient can schedule their surgeries, rather than wait for a last-minute telephone call about a cadaver organ.

Trained Coordinators. For many proposed reforms to be effective in raising donor rates, highly trained transplant coordinators and organ procurement specialists will be crucial. Even in a presumed-consent, opt-out system, families are often given a chance to decline the transplant. This highlights the importance of having well-trained coordinators available to discuss the organ donation option with the family members. In addition, if a legalized payment system were to be implemented, transplant coordinators who are highly skilled in analyzing a donor’s potential motivations and legitimacy could screen unhealthy patients who may conceal health issues. Furthermore, coordinators should have appropriate community representation and sensitivity training to reflect the diversity and cultural considerations of the different ethnic groups in the U.S. which have disparate rates of organ donation and supply.

Awareness and Education. If reform options were implemented without a well-funded and strategic public relations campaign, actual improvements will be minimal (Kleiman, 2009). Additionally, attitudes of the public, medical community, hospital staffs, relatives, politicians, and opinion leaders can influence organ donation rates. In 2006, a European study found that discussion of organ donations produced positive per-
In an interview for CNN, Joel Newman of the United Network for Organ Sharing stated that most people – even if they have positive feelings about organ donation – do not make a commitment to opt in and actually take action by filling out donor cards (Wong, 2009). Likewise, Donate Life America reported that, although 90% of Americans claim to support donation, only 30% know how to become designated as an organ donor (www.donatelife.net). Consequently, another proposed solution to decreasing the organ shortage in the United States is to follow the lead of European countries like Spain and change the system to one where people must opt out. Donation would therefore be the default, requiring no action on anyone’s part. Individuals who disagree with this type of presumed consent system because of objections on scientific or ethical grounds would simply need to mark a box on their driver’s license stating they do not want their organs harvested (Kleiman, 2009). It is estimated that there are 17,000 deceased potential donors annually in the United States (Laeng, Fant, & St. Martin, 2005); but, currently, only 38% of the population is registered as donors (Pathania, 2009). In countries that have an opt-out system, the average registration rate is 82% (Johnson & Goldstein, 2003).

Notably, however, are the findings of a recent study published in the Annals of Internal Medicine that investigated the rates of kidney transplants from living and deceased donors in 44 countries between 1997 and 2007 (Horvat et al., 2010). Half of the countries, including the U.S., Canada, Japan, and Australia, required explicit consent whereas the other half, including France, Germany, Italy, and Spain, used presumed consent for organ donors. The study found that nations with presumed consent generally had a higher rate of cadaver transplants than nations with explicit consent (with a median, or midpoint, rate of 22.6 transplants per million people as compared to 13.9 per million in countries with explicit consent). In contrast, countries with presumed consent had a lower donation rate of 2.4 per one million people for live donors, versus a 5.9 per million live donation rate in countries that required explicit consent. The study found that, although having the automatic presumed consent increased transplants from deceased donors, the live donor transplant rate was significantly less in countries with presumed consent.

Legal Payments. Historically, the selling of organs by live donors has been a controversial practice. Some believe that people who buy organs are exploiting victims who are desperate enough to sell their organs. Others argue that, although some exploitation may occur in certain cases, a life may still be saved. Nevertheless, while it is illegal in most countries, organs are being bought and sold today in an international black market fueled by desperation. Many people in the United States and other wealthy nations where buying an organ is illegal, have traveled to lower socioeconomic countries to get a transplant, a practice known as “transplant tourism” (The Lancet, 2007). In the case of Feldman’s victims, many who took the risk to obtain a black market organ were duped. This raises the question of harm reduction: Would the harm of legal payments for organs be reduced and better controlled in a regulated market, making it safer and fairer for both buyers and sellers? (Major, 2008). Furthermore, a legal payment system may not only increase supply, but it also may bring prices to a level that would make organs affordable to more than just the wealthy.

In 2007, Nobel Laureate economist, Gary Becker, and Julio Elias, estimated that $15,000 payments to living kidney donors in the United States would potentially eliminate the waiting list (Becker & Elias, 2007). He proposed that the government make these payments, which sounds ludicrous until it is taken into consideration that the government, through Medicare’s end-stage renal-disease program, paid an average of $27,000 per beneficiary ($9.2 billion in total) for dialysis services in 2009 alone (MedPAC, 2011).

Future Options. One promising area of research is xenotransplantation, or utilizing animal organs in humans. Though pig organs would be most feasible, research in pigs has been cost prohibitive. Thus far, research studies using mice carrying functional human genes are growing more sophisticated and less antigenic (Kleiman, 2009). With the potential to harvest human organs using advances in animal research, part of the United States’ plan could allocate funding toward the emerging science of xenotransplantation.

Alternatively, an area of research that is certain to generate not only much promise but also much controversy is cloning to produce organs for transplant. Human cloning has many applications, including the production of organs identically matching an individual in need of them, with a 0% chance of rejection (Human Genome Project, 2009). Concurrently, however, ethical questions surround the creation and disposal of a living being for the sole purpose of harvesting organs.

Possibly less controversial is the use of novel regenerative technology to grow new organs without creating a human being. While tissue engineering to create skin grafts has been FDA-approved for almost 25 years (Herman, 2002), successful use of a biosynthetic or natural matrix serving as a scaffold for
adult stem-cell regeneration to produce tissues, such as tracheas (University of Bristol, 2008) has been much more recent. In the future, researchers may be able to develop functional kidneys, the organ in highest demand (Brigham and Women’s Hospital, 2011). Other biomedical devices, such as the wireless heart pump, which could negate the need for heart transplants, are also under development (Technology Quarterly, 2011).

Conclusion

With advances in medical technology and an aging population, the demand for organs will rise, and the gap between supply and demand is sure to increase. In particular, the prevalence of diabetes is reaching epidemic proportions, and diabetes is the leading cause of kidney failure. According to the Centers for Disease Control and Prevention, the percentage of diagnosed diabetes cases has demonstrated a rising trend over the last 30 years in all age groups (CDC, 2011). Already, three quarters of those on the transplant waiting list need a kidney.

A concerted approach for the United States to overhaul the organ donation system could involve the following actions:
1. Consideration of a presumed consent policy for cadaveric donors nationwide,
2. Health insurance and tax incentives for living donors,
3. More highly trained coordinators to staff transplant centers in every state, and
4. A nationwide media campaign to raise awareness about organ donation to maximize the impact of these initiatives.

If the proposed changes do not significantly decrease the gap between the availability of donated organs and demand, the United States may well also consider a legalized payment system with strong safeguards for accessibility, equity, and safety of both the donor and the recipient.

Moreover, future biomedical research developments in the fields of xenotransplantation and regenerative medicine may save thousands of lives that would have been lost while people are waiting for a suitable organ to become available. Aside from the technological imperative to perform complex organ transplants, the human desire to live, the inevitability of aging, and the increasing incidence of chronic disease are global phenomena. Learning from the experience in other countries may alleviate the critical organ shortage in United States, with the caveat that cultural, ethical, and political factors will influence any proposed policy changes. Success in subsequent implementation will depend not just on the resulting medical outcomes of organ transplant procedures, but also on the broad acceptance of the incentives and the means used to obtain the scarce, needed organs.

References


