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## **FINANCIAL BARRIERS TO ORGAN TRANSPLANTATION: A COMPARATIVE ANALYSIS**

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### **ABSTRACT**

*Organ procurement and transplantation is an expensive process. Because of economic concerns, hospitals often refuse to list otherwise qualified patients for transplant unless that patient has the financial means to pay for the transplant and related services. This prevents patients from receiving lifesaving organ transplants even when they are medically qualified. Since the financial aspect of transplant is a concern in the United States, this paper explores the origin of the barriers, and through the literature compares barriers to those in other countries performing organ transplants. It also explores ways for patients to overcome financial barriers to transplantation.*

*Keywords: organ transplant, financial barriers, international comparison*

### **INTRODUCTION**

Capitalism reserves goods for those that can afford to buy them. In the case of organ donation in the United States, it is illegal to buy or sell organs; however, a significant economy exists surrounding the business of procuring and transplanting organs. The transplant recipient incurs all charges related to organ procurement and transplantation. This creates an enormous burden for the patient or his insurance provider. Obtaining funding for an organ transplant can be the difference between life and death for patients who don't have adequate health insurance, or lack health insurance.

Major religions, organ procurement organizations (OPO), and transplant centers consider organ donation a benevolent act. Despite this, the price tag affixed to each lifesaving organ is far from benevolent. While we (as a society) shift the cost of procurement and transplantation away from the donor and her family, we don't always consider the burden for the transplant recipient. Defining financial barriers to solid organ transplant as: A condition related to paying for an organ transplant that if not met, precludes the patient from receiving a solid organ transplant; it is important to understand the charges associated with organ transplant and their origins in order to grasp the burden placed on patients who need lifesaving transplants. It is also necessary to understand the financial burden in order to explore alternatives for funding procedures and medications associated with transplantation, noting that payment for organ transplants is a subjective arrangement defined by the specific transplant center treating the patient, and necessary conditions may vary from center to center.

Most importantly, we can learn from and compare the American transplant system to other developed countries with modern healthcare systems. There is a principal question in this paper: What financial barriers to solid organ transplantation exist; and comparatively, do Americans

face more financial barriers to transplantation than patients in other developed nations with modern healthcare systems? These issues are explored considering the current limitations of living and deceased organ donor availability, and the realities of profit in the American healthcare system.

## **ORGAN PROCUREMENT AND TRANSPLANT OVERVIEW**

### **Procurement and Transplantation**

Procurement and transplantation are two unique processes in the American donation and transplantation system. Organ procurement encompasses donor evaluation, obtaining consent for donation, medically managing the donor, and placing the organs with transplant centers according to United Network for Organ Sharing (UNOS) policy. Currently, UNOS indicates over 111,000 patients are waiting for an organ transplant (a number which increases by thousands of patients every year), while numbers of organs donors remain relatively static over time (OPTN 2009).

Organ procurement is managed by one of 58 federally designated OPOs who are either independent nonprofit organizations or nonprofits associated with a major university (*e.g.* the University of Wisconsin). Transplantation occurs after a transplant center (a hospital that performs organ transplants) accepts an organ from a donor managed by an OPO. Typically, the transplant center's surgeons surgically recover an organ for their patient. Alternatively, the OPO can arrange for a compensated, qualified, third-party surgeon to recover the organ. The organ is then transported back to the transplant center and the transplant surgery is performed on the recipient. All of the costs related to donor's medical management, the procurement of a specific organ, and the transplant surgery are billed to the recipient via the transplant center. The distribution of charges is a complex process managed by the OPO in collaboration with the transplant center and donor hospital.

### **Aftercare and Medication**

Aside from charges associated with organ procurement and transplantation procedures, there is a significant cost associated with the recipient's aftercare and anti-rejection medication. This adds an onerous annual expense to the existing financial burden associated with the transplant surgery. Many transplant centers include the cost of anti-rejection medication in their assessment of a patient's ability to pay for a transplant. This additional consideration increases the likelihood that a patient won't have the appropriate funds for their transplant, and won't be listed at a transplant center because of their financial status. Transplant centers often require proof of assets or adequate health insurance to consider listing a patient with UNOS. The rationale behind this practice is to ensure that the patient will have appropriate aftercare, and be able to afford their anti-rejection medication. It also ensures that the transplant center is reimbursed for its expenditures related to the donation.

Although this process may seem fair and equitable for reimbursing involved parties, it often presents such an enormous burden for the patient and her family that she is unable to survive the

process of finding insurance or other funds, and becomes one of 16-17 people who die each day waiting for an organ transplant (OPTN 2009).

### **Expenditures Associated with Transplantation and Related Processes**

In 2008 the Milliman firm developed an actuarial report that outlined the total cost of solid organ transplant. In the report, Milliman uses data provided by the Organ Procurement and Transplant Network (OPTN), whose programs are currently managed by UNOS. Milliman (2008) averaged costs associated with all transplantations performed on American citizens the year prior, and estimates the cost of procurement according to 2005 and 2006 data from Texas and Washington based OPOs. The firm included the following data: thirty days of pre-transplant hospitalization and associated charges; procurement services; hospital charges associated with the transplant; physician's fees; 180 days post-transplant hospital admission (initial hospitalization and repeat hospitalization after initial discharge, and outpatient procedures and laboratory services); and the cost of medication (anti-rejection, etc.) associated with pre and post-transplant prescriptions within 180 days (Milliman 2008). This thorough analysis of the overall cost of obtaining an organ transplant is the basis for further analysis.

The intestine is the most expensive single organ transplant, averaging \$1,121,800 per transplant (Milliman 2008). The kidney is the least expensive at only \$259,900. Other transplants range from \$275,500 to \$787,700 per organ (Milliman 2008). Multiple organ transplants escalate these costs to well over the million-dollar mark, with the exception of liver-kidney and kidney-pancreas transplants. Lung transplants are considered single organ transplants whether or not both lungs are transplanted into the same recipient, and Milliman provides estimates for both single and double lung transplants. It is important to note that Milliman assumed in their calculations that these charges are associated with patients with full-coverage insurance (Milliman 2008). The total cost for a private-pay patient could be much higher without the benefit of an insurance company's negotiated rate agreements. In Chisholm (2007), a 2001 survey conducted by the author indicated that the first year of post-transplant medication exceeded \$20,000. In Chisholm (2005), the estimate stood at \$12,000 per year in the years following the initial post-transplant year. This data is also reflected in the Milliman (2008) study.

There is an argument within the transplant community that only those who have the ability to take care of their organ post-transplant should be listed at a transplant center. Because of this consideration, and the economic needs of the hospital, finances appear among the various and extensive criteria used to assess the health status of a potential transplant patient. With a noted increase in patients waiting for a transplant, and relatively stable donation rates, it is apparent transplant centers have some place to be "picky" about their patients (Pomfret *et al.* 2007). For example, the state of Michigan has approximately 3,000 patients waiting for an organ per month, and approximately 300 donors per year donating approximately 950 organs (OPTN 2009). With no shortage of transplant business and a large shortage of organs, some could argue that only the "best" candidates should receive organ transplants.

If the transplant center wants to improve its cost structure, it will probably have to transplant only better candidates with better organs so that the patients will have short lengths of stays and use fewer resources. But transplant volume may decrease (Howard 2007).

On the other hand, considering the financial assets or insurance of a patient in the listing process could prevent patients who are very medically suitable for donation (“better candidates”) from receiving their life saving transplants.

The importance of finance in transplant is apparent in the materials provided to transplant patients by Tulane Medical Center in New Orleans, Louisiana:

The staff at the Tulane Abdominal Transplant Institute (TATI) understand the importance of considering the financial aspects of organ transplantation. Because of this, we have included financial issues in our patient care services...[Transplant Financial Counselors] collaborate and communicate with the Insurance Companies, Medicare and Medicaid offices, and with the clinical and social services of the transplant team to provide a complete financial plan of care for each individual patient . Most patients cannot afford a transplant without some type of health insurance coverage (Tulane 2009).

This is strong language defining the importance of money in the process of being listed at a transplant center and subsequently receiving a transplant. While transplant centers are often willing to work with patients to secure funding, some patients don’t survive the lengthy process.

Hospital administrators want both high volume and outstanding results. But they also want the program to have an ‘excess of revenues over expenses’ (not-for-profit hospitals do not have ‘profits’) (Howard 2007).

If a patient doesn’t have the financial resources to pay for a transplant and associated care and medications, transplant centers will not place a patient on the waiting list despite the ability to save his life with a transplant.

## **COMPARATIVE FINANCIAL ANALYSIS AND BARRIERS OUTSIDE THE U.S.**

Hospitals in the United States are not unique in their ability to perform organ transplants. Many other countries perform organ transplants successfully. Comparatively, do other countries’ citizens face the same financial considerations when confronted with organ transplantation?

### **Italy**

Comparatively, Italy’s transplant rates are much lower than the United States; Italy transplants 19 per million population while the United States transplants 24 per million (Miceli 2000). Miceli (2000) studied a patient’s level of education as a socio-economic indicator related to organ donation. The results of the study showed that despite free healthcare and organ transplantation in Italy (on all accounts, an absence of economic barriers), the absence did not reduce the level of discrimination in access to transplant (Miceli 2000). It is interesting to note when considering the burden of cost related to American transplants that there were still other barriers associated with transplant in Italy, preventing people from being transplanted when appropriate. Other barriers included community support of organ donation, with the level of community education as a strong indicator for or against organ donation support.

## **Japan**

The Japanese enjoy relatively healthy lives and the third longest average lifespan in the world at 82.12 years (CIA World Factbook 2009). Healthcare is accessible, and insurance is affordable (Fukuhara 2007). The Japanese do not pay significant out-of-pocket healthcare expenses, and insurance co-pays are capped per month. Despite this relative affordability, Japanese citizens also have barriers to organ transplantation:

Experts from various fields have hypothesized why organ transplant rates are so low in Japan and why so few are from donation after brain death (DBD) donors. Several of their theories stem from spiritual beliefs...Others, including members of congress and some physician groups, believe that a DBD donor still contains a spirit. Under this belief system, removing organs from a DBD donor is equivalent to murder...even today, physicians who perform organ transplantation are sometimes sued for their actions (Fukuhara 2007).

Further confounding the lack of organ donations and transplants in Japan is the nation's cultural opposition to brain dead organ donation. From 1968 to 1999 there were no brain dead organ donors in Japan (Sato 1999). In 1992 the Japanese government determined that brain death was in fact death, but cultural taboos surrounding the condition of a dead patient with a heartbeat continued to create a non-financial barrier to donation (Sato 1999). Nearly 300 Japanese citizens sought solid organ transplants outside of Japan in those years (Sato 1999). Donation after cardiac death (patients declared death by cardio-respiratory means) supplied kidneys to Japanese donors during this time. Japan's transplants per million have not been adequately reported in the literature, and donation remains a relatively taboo subject.

Japanese citizens still face a shortage of transplant services even without financial barriers. Unfortunately, without major cultural change in Japan, whole organ transplant will remain an unusual occurrence (Fukuhara 2007).

## **The United Kingdom**

The United Kingdom lags behind the United States, Spain, and Italy with only 13 transplants per million (Rudge 2006). The United Kingdom publicly funds healthcare for all residents with tax dollars. Some residents choose to supplement their government funded healthcare with private insurance in order to circumvent wait times and public facilities. Patients in need of an organ transplant are not faced with financial barriers. Transplant patients in the United Kingdom face issues related to a low supply of transplantable organs (Rudge 2006). A lack of physician consensus on the appropriate time to declare brain death results in fewer patients being considered for organ donation overall, despite the ability for a patient to become a donor after cardiac death (Rudge 2006). Patients that donate after cardiac death are typically only able to donate livers and kidneys, creating a shortage of other organs if brain dead donors are not available. Of all brain dead patients eligible to donate their organs, organ donation officials only approach 85 percent of patients' families about donation (Rudge 2006). Out of the 85 percent of all organ donor families approached for donation, 41 percent declined donation (Rudge 2006). Again, despite a lack of financial barriers, patients in the UK face organ shortages that result in fewer transplanted organs per million than in the United States.

## Spain

Spain excels in the area of organ donation. Spain's presumed consent system results in significantly higher consent rates for donation than other developed countries; as a result, Spain has 33 transplants per million population (Matesanz 2009). The Spanish single-payer healthcare system provides free care to all residents:

The most common complaint of patients is the long wait to see specialists and undergo certain procedures. On the other hand, a study published last year in the U.S. journal *Health Affairs* found that in Spain, there are a third fewer deaths caused by delayed access to health care than in the United States. Spain's constitution, drawn up in 1978 following the Franco dictatorship, not only guarantees the right to universal health care, it also requires the state to provide it. The World Health Organization's ranking system puts Spain's health care system seventh in the world, well ahead of America, even though it spends much less on health care (Socolovsky 2009).

Like the United Kingdom, Spanish residents also have the option of supplementing their free healthcare with private pay insurance (Socolovsky 2009). Access to private pay insurance may expedite a patient's initial assessment for transplantation, but Spanish residents, like those in the United Kingdom, cannot be turned away from a transplant waiting list because of their inability to pay. Spanish patients do cover the burden of some of their medication costs; however, this is not considered a significant cost within the Spanish transplant system, known as the world's best (Socolovsky 2009).

## DISCUSSION

These comparisons offer perspective on the financial barriers effecting patients in the United States; however, any barriers to transplant result in additional preventable deaths. It is important to overcome barriers of any origin to maximize a patient's chances of receiving a lifesaving organ. The comparisons between the American transplant system and other developed countries are limited by the profit-driven nature of the American medical culture. Developed healthcare systems in the United Kingdom, Japan, Spain, and Italy offer either low-cost health insurance or are engaged in single-payer government-funded systems. Despite these differences, it is apparent that while the primary barrier to transplantation in the United States (other than a shortage of organs) is financial in nature; other developed countries face non-financial barriers that restrict their relative rates of organ donation and transplantation. Excluding Spain, the United States is still able to transplant more organs per million population than any other healthcare system in this comparison. The keen difference lies in the ethical nature of financial barriers and a patient's ability or inability to pay as the line between life and death. In single-payer government funded healthcare systems and systems with easily accessible affordable healthcare insurance, every patient has roughly the same access to healthcare services where they would receive services based on organ availability.

In Jacobson and Mathur (2010), the competing values of profit and mission in healthcare are explored in the context of improving healthcare delivery through health law. Economic realities of the market force hospitals to compete for patients and resources (Jacobson and Mathur 2010). The American hospital's need to remain financially viable in order to serve a patient population

is especially relevant to the conundrum of financial barriers in organ transplantation. Without radical public policy reforms that move the United States into a single-payer government healthcare system, or into a system that offers widespread affordable healthcare insurance plans, Americans have to work with the existing systems of organ procurement and transplantation. It stands that without profit, or some source of revenue to sustain operations, a transplant center would cease to exist, removing an important healthcare resource from the community (Jacobson and Mathur 2010). Although the other countries in this analysis may have more consistent access to transplant services because of the nature of their payment systems, their other barriers to transplantation result in systems where fewer organs are transplanted per capita than in the United States; Spain being the exception, enjoying the fruit of a presumed-consent culture of donation. Ideally, a system that combined the donation culture of the United States and Spain (increasing available organs for transplant) and the payment systems of Spain and its counterparts (roughly leveling the financial playing field) would provide the best possible conditions for receiving an organ transplant in our current age of medical technology.

### **APPROACHES TO OVERCOMING FINANCIAL BARRIERS**

Barriers to being listed for a possible organ transplant emerge as patients face financial obstacles. Finances related to the actual procedures and medications have been discussed at length; however, there are a number of ways patients can supplement their own assets or insurance in order to qualify for transplantation. In Chisholm (2007), the author explores a problem associated with the high cost of transplant: “One of the leading causes of nonadherence among renal transplant recipients is the high cost of posttransplant medications, including immunosuppressant agents and medications to treat comorbid conditions” (Chisholm 2007). “Medication Assistance Programs” for transplant recipients (like the Michigan-based grants funded by the Gift of Life Foundation) result in better organ function over time, and increase the likelihood that a patient will treat transplant-jeopardizing co-morbidities and reduce their overall financial burden (Chisholm 2007). Reducing the patient’s financial burden can help him obtain the transplant services he desperately needs. Chisholm (2007) also notes that there are a number of ways to obtain assistance with medication costs, including: commercial prescription insurance, Medicare, Medicaid, private foundations, and pharmaceutical company medication assistance programs.

In addition to help with the cost of transplant related medications, Medicare, Medicaid, and Veteran’s Tricare all pay toward the cost of solid organ transplant. For individuals eligible for Medicare under the End Stage Renal Disease diagnosis, the total cost of transplantation is covered. In addition, though Medicaid programs vary by state, there is Medicaid insurance available to non-elderly and elderly individuals who are indigent and need an organ transplant (Center for Medicare and Medicaid Services 2009).

By overcoming these financial barriers to transplant, patients are able to qualify for transplant center lists and receive organ transplants. This eliminates the inequality seen in transplantation, and gives every patient a fair chance of receiving an organ. Additional support from the transplant center through case management workers, social workers, and other coordinators helps patients obtain necessary insurance in a timely fashion. With the possibility of insurance enrollment denial, it is important that patients facing terminal illness without organ transplantation seek out sources of funding for both the transplant and their medication before it is too late in their disease process.



## **Medical Tourism**

Transplant medical tourism is an ethically controversial way for patients to obtain cheaper organ transplants, often more quickly than in their developed home countries with modern healthcare systems. For patients who are poor or lack adequate health insurance, seeking overseas transplants not covered by Medicare or Medicaid might offer a cheaper alternative when the other option is to die in the United States (Bramstedt and Xu 2007). Transplants performed in China and India are a fraction of the cost of American transplants, and private insurance groups have encouraged transplant tourism to reduce the initial surgical cost of transplantation (Bramstedt and Xu 2007). Organs used in transplant tourism are recovered from living and deceased donors. Typically deceased donor organs are reserved for patients within the country's normal organ donation system (if one exists). In under-developed countries with little regulation surrounding living and deceased organ transplant, there is the opportunity for living donor monetary compensation (Bramstedt and Xu 2007). In China, it is not known where the majority of deceased organs come from due to the lack of transparency in Chinese organ donation programs (Bramstedt and Xu 2007).

Aside from an American patient traveling with an uncompensated, un-coerced, consented, living donor, the origin of organs available for transplant tourists is ethically questionable at best. Residents of chronically underprivileged countries may feel forced into consenting to donation when they are unable to feed their families, or do not feel comfortable saying no to their government officials (Bramstedt and Xu 2007). There are also sanitation risks at many hospitals in countries with underdeveloped healthcare systems. Transplant tourists often face complications after returning to the United States (Bramstedt and Xu 2007). Infections, rejection secondary to poor donor/recipient matching services, incomplete medical records, and an inability to pay for expensive American aftercare are all issues related to transplant tourism (Bramstedt and Xu 2007). However, if an American transplant patient is unconcerned with the ethical and medical risks associated with transplant tourism, or has a living donor willing to travel with her who is also unconcerned with the medical risks, transplant tourism does result in cheaper transplant surgeries and remains an option for some American patients (Bramstedt and Xu 2007).

## **CONCLUSION: TRANSPLANTS WITHOUT BARRIERS**

Obviously, with the shortage of transplantable organs some patients will inevitably die on or off transplant waiting lists; however, without financial barriers, it won't be because of their inability to pay. Transplantation programs without financial barriers give hope to terminally ill patients and their families. Despite the lack of financial barriers to transplant as seen in countries like Spain, Italy, the United Kingdom, and Japan, other barriers to donation exist, resulting in overall lower numbers of transplants in these countries. Reducing the financial barriers to transplant in the United States is a step in the right direction for medical ethics and patient equality. The reduction of financial barriers combined with the culture of donation in the United States and Spain could result in a donation and transplantation system that truly seeks to save lives, lacking profit and market driven motives. As we take steps to decrease financial barriers to organ transplant, we may see an increase in the amount of transplantable organs as donors and

their families give consent, knowing that the process is truly free of financial influence. Putting the politics of healthcare finance ahead of the importance of saving lives does a disservice to American transplant patients who otherwise have access to the best medical care in the world. Until there is radical change in the funding methods for organ donation in the United States, patients will continue to die because they are not considered eligible for a transplant based on their financial status. The American healthcare system's bond to the financial market will prevent OPOs and transplant surgeons from saving lives more valuable than the almighty dollar.

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*After transferring to GVSU from another graduate school to finish her MPA, Ashley enjoyed the smaller class sizes, engaged faculty, and collegial student community. She currently lives in Lansing, Michigan with her husband, 2004 GVSU graduate and attorney, Robert Jenkins. Ashley is thankful she made the decision to transfer "home" to GVSU and become a two-time Laker graduate.*