

Copyright by
Jaswant Singh Basraon
2012

The Thesis Committee for Jaswant Basraon Certifies that this is the approved version of the following dissertation:

ORGAN DONATION IN THE UNITED STATES

Committee:

| |
|---|
| Christine M. Arcari PhD MPH, Committee Chair and Supervisor |
| Karl Eschbach PhD, Committee member |
| Laura Rudkin, PhD, Committee member |

Dean, Graduate School

ORGAN DONATION IN THE UNITED STATES

by

Jaswant Singh Basraon, DO

Presented to the Faculty of the Graduate School of The University of Texas
Medical Branch in Partial Fulfillment of the Requirements for the Degree of
Master of Public Health

The University of Texas Medical Branch

December 2012

Dedication

Dedicated to the my teachers and mentors who have guided me at every step,

&

My dearest wife and son who have been my support and have shown
tremendous patience with my endeavors

Acknowledgements

My sincere thanks goes to Dr. Christine Arcari, who is my mentor and committee chair. Her guidance during the course of my Graduate school has been invaluable. Her vigilance in demanding excellence and her support in many ways during these last two years has been extraordinary.

In addition, I also who like to thank Dr. Laura Rudkin for her valuable feedback in helping me to produce quality work and last but not the least; I am grateful to Dr. Karl Eschbach who provided me with timely insights when formulating my thesis. All of them have contributed to my edification through didactics and personal commitments and I would like to unequivocally say that completing my Masters of Public Health has been a gratifying experience and has added to my breadth of my knowledge.

ORGAN DONATION IN THE UNITED STATES

Publication No. _____

Jaswant Singh Basraon, DO, MPH
The University of Texas Medical Branch, 2012
Supervisor: Christine M. Arcari

Abstract:

Introduction: The demand for donor organs far exceeds the number of donors. Approximately 18 people in the United States die every day waiting for an organ transplant. The purpose of this capstone is to describe the demographic characteristics of organ donors, recipients and waitlist populations in the United States. This information is essential to guide the planning and implementation of focused interventions to improve organ donation participation rates and diminish inequities.

Methods: We analyzed data from the Organ Procurement and Transplantation Network (OPTN) for the years Jan 1, 1988 – Aug 15, 2012. We describe characteristics of organ donors, transplant recipients and waiting list candidates by age, gender and race/ethnicity for the United States.

Results: The rate of organ donation has steadily increased in the United States, from a rate of 2.10 per 100,000 in 1988 to 5.16 per 100,000 in 2010 ($R^2=0.963$). In 2010, 14,503 individuals donated organs (7,943 (54.7%) deceased donors and 6,560 (45.3%) living donors) and 28,662 individuals received one or more organs. There are differences in organ donation and transplantation by gender, age and race/ethnicity. As of August 2012, 114,719 individuals are on the waiting list for an organ transplant.

Conclusion: Increased awareness of the importance of organ donation and registering as an organ donor is needed among young adults and females. Males need to be encouraged to be living donors. Efforts to educate the Hispanic and Asian communities are needed to promote awareness and willingness to be an organ donor.

Table of Contents

| | |
|--|----|
| Chapter 1 Introduction..... | 1 |
| Specific aims..... | 2 |
| Chapter 2 Significance | 3 |
| History of organ transplantation..... | 3 |
| Description of living and deceased donation..... | 6 |
| Process of transplantation..... | 9 |
| Strategies to increase organ donation..... | 11 |
| Chapter 3 Materials and Methods..... | 13 |
| Chapter 4 Results | 14 |
| Characteristics of US organ donors..... | 14 |
| Characteristics of US transplant recipients..... | 16 |
| Characteristics of US organ waiting list candidates..... | 17 |
| Chapter 5 Discussion..... | 22 |
| Bibliography..... | 28 |
| Vita..... | 31 |

List of Figures

Figure 1:
Organ Donors per 100,000 population, United States 1988-2010.....14

Figure 2:
Waitlist by Type of Organ, United States August 2012.....18

List of Tables

| | | |
|----------|---|----|
| Table 1: | Most Common Indication for Organ Transplantation by Type of Organ, United States, 2010..... | 3 |
| Table 2: | Milestones in organ transplant, 1954-present..... | 5 |
| Table 3: | Characteristics of Organ Donors, United States 2010 | 15 |
| Table 4: | Organ Donor Rates by Demographic Characteristics, United States 2010..... | 15 |
| Table 5: | Characteristics of Transplant Recipients (n=28,662), United States 2010..... | 17 |
| Table 6: | Characteristics of Waiting List Candidates (n=114,719), United States August 2012..... | 19 |
| Table 7: | Time on Waiting List by Organ (n=114,719), United States August 2012..... | 20 |
| Table 8: | Median Waiting Times by Organ for Registrants Listed 2003-2004, United States, August 2012..... | 21 |

List of abbreviations

| | |
|-------|---|
| DM: | Diabetes Mellitus |
| HCV: | Hepatitis C Virus |
| HHS: | U.S. Department of Health and Human Services |
| HLA: | Human leukocyte antigen |
| HTN: | Hypertension |
| MELD: | Model for End-Stage Liver Disease |
| NOTA: | National Organ Transplant Act |
| OPTN: | Organ Procurement and Transplantation Network |
| PELD: | Pediatric End-Stage Liver Disease |
| PRA: | Panel Reactive Antibody |
| UNOS: | United Network of Organ Sharing |

Chapter 1- Introduction

Transplant medicine is one of the most challenging and scientifically complex areas of modern medicine. The prognosis and quality of life of transplanted patients has significantly improved in the last decade(1). Primarily improvements are due to pharmacologic immunosuppressive advancements and predictive immunological molecular tissue matching. Both of which have served to mitigate the impact of post transplant infection and tissue rejection.

One of the greatest challenges currently faced by transplantation medicine is the enormous discrepancy between supply and demand for donor organs, with the need continuously exceeding supply. Every ten minutes there is a new addition to the waiting list, and every day eighteen people die waiting for an organ(2).

The only way to increase the supply of donor organs is to increase the number of people willing to be an organ donor. Steps that can be taken to increase the number of organ donors are: educating the public as to their the role in the organ transplant ecosystem; promoting awareness of organ donation in the population; increasing donor drives to add people to state donor registries; and supporting legal and community advocacy.

The purpose of this capstone is to describe the demographic characteristics of organ donors, transplant recipients and waiting list candidates. Understanding the demographics of the deficiencies in the organ supply in not meeting the demand will assist in the development of

focused strategies to increase the supply of donor organs and reduce the wait times for organ transplantation.

The specific aims of this capstone are to:

1. Describe the demographic characteristics of organ donors, donor recipients, and waiting list candidates using the United States Organ Transplant Registry data.
2. Identify disparities by population subgroups (age, gender, race/ethnicity) of organ donors, donor recipients and waiting list candidates.

Chapter 2 – Background and Significance

History of Organ Transplantation

The aging population and increasing prevalence of chronic diseases in the United States are a major public health burden on our society. Chronic medical conditions such as heart disease, cancer, lower respiratory disease and diabetes, leading causes of mortality in the United States, are also the most common indications for organ transplantation (Table 1)(3).

| Organ | Indications |
|--------------|--|
| Kidney | <ol style="list-style-type: none">1. Glomerular disease2. Diabetes3. Hypertensive Nephrosclerosis |
| Heart | <ol style="list-style-type: none">1. Coronary Artery Disease2. Cardiomyopathy3. Congenital Heart Disease |
| Lung | <ol style="list-style-type: none">1. Chronic Obstructive Pulmonary Disease2. Cystic Fibrosis3. Idiopathic pulmonary fibrosis |
| Liver | <ol style="list-style-type: none">1. Cirrhosis2. Malignant Neoplasms3. Acute Hepatic Necrosis |

A brief timeline of important milestones in transplantation medicine is shown in Table 2 (4). The history includes key actions taken that have led to increasing the amount of regulatory structure. Important legal milestones include The Uniform Anatomical Gift Act initially passed in July 30 1968 by the National

Conference of Commissioners on Uniform State laws and later revised in 2006(5). This gave the legal definition of organ donation, its execution and purpose, and revocation of an anatomical gift. Although this helped define the states' legal role, an increasing need to provide federal legislation to coordinate the distribution of vital organs, which were increasingly in short supply, became apparent. Further action was necessitated by the inequitable allocation climate that existed. This led to the important development in 1984, when the U.S. congress enacted the National Organ Transplant Act (NOTA)(6).

| Table 2: Milestones in organ transplant, 1954 - present | |
|--|--|
| 1954 | First successful kidney transplant performed. |
| 1966 | First simultaneous kidney/pancreas transplant performed. |
| 1967 | First successful liver transplant performed. |
| 1968 | First successful isolated pancreas transplant performed. First successful heart transplant performed. The Southeast Organ Procurement Foundation (SEOPF) is formed as a membership and scientific organization for transplant professionals. |
| 1977 | SEOPF implements the first computer-based organ matching system, dubbed the "United Network for Organ Sharing." |
| 1981 | First successful heart-lung transplant performed. |
| 1982 | SEOPF establishes the Kidney Center, the predecessor of the UNOS Organ Center, for round-the-clock assistance in placing donated organs. |
| 1983 | First successful single-lung transplant performed. Cyclosporine introduced. |
| 1984 | National Organ Transplant Act (NOTA) passed. The United Network for Organ Sharing (UNOS) separates from SEOPF and is incorporated as a non-profit member organization. |
| 1986 | First successful double-lung transplant performed. UNOS receives the initial federal contract to operate the Organ Procurement and Transplantation Network (OPTN). |
| 1987 | First successful intestinal transplant performed. |
| 1988 | First split-liver transplant performed. |
| 1989 | First successful living donor liver transplant performed. |
| 1990 | First successful living donor lung transplant performed. |
| 1992 | First successful living donor lung transplant performed. UNOS helps found Donate Life America to build public support for organ donation. UNOS prepares first-ever comprehensive report on transplant survival rates for all active U.S. transplant centers. |
| 1995 | UNOS launches its first Web site for all users with an interest in transplantation. |
| 1998 | First successful adult-to-adult living donor liver transplant performed. |
| 1999 | UNOS launches UNetsm, a secure, Internet-based transplant information database system for all organ matching and management of transplant data. |
| 2000 | U.S. Department of Health and Human Services publishes Final Rule (federal regulation) for the operation of the OPTN. |
| 2001 | For the first time, the total of living organ donors for the year (6,528) exceeds the number of deceased organ donors (6,081). |
| 20006 | UNOS launches DonorNet sm , a secure, Internet-based system in which organ procurement coordinators send out offers of newly donated organs to transplant hospitals with compatible candidates. |
| <i>Source: UNOS (United Network for Organ Sharing)(4)</i> | |

NOTA established a federal task force that made recommendations for guidance of organ transplantation and authorized federal assistance for organ procurement management. In addition, this task force was instructed to do a comprehensive review of the economic, social, medical and ethical issues involved in organ transplant(6). The task force was also entrusted to make an assessment of immunosuppressive medication involved in prevention of rejection(6). Importantly, the task force was charged with assessing current methods utilized in coordination and procurement and highlighting barriers that would lead to improved equitable access.

Another positive outcome from this act was the establishment of the Organ Procurement and Transplantation Network (OPTN)(7) that would establish a unified national standard of coordination and provide data regarding listing of organs and adopt standards for acquisition and transport of donated organs(7). This OPTN was to be overseen by the U.S. Department of Health and Human Services (DHHS). The NOTA sought to establish a private non-profit organization under federal contract to operate the OPTN(6). The initial administration contract was awarded to the United Network of Organ Sharing (UNOS)(8) on September 30, 1986 and continues to this day(9).

Description of Living and Deceased Donation

According to the U.S. Department of Health and Human Services (HHS), organ donation is defined as the “surgical process of providing one or more organs to be used for transplantation into another person”(10).

There are two types of organ donors, living and deceased. A living donor can provide one kidney, one lung, and in some limited instances partial liver tissue. A deceased donor can donate six types of organs: heart, lungs, liver, pancreas, kidney and intestines. Deceased donors can also provide other viable tissue such as veins, heart valves, skin grafts and corneas. Organ donation by living donors, either genetically related or non-related, yields a better prognosis for the recipient compared to deceased donors. Recipients receiving organs from deceased donors are 20% less likely to have a functioning organ at 5 years(7). Projected graft half-life estimates have shown living graft survival to be 21.6 years for living donors compared with 13.8 years for deceased donors(11).

However, availability of organs from living donors is limited the ability to extract a limited number of organs such as only one kidney, partial liver, lung lobe and portion of pancreas or intestine. Additionally, donations of the heart, intestine, and cornea are limited. Deceased donors on other hand are capable of donating multiple organs; therefore deceased donors constitute the majority of the donor pool. To date 82% of donated organs come from deceased donors and 18% from living donors(7).

Deceased donation allows for multiple organs to be harvested from deceased donors who previously consented to organ donation, after being declared clinically brain dead or expired. Whereas the process differs slightly by locale, adults over 18 years and minors with parental consent can register to be

deceased donors with state agencies at their public offices. For example, in Texas a person may register at the local Department of Public Safety office, or via mail, fax or online at the Glenda Dawson Donate Life Texas Registry, which is the official state site. In addition, there are many non-profit organizations that conduct donor registration drives.

Living donations are categorized into related, non-related, non-directed, paired exchange donations (two recipients exchange organs that are more compatible), blood type incompatible, positive cross match (incompatible antibodies) and deceased exchange (similar to paired exchange except one organ is from a deceased donor)(12).

In order to become a living donor, the process requires much more engagement. First, one must contact the transplant center of choice. Then introduction to the transplant team that deals with your donor organ of interest takes place along with tests to qualify the donor for medical clearance. These tests may include blood testing, tissue typing, cross matching, antibody screening, urine test, psychiatric and psychological evaluation (relationship to donor, financial support, employment impact, childcare, emotional preparations etc.) and gynecological examinations for female donors(12).

After completion of the required testing, thorough considerations and risk identification, living donors can then be listed as donors in the UNOS database. The UNOS computer system identifies recipient candidates with a matching donor profile similar to donor profile, and the transplant centers are provided with an electronic rank list. The recipient transplant team will then consider the organ

and choose to either accept or decline the offer. If declined, then the organ is made available to the next recipient on the rank list, and this process continues until the organ is accepted(8).

Process of Transplantation

Organ procurement organizations (OPOs) serve as a bridge between organ donors and transplant recipients. By federal law there are 58 designated OPOs that serve to facilitate recovery and transport of a viable organ to the recipients transplant team(13). The team identifies a donor via UNOS and then notifies the affiliated OPO, and the procurement coordinator communicates with families to further the organ procurement process.

The waiting list for patients is maintained by UNOS. In order to be put on the waitlist, the decision is made by the clinical team at an affiliated transplant center with a committee that includes physicians determining the eligibility criteria using clinical guidelines. These eligibility criteria differ for each organ and institution. However, a common theme is objective assessment of organ dysfunction and associated decrease in functional capacity, patient life expectancy, and failure of all currently available medical therapy. An additional consideration is the significant loss of quality of life due to repeated hospitalization without existences of exclusionary factors, such as concomitant organ damage and no other coexistent chronic diseases.

To most families, the organ transplantation process begins when the hospital places a call to OPOs after the caring physician has declared the patient's death. Although an organ can be recovered from deceased donors that expire from cardiac arrest, patients on breathing machines who are clinically brain dead provide more viable organs, as their blood pressure, respiration and heart rate can be maintained artificially until the required surgery for donation.

The family is then approached regarding organ donation. If the patient was listed as a donor, the process is explained to the next of kin. If the patient was not a registered donor then all donation options are discussed with the next of kin. If donation is agreed, then a medical discovery process is undertaken, and UNOS cross checks waiting list priorities by entering donor criteria into the UNOS computer system UNetSM(13). Once matched to a potential recipient and accepted, the surgical transplant teams are coordinated by the OPOs for recovery and transport of organs. The typically process can be between 8-12 hours(13).

Organ(s) recovery is critically focused on time. From the declaration of death to completion of transplant, the clock begins. This is especially important for patients that are not on breathing machines and who died from cardiopulmonary-arrest or accident. The consequence of ischemia (restriction of blood supply reducing oxygenation to tissue) becomes immediately relevant. Since tissues need a continuous supply of blood delivering vital oxygen and nutrients necessary for metabolic maintenance functions, and the lack thereof immediately beings to impact vitality and injury to tissue membranes, timing is

crucial. There are two subtypes, warm and cold ischemic times. Warm ischemic time is from death up to tissue extraction from the donor, while cold ischemic time represents the time from storage of an organ in a cold medium until successful transplantation with restoration of tissue reperfusion. Prolongation of both can be catastrophic; however, since the cold preservation slows metabolism and enhances preservation, warm ischemic time represents the more urgent imperative.

Strategies to Increase Organ Donation

The most significant approach to increase the supply of organs is to increase the number of voluntary organ donors. This can be effected by: educating the public as to their the role in the organ transplant ecosystem; promoting awareness of organ donation in the population; increasing donor drives to add people to state donor registries(14); and supporting legal and clinical community advocacy(15). The use of social media such as Facebook, YouTube and other websites linking donors to recipients(16) can be utilized to engage prospective donors. Another incentive that has been purposed is offsetting donor's fiduciary responsibilities, such as in the form of income tax credit and guaranteeing health insurance (17). However, early experience with pure monetary incentives especially in developing countries has been associated with poor outcomes(18).

Another strategy proposed in attempts to increase donor availability is the use of expanded donor criteria (EDC), where the donor has pre-existing medical conditions that may lead to organ dysfunction making those organs less than ideal for transplantation, but are nevertheless accepted for donation. However, transplanting such organs has not led to a significant improvement in the morbidity and mortality rates in the recipient post transplant. (19).

A better understanding of organ donor and recipient populations is needed to develop strategies that can effectively address the challenges facing the organ supply chain and reduce the impact of chronic diseases for key groups. The viability of our current transplant medical-structure is questionable and a multipronged approach is necessary so that the system can function in its original intent.

Chapter 3 - Material and Methods

Data on characteristics of organ donors and transplant recipients were obtained from the OPTN Network Database for the years January 1, 1988 – December 31, 2010. Data on characteristics of the waiting list candidates were obtained from the OPTN Network Database for August 2012. The OPTN database is a public use database and all data is presented in aggregate.

Variables used for analysis include age groups (<18 years, 18-34 years, 35-49 years, 50-64 years and 65 years and older), sex (male/female), and race/ethnicity (White, Black, Hispanic, Asian, Other). Other includes American Indian, Pacific Islander, Multiracial, and Unknown. Data were analyzed using Microsoft Excel.

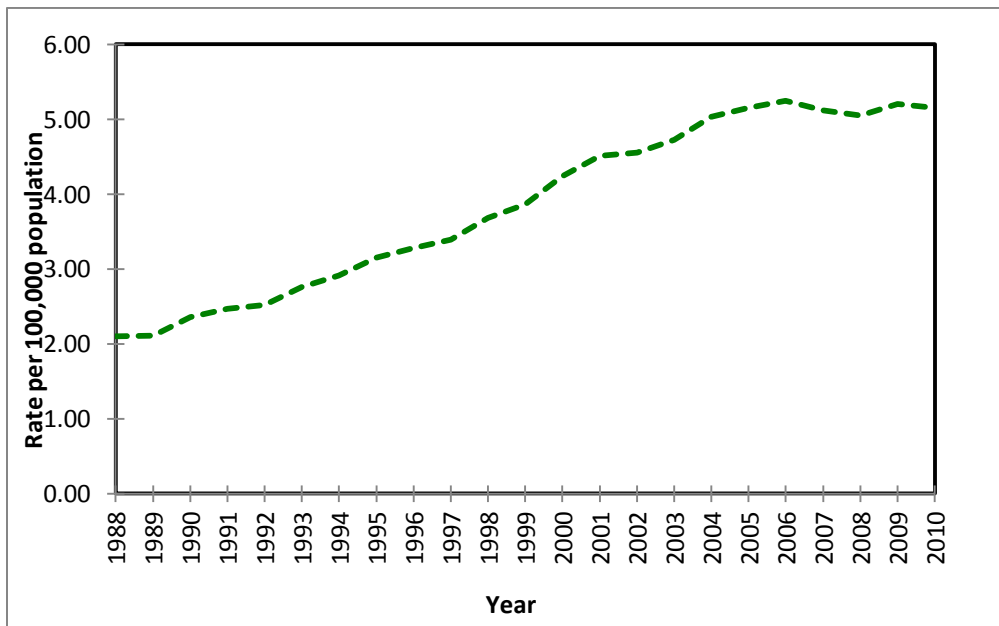
We used U.S. Census Data 2000 to calculate the rate of organ donation per 100,000 by year beginning with 1988. A linear trend line was calculated using the least squares fit for a line ($y = mx + b$): where m is the slope and b is the intercept. Data for organ donors was stratified by type of donor, deceased or living. U.S. Donation Rates for 2010 were calculated using Census Data 2010. Chi-square analysis of categorical variables generated 2-tail P-values at the 0.05 level of significance. Waiting list candidates included patients listed on the OPTN database as waiting for a transplant. Persons listed at multiple transplant centers are counted only once. Median waiting times were calculated based on persons who registered 2003-2004.

Chapter 4: Results

Characteristics of U.S. Organ Donors

Over the last two decades, the rate of organ donation has steadily increased in the United States, from a rate of 2.10 per 100,000 in 1988 to 5.16 per 100,000 in 2010 ($R^2=0.963$) (Figure 1).

Figure 1. Organ Donors per 100,000 population, United States 1988-2010.



In 2010, 14,503 individuals donated organs; 7,943 (54.7%) were deceased donors, and 6,560 (45.3%) were living donors (Table 3).

Although the overall percentages of males and females donating organs are similar, males were more likely to be deceased donors compared to females (65.3% vs. 44.5%, $p<0.001$).

| <u>Characteristic</u> | <u>All Donors</u> <u>(n=14,503)</u> N (%) | <u>Deceased Donors</u> <u>(n=7,943)</u> N (%) | <u>Living Donors</u> <u>(n=6,560)</u> N (%) |
|-----------------------|---|---|---|
| <u>Gender</u> | | | |
| Male | 7174 (49.5) | 4683 (65.3) | 2491 (34.7) |
| Female | 7329 (50.5) | 3260 (44.5) | 4069 (55.5) |
| <u>Age</u> | | | |
| <1 - 17 | 847 (5.8) | 841 (10.6) | 6 (0.1) |
| 18-34 years | 4208 (29.0) | 2169 (27.3) | 2039 (31.1) |
| 35-49 Years | 4830 (33.3) | 2070 (26.1) | 2760 (42.1) |
| 50-64 Years | 3829 (26.4) | 2194 (27.6) | 1635 (24.9) |
| 65+ | 789 (5.4) | 669 (8.4) | 120 (1.8) |
| <u>Race/Ethnicity</u> | | | |
| White | 9847 (67.9) | 5284 (66.5) | 4563 (69.6) |
| Black | 2090 (14.4) | 1323 (16.7) | 767 (11.7) |
| Hispanic | 1960 (13.5) | 1029 (13.0) | 931 (14.2) |
| Asian | 405 (2.8) | 182 (2.3) | 223 (3.4) |
| Other | 201 (1.4) | 125 (1.6) | 76 (1.2) |

Organ donor rates vary greatly by race/ethnicity (Table 4). Whites and Blacks have the highest rate of organ donation (5.00 and 5.54 per 100,000, respectively). Much lower rates are observed among Hispanics (3.89 per 100,000) and Asians (2.80 per 100,000).

| | <u>U.S. Population</u> | <u>All Donors</u> | <u>Rate per 100,000</u> |
|-----------------------|------------------------|-------------------|-------------------------|
| <u>Gender</u> | | | |
| Male | 151,781,326 | 7,174 | 4.72 |
| Female | 156,964,212 | 7,329 | 4.67 |
| <u>Age</u> | | | |
| <1 - 17 | 74,181,467 | 847 | 1.14 |
| 18-64 years | 194,296,087 | 12,867 | 6.62 |
| 65+ | 40,267,984 | 789 | 7.96 |
| <u>Race/Ethnicity</u> | | | |
| White | 196,817,552 | 9,847 | 5.00 |
| Black | 37,685,848 | 2,090 | 5.54 |
| Hispanic | 50,477,594 | 1,960 | 3.89 |
| Asian | 14,465,124 | 405 | 2.80 |
| Other | 9,299,420 | 201 | 2.16 |

From the 6,560 living donors, 6,560 organs were recovered and all (100%) were transplanted while only 77.7% (22,102 transplanted out of 28,461 retrieved) could be transplanted from 7,943 deceased donors. This was mostly due to increased ischemic time or loss of organ viability before the retrieved organ could be transported to the recipient. Over half (56.3%) of the donations from a living donor went to a family member: 1,078 (16.4%) blood related child, 554 (8.4%) parent, 1,273 (19.4%) sibling and 789 (12.0%) spouse.

Number of organs captured per donor is highest in young healthy donors; for 2010, a total of 2169 deceased donors in age group 18-34 years donated 9604 organs (average capture 4.42 organs per donor) compared with age group 50-64 years in whom 6392 organs were donated by 2194 donors (average capture 2.9 organs per donor).

Characteristics of U.S. Transplant Recipients

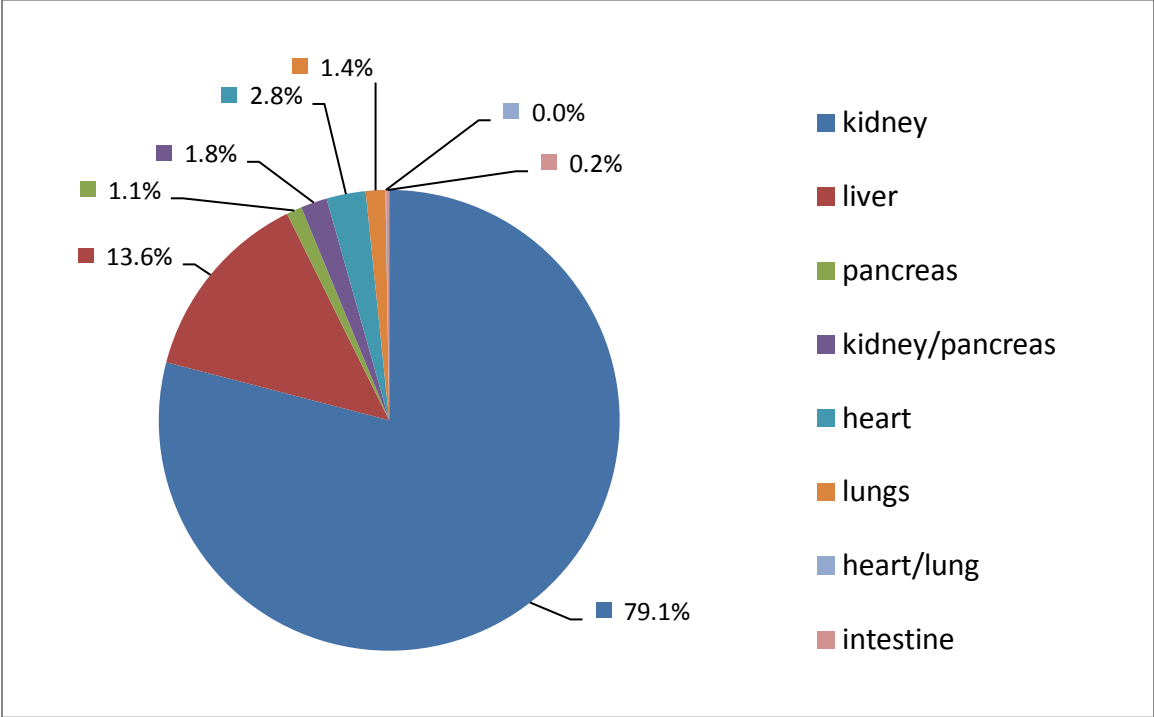
There were a total of 28,662 transplant recipients in U.S. in 2010 (Table 5). Transplant recipients were more likely to be males (62.4%) compared to females (37.6%) ($p < 0.001$). Males outnumber females in all age groups (data not shown). Almost half (43.3%) of all transplant recipients were 50-64 years of age. Transplant recipients were mostly White (60.8%), followed by Black (20.0%), Hispanic (13.3%) and Asian (4.5%).

| Table 5: Characteristics of Transplant Recipients (n=28,662), United States 2010. | | |
|--|-----------------|-----------------|
| | <u>N</u> | <u>%</u> |
| <u>Gender</u> | | |
| Male | 17,879 | 62.4 |
| Female | 10,783 | 37.6 |
| <u>Age</u> | | |
| <1 - 17 | 1,826 | 6.3 |
| 18-34 years | 3,225 | 11.2 |
| 35-49 Years | 6,897 | 24.1 |
| 50-64 Years | 12,420 | 43.3 |
| 65+ | 4,294 | 15.0 |
| <u>Race/Ethnicity</u> | | |
| White | 17,151 | 60.8 |
| Black | 5,964 | 20.0 |
| Hispanic | 3,798 | 13.3 |
| Asian | 1,342 | 4.6 |
| Other | 407 | 1.3 |

Characteristics of U.S. Organ Waiting List Candidates

As of August 2012, there are 114,719 individuals on the waiting list for an organ transplant. Of these, 92,841 (80.9%) are waiting for a kidney, 16,014 (14.0%) a liver, 1,272 (1.1%) a pancreas, 2,165 (1.8%) a kidney/pancreas, 3,232 (2.8%) a heart, 1,612 (1.4%) a lung, 55 (0.05%) a heart/lung, and 251 (0.22%) an intestine (Figure 2). The overall total is less than the sums of each organ due to patients included in multiple categories.

Figure 2. Waitlist by Type of Organ, United States August 2012.



Waiting list candidates are more likely to be males (59.7%) compared to females (40.3%) ($p < 0.001$). Males dominate the waiting list for all organ types, age groups, and race/ethnicities (data not shown). Almost half (45.4%) of all waiting list candidates are 50-64 years of age. Waiting list candidates are White (44.2%), followed by Black (29.4%), Hispanic (18.2%) and Asian (6.5%) (Table 6).

| | N | % |
|-----------------------|----------|----------|
| <u>Gender</u> | | |
| Male | 68,477 | 59.7 |
| Female | 46,272 | 40.3 |
| <u>Age</u> | | |
| <1 - 17 | 1,762 | 1.5 |
| 18-34 years | 10,577 | 9.2 |
| 35-49 Years | 28,468 | 24.8 |
| 50-64 Years | 52,123 | 45.4 |
| 65+ | 21,798 | 19.0 |
| <u>Race/Ethnicity</u> | | |
| White | 50,693 | 44.2 |
| Black | 33,768 | 29.4 |
| Hispanic | 20,910 | 18.2 |
| Asian | 7,489 | 6.5 |
| Other | 1,859 | 1.7 |

Time spent on the waiting list varies by organ (Table 7). By far, the longest time on the waiting list is for heart/lung candidates, with 49.1% on the waiting list for 5 or more years. Median waiting times, calculated for candidates who were listed 2003-2004 (Table 8) show large discrepancies by race/ethnicity.

Table 7: Time on Waiting List by Organ (n=114,719), United States August 2012.

| <u>Time on Waiting List</u> | <u>All Organs</u> N (%) | <u>Kidney</u> N (%) | <u>Liver</u> N (%) | <u>Pancreas</u> N (%) | <u>Kidney / Pancreas</u> N (%) | <u>Heart</u> N (%) | <u>Lung</u> N (%) | <u>Heart / Lung</u> N (%) | <u>Intestine</u> N (%) |
|-----------------------------|----------------------------|------------------------|-----------------------|--------------------------|-----------------------------------|-----------------------|----------------------|------------------------------|---------------------------|
| < 30 Days | 4,064 (3.5) | 2,741 (3.0) | 854 (5.3) | 47 (3.7) | 130 (6.0) | 267 (8.3) | 165 (10.2) | 5 (9.1) | 8 (3.2) |
| 30 to < 90 Days | 7,411 (6.5) | 5,453 (5.9) | 1,288 (8.0) | 76 (6.0) | 216 (10.0) | 379 (11.7) | 202 (12.5) | 5 (9.1) | 13 (5.2) |
| 90 Days to < 6 Months | 10,320 (9.0) | 7,999 (8.6) | 1,605 (10.0) | 100 (7.9) | 263 (12.1) | 441 (13.6) | 199 (12.3) | 4 (7.3) | 23 (9.2) |
| 6 Months to < 1 Year | 16,987 (14.8) | 13,592 (14.6) | 2,350 (14.7) | 175 (13.8) | 399 (18.4) | 574 (17.8) | 290 (18.0) | 3 (5.5) | 39 (15.5) |
| 1 Year to < 2 Years | 25,957 (22.6) | 21,768 (23.4) | 2,998 (18.7) | 249 (19.6) | 481 (22.2) | 641 (19.8) | 322 (20.0) | 5 (9.1) | 39 (15.5) |
| 2 Years to < 3 Years | 18,637 (16.2) | 16,087 (17.3) | 1,850 (11.6) | 172 (13.5) | 275 (12.7) | 367 (11.4) | 181 (11.2) | 4 (7.3) | 48 (19.1) |
| 3 Years to < 5 Years | 20,364 (17.8) | 17,484 (18.8) | 2,243 (14.0) | 206 (16.2) | 297 (13.7) | 288 (8.9) | 125 (7.8) | 2 (3.6) | 41 (16.3) |
| 5 or More Years | 15,646 (13.6) | 11,859 (12.8) | 3,048 (19.0) | 253 (19.9) | 152 (7.0) | 288 (8.9) | 146 (9.1) | 27 (49.1) | 40 (15.9) |

Table 8: Median Waiting Time (Days) by Organ for Registrants Listed 2003-2004, United States, August 2012.

| <u>Race/ Ethnicity</u> | <u>Kidney</u> Days (95% CI) | <u>Liver</u> Days (95% CI) | <u>Pancreas</u> Days 95% CI) | <u>Kidney / Pancreas</u> Days (95% CI) | <u>Heart</u> Days (95% CI) | <u>Lung</u> Days (95% CI) | <u>Heart / Lung</u> Days (95% CI) | <u>Intestine</u> Days (95% CI) |
|----------------------------|-----------------------------------|----------------------------------|------------------------------------|--|----------------------------------|---------------------------------|---|--------------------------------------|
| White | 1310 (1271, 1353) | 357 (331, 386) | 474 (428, 535) | 591 (543, 628) | 152 (139, 165) | 580 (542, 617) | 897 (401, .) | 178 (132, 204) |
| Black | 1832 (1785, 1871) | 169 (146, 202) | 1199 (604, .) | 666 (588, 769) | 132 (115, 158) | 755 (622, 1209) | * | 300 (191, 620) |
| Hispanic | 2011 (1934, 2099) | 651 (529, 799) | 138 (483, 2651) | 651 (577, 929) | 106 (86, 137) | 1093 (575, 2146) | 386 (120, .) | 248 (170, 368) |
| Asian | 1826 (1695, 1970) | 311 (251, 434) | * | 579 (442, 1117) | 86 (52, 121) | 784 (250, .) | * | * |
| American Indian | 1501 (1338, 1705) | 140 (85, 250) | * | 582 (88, .) | 168 (67, 407) | 1096 (85, 1379) | * | * |
| Pacific Islander | 2604 (2265, .) | 250 (47, 1706) | * | 1667 (57, .) | 117 (28, .) | * | * | * |

*Denotes a Median Waiting Time was not computed due to N less than 10, or fewer than half the registrants have been transplanted.

Chapter 5- Discussion

Understanding the demographic characteristics of organ donors, transplant recipients and waiting list candidates can assist us in developing focused and effective interventions to increase organ donation in the United States. While the overall trend of organ donors is increasing, the scarcity of organs for donation is still a major limiting factor in transplant medicine.

Deceased donors are the largest contributors to the organ pool. Increasing personal registration for organ donation with state registries is essential so that in the case of untimely death, organs could be harvested as per the person's prior wish and consent. An examination of the database shows that the number of organs captured per individual is highest in young healthy donors, therefore encouraging the registration of young people to be donors may be more efficient in terms of available organs for donation compared to donor registration drives of older individuals.

Most transplant recipients are 50 – 64 years of age which makes sense as the burden of cardiovascular and chronic renal diseases is highest in this age group. The relatively younger age group of 18-34 years frequently requires a transplant secondary to late discovery of congenital issues that are often undiagnosed during childhood, or complications from familial or acquired conditions. The age group of 35 – 49 years contains patients predominately with end organ damage from alcohol and

substance abuse. Young transplant candidates are considered the most challenging transplant population. This is in part due to many factors such as non-compliance to medical therapy, robust immune response, return to high-risk behavior after improvement and elevated exposure to dietary and social stressors requiring vigilant social support to promote transplant candidacy(20). These young adults should be considered a major target of early educational programs, including outreach to their families and caregivers. Promoting continuous communication between healthcare personnel, the patient and their support system may lead to improved patient outcomes and a more efficacious donor process.

We found that the majority of living donors come from those aged 35-49, which corresponds to the age when it is likely that a child/parent or spouse may need a transplant and family members or friends come forward. Additionally, the need for an organ in a family member, spouse or child is more likely to be met by a female as the donor. One explanation for this finding may be guided by economics, as females in the family may be more likely to have jobs that allow them to take time off to be an organ donor.

The majority of waitlisted patients are males, and in 2010, the male to female ratio of transplant recipients nearly 2:1. This under-representation raises an important question as to whether women have equal access to organ transplantation. It is known that women have generally delayed exposure to cardiovascular disease, due to protective

effects of estrogen, however, the lower number of female recipients and waiting list candidates might be attributed to delays in diagnosis and under diagnosis and not decreased incidence or prevalence of diseases which are indicators for transplants(21). Thus, there may be many women who are at equally or higher risk of becoming a transplant recipient, but they are not being adequately evaluated. There is a significant movement underway to promote awareness and recognition in women (22). Women are also shown to be more prone to decline transplantation surgery, which may also contribute to their under-representation as recipients(23).

The United States has seen tremendous growth in population and increases in diversity of the population by race/ethnicity. A potential organ when harvested is HLA matched against a possible recipient and secondary to genetic conservation, the chances of HLA match are higher among members of similar race/ethnicity origins. This underlines the importance of maintaining a relatively stable number of donors and recipients from each race/ethnicity to ensure availability of HLA matched organs for all the recipients. While there has been an increase in the number of organs donated by Hispanics that is consistent with their population growth,, there has been a 43 % rise in the Asian population from 2000 to 2010 with only a 28% rise in organ donation in the Asian population during the same time period. The Asian population specifically needs to be targeted to increase organ donation. An important step towards addressing social and cultural barriers to organ donor registration

in this group may be an outreach in the form of campaigns organized at local religious congregations and social organizations. Awareness pamphlets made available in local languages and social leaders guiding the community in a common conversation about organ donation, the need in their population and the lack of available matching organs. Availability of experts in the field to answer questions about donor registration are essential to correctly address concerns and allay common myths.

A public education campaign to increase awareness and access to donor enlistment services needs to be pursued. An important place where people can be reached and asked to register for organ donation is blood donation campaigns. People willing to donate blood may be more likely to register for organ donation compared to people who do not donate blood.

An alternative that is widely debated to increase donor registration enlistments, especially among living donors, is establishing a legal monetary system for individuals as compensation for their organs. Although some of these monetary systems are currently functioning as encouragement for organ donors to “sell” their organs, the outcomes associated with these processes are generally poorer due to a host of socio-economic factors(18).

While increasing the enlistment of individuals on donor rosters is one way to reduce the waitlist times, the number of organs available for transplant may be increased as a result of focused efforts directed at preventive strategies. Targeted programs aimed at the populations at

highest risk of the chronic diseases that lead to organ failure could lead to decreasing the number of individuals who require a transplant. The recent trends of health status of US population shows a steep rise in heart diseases, pulmonary diseases and cancer, and thus, organ transplant will continue to be core therapeutic option. However, implementation of certain primary and secondary preventive strategies can help mitigate the burden of chronic diseases culminating into need for transplant.

It is well known, but not effectively implemented that prevention and early treatment of hypertension, diabetes, hyperlipidemia, can effectively reduce the need of progression to ESRD and heart failure, the most common indications for renal and cardiac transplant respectively. Additionally, adequate immunizations against Hepatitis B (24), and programs to promote clean needles and awareness of transmission of Hepatitis C Virus (HCV) and Human Immunodeficiency Virus (HIV) need to be reconsidered and assessed for their impact(25). One daunting task that will be challenging is managing HCV especially in incarcerated populations(26) and it continues to be a significant risk factor for development of hepatocellular carcinoma and liver cirrhosis in this population predisposing to end stage liver disease requiring transplant.

In conclusion, early education coupled with increased access to preventive medicine and promoting good communication appear to be simple and yet elusive goals. Should successful methods for encouraging healthier behaviors be incorporated, many who are waitlisted and those in

the chronic disease population could be spared from entering the transplant path. As the field of organ donation continues to evolve, so does our need to target the communities and populations that are impacted. Therefore, an aggressive campaign needs to be waged on multiple fronts; increasing listing of donors, increasing awareness, promoting gender equality in transplantation, mitigating the impact of chronic diseases, and increasing focal outreach to minority communities in order to confront and manage the escalating, diverse demands on our transplant programs.

Bibliography

1. Shamaskin AM, Rybarczyk BD, Wang E, White-Williams C, McGee E, Jr., Cotts W, Grady KL. Older patients (age 65+) report better quality of life, psychological adjustment, and adherence than younger patients 5 years after heart transplant: A multisite study. *The Journal of heart and lung transplantation* 2012 May;31(5):478-484
2. U.S. Department of Health & Human Services: About Donation & Transplant. <http://www.organdonor.gov/about/data.html>. Accessed June 05, 2012
3. Centers for Disease Control and Prevention: Leading Causes of Death. : <http://www.cdc.gov/nchs/fastats/lcod.htm>. Accessed March 3, 2012
4. United Network for Organ Sharing: History of Transplant. <http://www.unos.org/donation/index.php?topic=history>. Accessed July 12, 2011
5. Uniform Law Commission, Anatomical Gift Act (2006). [http://uniformlaws.org/Act.aspx?title=Anatomical%20Gift%20Act%20\(2006\)](http://uniformlaws.org/Act.aspx?title=Anatomical%20Gift%20Act%20(2006)). Accessed June 05, 2012
6. National Organ Transplant Act: Public Law 98-507. United States statutes at large 1984;98:2339-2348.
7. Health Resources and Services Administration, U.S. Department of Health & Human Services. OPTN (Organ Procurement and Transplantation Network). <http://optn.transplant.hrsa.gov/>. Accessed June 14, 2011
8. United Network for Organ Sharing: About UNOS <http://www.unos.org/about/index.php>. Accessed July 12, 2011
9. Pomfret EA, Sung RS, Allan J, Kinkhabwala M, Melancon JK, Roberts JP. Solving the organ shortage crisis: the 7th annual American Society of Transplant Surgeons' State-of-the-Art Winter Symposium. *American journal of transplantation : official journal of the American Society of Transplantation and the American Society of Transplant Surgeons* 2008;8(4):745-752.
10. U.S. Department of Health & Human Services. <http://www.organdonor.gov/about/index.html>. Accessed Oct 05, 2011
11. Hariharan S, Johnson CP, Bresnahan BA, Taranto SE, McIntosh MJ, Stablein D. Improved graft survival after renal transplantation in the United

States, 1988 to 1996. *The New England journal of medicine* 2000;342(9):605-612.

12. United Network of Organ Sharing (UNOS): Living Donation. <http://www.transplantliving.org>. Accessed on June 05,2012

13. Association of Organ Procurement Organization. <http://www.aopo.org/about-opo>. Accessed June 05, 2012

14. Texas Donor Registry: Donate Life Texas. <https://www.donatelifetexas.org/about-the-registry>. Accessed June 07, 2012

15. American Society of Transplantation <http://www.a-s-t.org/content/ast-transplant-advocacy-award>. Accessed June 07, 2012

16. Davis CL. How to increase living donation. *Transplant international : official journal of the European Society for Organ Transplantation* 2011;24(4):344-349.

17. Rodrigue JR, Crist K, Roberts JP, Freeman RB, Jr., Merion RM, Reed Al. Stimulus for organ donation: a survey of the American Society of Transplant Surgeons membership. *American journal of transplantation : official journal of the American Society of Transplantation and the American Society of Transplant Surgeons* 2009;9(9):2172-2176.

18. Rizvi SA, Naqvi SA, Zafar MN, Mazhar F, Muzaffar R, Naqvi R, Akhtar H, Ahmed E. Commercial transplants in local Pakistanis from vended kidneys: a socio-economic and outcome study. *Transplant international : official journal of the European Society for Organ Transplantation* 2009;22(6):615-621.

19. Iordanous Y, Seymour N, Young A, Johnson J, Iansavichus AV, Cuerden MS, Gill JS, Poggio E, Garg AX. Recipient outcomes for expanded criteria living kidney donors: the disconnect between current evidence and practice. *American journal of transplantation* 2009;9(7):1558-1573.

20. Phillips KM, Burker EJ, White HC. The roles of social support and psychological distress in lung transplant candidacy. *Progress in transplantation* 2011;21(3):200-206.

21. Csete M. Gender issues in transplantation. *Anesthesia and analgesia* 2008;107(1):232-238.

22. Giardina EG, Sciacca RR, Foody JM, D'Onofrio G, Villablanca AC, Leatherwood S, Taylor AL, Haynes SG. The DHHS Office on Women's Health Initiative to Improve Women's Heart Health: focus on knowledge and awareness

among women with cardiometabolic risk factors. *Journal of women's health* 2011;20(6):893-900.

23. Aaronson KD, Schwartz JS, Goin JE, Mancini DM. Sex differences in patient acceptance of cardiac transplant candidacy. *Circulation* 1995;91(11):2753-2761.

24. Centers for Disease Control and Prevention. Vaccines and Preventable Disease: Hepatitis B Vaccination. <http://www.cdc.gov/vaccines/vpd-vac/hepb/default.htm>. Accessed February 15, 2012.

25. Centers for Disease Control and Prevention Morbidity and Mortality Weekly Report (2010): Prevention CfDCa. Syringe Exchange Programs --- United States, 2008.

26. Williams IT, Bell BP, Kuhnert W, Alter MJ. Incidence and transmission patterns of acute hepatitis C in the United States, 1982-2006. *Archives of internal medicine* 2011;171(3):242-248.

Vita

Jaswant Singh Basraon was born in India. He completed his Bachelors of Science in Biological Science at University of California, Davis. After completing his Medical Degree from Touro University College of Osteopathic Medicine, California, he entered into residency training in Internal Medicine at The University of Texas Medical Branch, Galveston, TX in Summer 2006.

After completing his residency training in 2009, and he started his clinical fellowship in Advanced Heart Failure and Cardiac Transplantation at the University of Texas Medical Branch, Galveston and Methodist Debakey combined fellowship program.

After completion he entered the Graduate School of Biomedical Sciences to pursue his Master of Public Health in Summer 2010. He is currently a clinical cardiovascular disease fellow at Aurora Healthcare Care in the Department of Medicine - Section of Cardiology in Milwaukee, Wisconsin.

Jaswant Singh Basraon typed this thesis and is responsible for its contents.

Permanent Address:

1973 Alluvial Ave

Clovis, CA 93611