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AN EXAMINATION OF THE MINORITY
ORGAN AND TISSUE
DONOR CRISIS

THESIS

BY

THERISA YVONNE CALLIER

2005

TEXAS SOUTHERN UNIVERSITY



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AN EXAMINATION OF
THE MINORITY ORGAN AND TISSUE DONOR CRISIS
THESIS

Presented in Partial Fulfillment of the Requirements for
the Master of Arts Degree in the Graduate School
of Texas Southern University

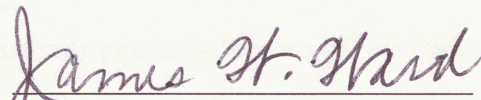
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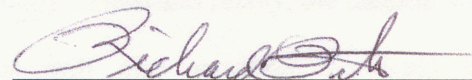
Therisa Yvonne Callier, B.B.A.

Texas Southern University

2005

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It is important to consider that the field of transplantation is an extraordinary life saving procedure and the issue is a complex one that requires input from the community, patients, health care professionals (physicians and non-physicians). The challenge in the minority community is twofold:

how to minimize the critical need for donors and how to communicate the benefits of organ donation to this community.

By

Therisa Yvonne Callier, M.A.

Texas Southern University, 2005

In the last 20 years, immunosuppressant (anti-rejection) drugs, such as tissue typing and


Professor James W. Ward, Advisor

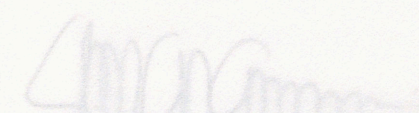
The importance of organ and tissue donation in the minority community has been very slow in gaining acceptance. The communicative challenge in the minority community has been historically hampered by fear of such drastic medical procedures. Information regarding organ and tissue donation has only recently begun to emerge in minority communities. In these communities, the shortage of organs is incredibly critical.

The ineffective communications of the life saving benefits of organ and tissue transplantation in the minority community can be attributed to many factors. This thesis examined three critical factors regarding the reasons why communication has not been successful in this group. First, the socioeconomic status of minorities correlates directly to the degree of healthcare received in their communities. Secondly, organ and tissue donation is critical in the African American community primarily because of economics, lack of knowledge, and historical fears. These factors partially support why the shortage is so disproportionate to that in the White community. Third and finally, the medical and social ethics of organ and tissue donation will also examine the issue of xenotransplantation (transplantation of an animal organ into a human) which scientists believe may become more of a necessity than an experimental option (DHH, 1997).

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It is important to consider that the field of transplantation is an extraordinary life saving procedure and the issue of organ and tissue allocation a complex one that requires input from the community – patients, donor families, and transplant professionals (physicians and non-physicians). The challenge in the minority community is twofold: how to minimize the critical need for donors and how to communicate the benefits of organ donation to this community as a life saving necessity.

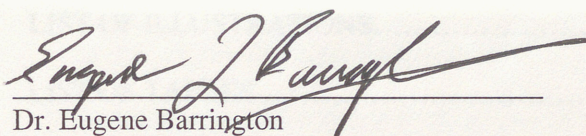
Dr. Eugene Barrington
In the last 20 years, important medical breakthroughs, such as tissue typing and immunosuppressant (anti-rejection) drugs have allowed for a larger number of organ transplants and a longer survival rate for transplant recipients (Sells, 1994). In the minority community, the shortage of organs is incredibly critical and life expectancy exponentially skewed towards certain death without donor organs and tissues.


Dr. Eui Bun Lee
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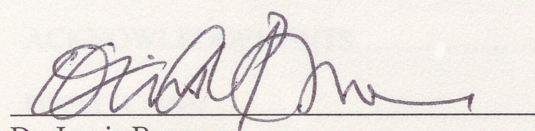

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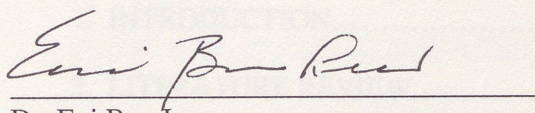
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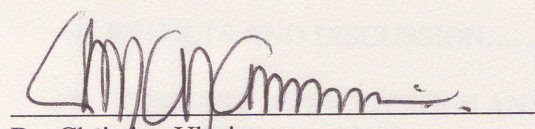
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I am also very grateful to my family, but especially to my mother, Mrs. Bonnie Sherouse Callier Sweeney and my daughter, Ms. Thérèse Roque, whose encouragement and phenomenal faith in me has been unyielding and incredible.

ACKNOWLEDGEMENTS

The author expresses sincere appreciation to Dr. James W. Ward in the preparation of this manuscript. Without his vision regarding the importance of health communications in minority communities, this thesis could not have been accomplished. In addition, special thanks to Dr. Louis Browne, Dr. Eugene Barrington, Dr. Eui Bun Lee, and Dr. Christian Ulasi for their guidance throughout this study.

Without question, my research would have been far more challenging without the support of Ms. Brender Payne, a heart transplant recipient and former Director of Nursing with Methodist Hospital, Texas Medical Center, of Houston, Texas. Ms. Payne introduced me to her transplant team who was very accommodating by offering suggestions regarding my research. Ms. Payne and her family also befriended me, which allowed me the opportunity of my witnessing the quality of life she experienced as a transplant recipient. Unfortunately, Ms. Payne died in 2002 after five years as a recipient.

I am also very grateful to my family, but especially to my mother, Mrs. Bennie Sherouse Callier Sweeney and my daughter, Ms. Thérèse Roque, whose encouragement and phenomenal faith in me has been unyielding and incredible.

CHAPTER I

INTRODUCTION

DEDICATION

The legacy of a purpose driven life and the importance of education instilled in my siblings and me are the inheritance my parents, Rev. and Mrs. Thurston and Bennie Ruth (Sherouse) Callier, II gave to us. They also instilled in us the greatest gifts by which to live: humility, humanity, compassion and integrity and the responsibility of each to God, family, self, and community. This work is dedicated in honor of my mother, the greatest educator I know, and to the memory of my father, who realized my potential before I knew I had potential. Thank you.

CHAPTER 1

INTRODUCTION

The purpose of this thesis is to identify successful approaches to increase organ donation (and transplantation) in minority communities. In this study, the minority communities consist of African Americans, Hispanics, Asian, and others (Native Americans, Alaska Natives, and Pacific Islanders). Given the emphasis of this thesis on the challenges of communicating the educational advantages of organ donation in the minority community, this study also emphasizes the necessity of organ donation as a life saving factor. This thesis also serves as a resource for future organ donation activities by highlighting the promising approaches for significantly increasing organ and tissue donations in minority communities. Also, it is to build on the experiences of public, private, and volunteer initiatives for expanding the number of minority donor organs available to the growing list of African Americans and other minorities awaiting transplants. In doing so, my research is twofold. First, it seeks to learn which program(s) would become self-generating interventions that would ultimately work in decreasing the number of minority organ/tissue recipients. And secondly, which programs would improve the educational benefits of organ/tissue donation in minority communities.

In defining methodologies, the objective is to elevate the knowledge and importance of organ and tissue donation to minorities. In doing so, one must consider the socioeconomic status of minorities and how healthcare may or may not be a contributing factor to preservation or longevity of life in these communities. Along with this factor, strong consideration must be given to addressing the historical fears, myths and other barriers sustaining non-donor cooperation or interest. The study of the critical need in the African American community (as well as other minority communities) for organ and tissue donation is also another consideration. Factors such as nutrition, economics, and lack of knowledge of the benefits of organ and tissue donation are directly related to the

statistics of the survival rate of minorities compared to that of Whites (ASPE, 1998). Finally, the ethics of live donor transplants, experimental organ and tissue transplants, and the responsibility of the medical community to donor, recipients, and their families will be examined in this study.

The methodologies represented here are evaluations of efforts to increase organ donation in all communities. The evaluations are focused on a range of approaches, such as those to increase consent, improve the efficiency of the donation system, promote behavioral change, and reach specific target populations. Although educational efforts have dispelled some of the myths about donating and many activities such as coordinated donor card signings have marginally improved awareness, minorities still have not been overwhelmingly convinced of the life saving attributes of organ and tissue donation.

Despite the diversity in design, costs, performance indicators, and other factors, the aim of the evaluation methods in this study is to assess the statistics of White organ and tissue donors to the statistics of minority organ and tissue donors. All evaluations have a control or comparison group, whether explicit or implied. In this study, the control group will be White donors/recipients and the comparison group will be minority donors/recipients.

Despite the notable improvements in the overall health of the United States in the last two decades, there continues to be striking disparities in the burden of illness and death experienced by African Americans, Hispanics, Asians, Native Americans, Alaska Natives, and Pacific Islanders compared to that of White patients. Health disparities is defined as differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions that exist among specific population groups in the United States. Research on health disparities related to socioeconomic status is also contained in the definition established by the Council of Economic Advisors in 1998.

donors A comprehensive national effort to prevent disease, promote health, and deliver appropriate care to racial and ethnic minorities – all of which are necessary to achieving the goal of reducing, and even eliminating, these disparities – cannot, however, be accomplished by this research alone. In order to make substantial inroads in the reduction of health disparities between minorities and Whites, the United States must, for example, monitor the health status of different minority populations; use the information gained from research to change the delivery of medical services to minority communities; and ensure the distribution of these services across all segments of the population. Organ and tissue procurement for minorities is underserved and critical, especially for African Americans.

family (Montgomery, 1993).

Minority Donor Demographics

current In 1980, Dr. Clive Callendar, founder of the Minority Organ and Tissue Transplantation Education Program (MOTTEP) and chairman of Howard University Hospital, explored why minorities donated less frequently than Whites. He discovered there were at least five reasons – lack of information, religious beliefs and superstitions, fear of premature death, mistrust of the medical community (i.e. the effort to save a minority who was injured in a bad accident would be compromised if the medical staff knew the patient was an organ donor), and racist fears that their organs would only go to Whites (MOTTEP, 2000).

10,619 With increased awareness of transplantation among minorities, organ donation in those communities has increased. The Scientific Registry of Transplant Recipients and Organ Procurement reported in 2002, African American donors numbered 991 (850 living; 141 deceased) – an increase from 1993 of 514 donors (402 living; 112 deceased). However, White donors in 2002 numbered 6,225 (5,566 living; 759 deceased) – an increase from 1993 of 3,066 (2,398 living; 668 deceased). Although African American

donors from 1993 to 2002 increased 48 percent and White donors increased 51 percent during the same time frame, the ratio of White donors to African American donors in 2002 was six to one.

In addition to convincing more African Americans to sign donor cards, Callendar stresses the importance of helping African Americans change certain behaviors that put them at risk for disease and disproportionately on organ donor waiting lists. He believes preventive measures such as convincing minorities to eat healthier, exercise, stop smoking, and not abuse drugs would go far in the prevention of health issues that lead to drastic measures such as organ transplants. However, in too many minority families, nutrition and other healthy alternatives are totally depended on the economic status of the family (Montgomery, 1993).

Minorities represent approximately 50 percent of the more than 87,000 patients currently awaiting transplants, yet only 25 percent of those donating organs (OPTN 2003 Annual Report). The risk of end stage kidney disease (renal failure) for some minorities (African American, Hispanics, and Native Americans) is three to four times higher than for the White population. African Americans and other minorities are hard hit by hypertension, diabetes, and kidney disorders, which ultimately leads to organ failure.

In fact in 1998, of the 60,525 people nationwide waiting for kidneys, more than 21,184 were African American (35 percent) and 5,447 (9 percent) were Hispanic (Lantz, 1998). As of January 31, 2005, of the 91,991 total donors in the United States, only 10,619 were African American and 8,922 were Hispanic. In the seven years, the number of African American donors declined by 23 percent and the number of Hispanic donors increased by only one percent. However, minorities still comprise over 50 percent of those needing transplantations (OPTN, 2005). Additionally, African Americans and Hispanics between the ages of 45 and 65 suffer from diabetes twice as often as do Whites in the same age group.

The minority population is predicted to increase from 28 percent in 1998 to an anticipated 40 percent in 2030. The need for minority donation and transplantation can be expected to grow as well (Robert Johnson's Letter, 1998). Yet while the number of minorities waiting for a transplant continues to grow, minority organ and tissue donations lag far behind those of the White population. A breakdown by race shows that 76 percent of cadaver donations are overwhelmingly from the White population (Appendix A). According to the 2000 United States Census, the African American population accounted for 13 percent of the population. Hispanics, Asians, Native Americans and Pacific Islanders accounted for a combined amount of 12.6 percent with Hispanics totaling 12.5 percent of that amount.

It is critical to increase the availability of minority donors in order to save lives in those communities. In fact, the best matches between donors and recipients often lie between members of the same race. Currently, the lack of minority organ and tissue donors decreases the number of well-matched kidneys and pancreases available for minority recipients (ASPE, 1998). The United Network for Organ Sharing (UNOS) Scientific Registry states that African Americans wait twice as long as Whites for a suitable kidney. What is more disturbing is that any attempt by the medical community to explain the waiting time discrepancies has not been successful. However, one viable explanation could very well be the complex issue of biologic factors, including cross matching challenges; and non-biologic factors such as patient refusal and administrative reasons (Council, 1998).

With regards to extra renal transplantation (liver, hearts, etc.), it has not been demonstrated that any ethnic inequities in the allocation or distribution of organs occurs (Weinick, 1996). However, this does not imply that there are not any minority issues. Historically, minorities tend to be represented disproportionately in the lower socioeconomic class and are frequently forced to rely upon Medicaid programs to meet

their health care needs. Further, the historical fear of minorities of medical procedures has been validated by the abuse of slavery; “experiments” like the Tuskegee syphilis study; and a realistic fear and knowledge of substandard medical care (ASPE, 1999). There is an apparent lack of uniformity in state government subsidy, such as Medicaid coverage for extra-renal transplants, and the fact that this may prevent Medicaid recipients from leaving their respective state to seek such a transplant (Gornick, 1996).

Discussions regarding the topic of academic and medical studies strongly suggest that the United States government assist UNOS, MOTTEP, Latin Organization for Liver Awareness (LOLA) and other related organizations to heighten the awareness and increase the acceptance of organ donation by the public, especially in the minority communities (ASPE, 1998). Deliberations have included proposals to educate children in preventive strategies leading to such drastic results as organ transplantation; inform high school students of the benefits of preventive lifestyle changes; and partnering with colleges and universities to enhance the communicative efforts of organ and tissue donation and its benefits.

On the corporate level, many Fortune 500 companies have partnered with organ donor organizations to inform employees of the significance of organ donation and living wills (ASPE, 1998). However, well-known minority organizations such as the NAACP, LULAC, and the Society for Asian Americans (SAA) are not a part of the charter list.

Definition of Terms

The following terms are characterized to identify language that is specifically related to the research study.

ABO – Includes blood types O, A, B, and AAB.

Acute rejection – The body’s attempt to destroy the transplanted organ. Usually occurs in the first year after transplant.

Allocation – The system of ensuring that organs and tissues are distributed fairly to patients who are in need of a transplant.

Allograft – An organ or tissue that is transplanted from one person to another of the same species: i.e. human to human. Example: a transplanted kidney.

Allograft failure – Failure of a transplanted organ.

Antibody – A protein made by the body's immune system in response to a foreign substance. Exposure to foreign cells from a previous transplant, blood transfusion, or pregnancy may cause a transplant recipient to make antibodies that can react against subsequently transplanted cells, tissues, or organs.

Antigen – A foreign molecule or substance with the capacity to trigger an immune response. Special antigens on the surface of each cell identify for the immune system whether or not that cell is foreign or native to an individual.

Anti-rejection drugs (immunosuppressive drugs) – Drugs that are taken to help the body accept the transplanted organ.

Brain death – When the brain has permanently stopped working, as determined by the physician. Artificial support systems (machines) may maintain functions such as heartbeat and breathing for a few days, but not permanently. Donor organs are usually taken from people who have been declared "brain dead."

Cadaver – A dead body.

Cadaveric – Refers to things about or relating to a dead body.

Cadaveric donor – A person who has been declared "brain dead" and whose family has offered one or more organs or tissues to be used for transplantation.

Cadaveric transplant – The transplant of an organ from a cadaveric donor.

Candidate – A person who is waiting for a transplant.

Cardiac – Having to do with, or referring to, the heart.

Cardiologist – A specialist who is an expert in the diseases of the heart and blood vessels.

Chronic – Developing slowly and lasting for a long time, or the rest of the patient's life. Example: Kidney failure.

Chronic allograft failure – The gradual failure of a transplanted organ.

Congenital heart disease – Heart disease that is present from birth.

Coronary artery disease – The most common cause of a heart attack. The coronary arteries supply blood and oxygen to the heart muscle.

Crossmatching – A blood test done before the transplant to see if the potential recipient will react to the donor organ. If the crossmatch is 'positive', then the donor and patient are incompatible. If the crossmatch is 'negative', then the transplant may proceed. Crossmatching is routinely performed for kidney and pancreas transplants.

Cross Reactive Antigen Group (CRAG) – The interaction of antigens with blood typing of donors and recipients of organ or tissue grafts.

Delayed function – A condition in which the transplanted organ does not work well right after the transplant. Many kidneys have a delay before they begin to function well. Kidneys can sometimes take as long as three weeks to "wake up." Sometimes a kidney recipient needs dialysis until the kidney starts to work.

Department of Health and Human Services (DHHS) – This department of the federal government is responsible for health-related programs and issues. Formally called HEW (the Department of Health, Education and Welfare).

Dialysis – A mechanical process which works to correct the balance of fluids and chemicals in your body, and to remove wastes from your body when your kidneys are failing.

Genetic – Referring to heredity, birth or origin.

Genetic matching – See tissue typing.

Disability (disabled) – An injury or illness that keeps you from working. Some disability insurance policies pay benefits if you are unable to work at your regular type of job. Others only pay if you can not do any type of gainful work at all.

Division of Transplantation (DOT) – The office of the federal government whose principal responsibilities include the management of the Organ procurement and Transplantation Network (OPTN), the Scientific Registry of Transplant Recipients (SRTR), and the National Marrow Donor Program (NMDN), conducts public education to increase organ/tissue donation and technical assistance to organ procurement organizations (OPOs).

Donor – An individual that supplies living tissue to be used in another person, as a person (cadaveric or living) who furnishes an organ for transplantation.

Donor card – A card that states your wishes to be an organ donor. Usually wallet sized.

End-stage organ failure – The irreversible and permanent need for organ replacement therapy. For kidney, liver, heart, lung, pancreas and intestine, there is the option of transplantation.

End-Stage Renal Disease/chronic kidney failure (ESRD) – A condition in which the kidneys no longer function and for which the patient needs dialysis or a transplant.

Experimental – New treatments, procedures or drugs that are being tested. Insurance companies do not usually pay for anything that is considered experimental.

Foreign body – An organ or tissue that does not normally belong where it is, such as a transplanted organ.

Gender – The particular sex of an individual; male or female.

Genetic – Referring to heredity, birth or origin.

Genetic matching – See tissue typing.

Graft - A transplanted organ or tissue.

Graft survival - The percentage of patients who have functioning transplanted organs. They are usually given in one, three, and five years time periods.

Harvest - The act of surgically removing an organ or tissue for transplantation; now referred to as "recover" rather than "harvest".

Health Resources and Services Administrative (HRSA) - An agency of the United States Department of Health and Human Services, is charged with the oversight of the Office of Special Programs, which in turn provides oversight to the Division of Transplantation.

Hypertension (high blood pressure) - When the force of the blood pushing against the walls of the blood vessels is higher than normal because the blood vessels have either become less able to stretch or have gotten smaller.

Immune response - The body's natural defense against foreign objects or organisms, such as bacteria, viruses or transplanted organs or tissue.

Immune system - The organs, tissue, cells, and cell products in your body that work to find and neutralize foreign substances, including bacteria, viruses, and transplanted organs.

Informed consent - The process of reaching an agreement based on a full understanding of what will take place. Informed consent has components of disclosure, comprehension, competence and voluntary response.

Justice - As applied to the medical ethics of transplantation, justice refers to allocation of organs to those patients in the most immediate need. Issues of justice are balanced by concerns of utility that, in this context, refer to allocating organs to those individuals who will make the best use of the transplanted organ or tissue.

Kidneys - A pair of organs that remove wastes from the body through the production of urine. All of the blood in your body passes through the kidneys about 20

times every hour. Kidneys can be donated by living and cadaveric donors, and transplanted.

Liver – The largest gland in your body, made up of a spongy mass of wedge-shaped lobes. The liver secretes bile, which aids in digestion, helps process proteins, carbohydrates, and fats, and stores substances like vitamins. It also removes wastes from the blood. The liver can be donated and transplanted. A living donor can give part of their liver.

Living donor – Living persons who donate organs for transplantation, including a kidney, or a segment of the lung, liver, pancreas or intestine. Living donors may be blood relatives, emotionally-related individuals, or altruistic strangers.

Living-related donor (LRD) – A family member who donates a kidney, part of a lung, liver or pancreas to another family member.

Living-unrelated donor – A person who is not related by blood, who donates a kidney, part of a lung, liver, or pancreas to another person (such as a husband to a wife).

Marginal donor – Donors that are not considered to be ideal. Characteristics may include donor age greater than 55 years, prior infection with Hepatitis B or Hepatitis C, hypertension or diabetes mellitus, and organs from non-heart beating cadaver donors.

Match – The compatibility between the donor and the recipient. The more closely they match, the greater the chance that the transplant will be successful.

Mortality – Death

Multiple listing – Being on the waiting list at more than one transplant center.

MOTTEP – Minority Organ/Tissue Transplant Education Program founded by Dr. Clive Callendar in 1991 at Howard University.

National Organ Transplant Act (NOTA) - Passed by Congress in 1984, outlawed the sale of human organs and initiated the development of a national system for organ sharing and a scientific registry to collect and report transplant data.

Non-function – A condition in which a transplanted kidney fails to work after being transplanted into the recipient.

Organ – A part of the body made up of tissues and cells that enable it to perform a particular function. Transplantable organs are the heart, liver, lungs, kidneys, pancreas, and intestines.

Organ procurement – The process of donor screening, and the evaluation, removal, preservation, and distribution of organs for transplantation.

Organ Procurement and Transplantation Network (OPTN) – Operates the national network for organ procurement and allocation and works to promote organ donation.

Pancreas – A long, irregularly shaped gland that lies behind the stomach, and secretes pancreatic juice into the lower end of the stomach that aids in the digestion of proteins, carbohydrates, and fats. If the pancreas fails, the individual becomes diabetic. The pancreas can be donated and transplanted.

Procurement – The process of donor screening, and the evaluation, removal, preservation, and distribution of organs, tissues, or cells for transplantation.

Race – For UNOS purposes: African American, Alaskan Native, Asian, Native American, Native Hawaiian, Pacific Islander, and White.

Recipient – One who receives an organ.

Recovery (organ) – The surgical procedure of taking an organ from a donor.

Rejection – Occurs when the immune system attacks a transplanted organ, tissue, or cell. Immunosuppressive drugs help prevent rejection.

Renal – Having to do with, or referring to, the kidneys.

Retrieval – The surgical procedure of taking an organ from a donor.

Xenograft – An organ, tissue, cell, or body fluid transplanted, implanted, or infused from a member of another species.

Scientific Registry of Transplant Recipients (SRTR) – Provides analytic support for the ongoing evaluation of the scientific and clinical status of solid organ transplantation in the United States.

Survival rates – Indicates what percentage of patients are alive or grafts (organs) are still functioning after a certain amount of time. Survival rates are used in developing UNOS policy.

Thoracic – Referring to the heart, lungs and chest.

Tissue Type – An individual's unique combination of antigens. Matching for tissue type is important in kidney and pancreas transplantation.

Transplant, transplantation – To transfer a section of tissue or complete organ from its original position to a new position.

United Network of Organ Sharing (UNOS) – A nonprofit charitable organization that holds the contract from the Health Resources and Services Administration of the United States Department of Health and Human Services to operate the OPTN.

Utility – As applied to the medical ethics of transplantation, utility refers to allocating organs to those individuals who will make the best use of them. Issues of utility are balanced by concerns of justice that, in this context, refer to allocation of organs to those patients in the most immediate need.

Vascular – Pertaining to blood vessels.

Waiting list – After evaluation by a team of transplant professionals, a patient is added to the national waiting list by the transplant center. Lists are specific to both geographic area and organ type: heart, lung, kidney, liver, pancreas, intestine, heart-lung, and kidney-pancreas.

Xenograft – An organ, tissue, cell, or body fluid transplanted, implanted, or infused from a member of another species.

Xenotransplantation – Any procedure that involves the transplantation, implantation, or infusion into a human recipient from nonhuman animal source.

Minority Transplantation Issues

Research Questions

The primary question is how can the benefits of being an organ donor be communicated to minority communities? The historical fears of the medical community have been validated within the minority demographic on numerous occasions. These groups also are, more often than Whites, both economically and educationally deprived of the necessary resources to understand the benefits an organ donor can provide.

Communicating this subject is difficult for three reasons:

1. Historically validated fears of the medical profession;
2. Ancestral and religious beliefs and practices; and
3. Lack of adequate health care in these communities.

Secondly, (a) can the moral and cultural conditioning of minority communities be transformed to pursue the dissemination of vital and accurate information that is of dire need among minorities; and (b) can methods be adopted by the minority community to prevent the disproportionate ratio of minority recipient to those of non-minority recipients? Finally, what are the moral and ethical implications if the number of donors does not increase?

A shortage of minority donors has made it difficult to find well-matched kidneys for minority patients in need of using standard compatibility matching guidelines. However, the distribution of CRAG antigen groups is similar among all races (Increasing Organ Donation, 1999).

Nationwide, there are many organizations that support the plight of awareness for organ donation. UNOS administers the National Organ Procurement and Transplantation Network under contracts with the United States Department of Health and Human

LITERATURE REVIEW

Minority Transplantation Issues

New guidelines for matching donated kidneys and patients waiting for transplants may increase the percentage of transplants for African-American and other minorities. According to James F. Burdick, M.D., transplant surgeon at Johns Hopkins Medical Center and President of the UNOS Board of Directors in 1992, the CRAG (cross reactive antigen group) matching pilot study done by the UNOS Board expected to increase the number of well-matched kidney transplants for African-Americans and other minorities. The study also anticipated shorter waiting times for highly sensitized patients who were difficult to match with donated kidneys (UNOS, 1992). Current UNOS Scientific Registry data shows that African Americans have significantly lower survival outcomes than Whites, Hispanics, and Asians. Highly sensitized patients also experience poorer graft survival outcomes.

To increase the likelihood that a kidney transplant will be successful, routine genetic matching in kidney transplantation compares groups of antigens (the parts of the DNA that tells the body what belongs to it and what is foreign to it). There are similarities in antigens among diverse racial groups with some differences that make it more likely that a patient will find a well-matched organ from a donor of the same race. A shortage of minority donors has made it difficult to find well-matched kidneys for minority patients in need of using standard compatibility matching guidelines. However, the distribution of CRAG antigen groups is similar among all races (Increasing Organ Donation, 1999).

Nationwide, there are many organizations that support the plight of awareness for organ donation. UNOS administers the National Organ Procurement and Transplantation Network under contracts with the United States Department of Health and Human

Service (DHHS). Through its policies, UNOS ensures that all patients have a fair chance at receiving the organ and tissue needed, regardless of age, sex, race, lifestyle, religion, financial or social status. However, the disparity of transplantation as well as health care in the case of minorities does exist. For example, African Americans wait twice as long as Whites to receive a kidney transplant. This waiting disparity phenomenon, however, is yet to be explained by the medical community (Osborne, 1992).

Although church organizations, including the Coalition of African American Churches, support organ donation, too many African Americans are reluctant to participate in organ and tissue donation because of religious convictions (MOTTEP, 2002). Many African Americans believe that if their bodies are not “whole” (no organs or tissues missing) in death, it will conflict with the afterlife or even the practice will interfere with religious practices. As previously stated, distrust of the medical community is due to past experiences with health care professionals and government officials. Along with harsh experimentation done on African Americans during slavery, the practice continued after slavery and is documented by the study of the infamous Tuskegee syphilis study on unsuspecting men in Macon County, Georgia (AIM, 1997).

Dr. Arthur Caplan, director of the medical ethics program at the University of Pennsylvania in Philadelphia, described the Tuskegee study as “America’s Nuremberg”.

Tuskegee was really the experiment that set American medicine on its ear. I think Americans had this belief that they couldn’t or wouldn’t do the kind of evil things that the Germans did. Tuskegee was a gigantic wake-up call (Caplan, 1992).

On the twenty-fifth anniversary signifying the end of the Tuskegee study, researchers, the public, and the United States government were still coping with the damage caused by the Tuskegee study. To promote healing, President Bill Clinton offered a formal apology on May 16, 1997. Dr. Louis Sullivan, then President of

Morehouse University School of Medicine in Atlanta and former secretary of the Department of Health and Human Services (DHHS) stated:

The President's apology will help the healing process. To me, one of the striking things here is that even among educated African Americans, there is a level of suspicion and mistrust (DHHS, 1997).

Many researchers agree with Sullivan's assessment, although the impact of the Tuskegee incident on the nonparticipation of African Americans in clinical trials has not been quantified. Sullivan, who is a hematologist, said that the result goes beyond difficulty in recruiting African Americans to participate in clinical trials. "It is also more difficult to get African Americans to donate blood or to sign up as potential organ donors" (DHHS, 1997).

George Annas, director of the Law, Ethics, and Medicine Program at Boston University in 1997 said that President Clinton missed the mark instructing DHHS Secretary Donna Schalala to encourage more African Americans to participate in research. Annas believed that the larger problems are racism and the inadequacy of health care provided to African Americans (Annas, 1997). If anything the government's top priority should be recruiting more African Americans as medical students rather than as medical research participants. But the apology served as a reminder to members of the research establishment who once seemed oblivious to the significance of the Nuremberg Code. Not only did the Tuskegee study continue after the Nuremberg Doctors' Trials, but also other questionable research was launched in the postwar United States, including studies on humans involving chemical warfare, radiation, sterilization, and lysergic acid. Evidently, Caplan's wakeup call had still gone unheeded by the medical community.

Americans basically thought that the German doctors were crazy, or lunatics, or third-raters. One way to cope with the involvement of medicine in Nazi crimes was basically to demonize and peripheralize them (Caplan, 1992).

will be given to non-African American recipients. Studies have confirmed that donors of African descendants tend to be more compatible with racially similar recipients. African

Caplan noted it took the Tuskegee incident for the United States medical community to learn the lessons of the Nuremberg Trials and to create more safeguards for research participants, he added.

Because of these atrocities and historical poor health care, African Americans have a concerned fear of premature death because they believe that health professionals will not take extended measures to save their life if they are known organ donors. By law, transplant surgeons are forbidden to take part in a patient's care prior to donation, becoming involved only after death has been declared and the family has given permission for donation (Faden, 1986).

The outrage over the Tuskegee study led to the requirement of informed consent and to other safeguards, such as the creation of institutional review boards, data and safety-monitoring boards, and continuing ethics education for researchers. In a small opinion survey conducted in 1978 by Dr. Clive Callendar, the results showed that the third most important obstacle to organ donation by African Americans was the Tuskegee experiment. The first obstacle was the myths associated with organ and tissue donations and the second obstacle was lack of knowledge. The eventual turnaround in organ donations by African Americans is one of the great success stories in the effort to overcome the aftermath of the Tuskegee study. The rate of organ donation among African Americans in 1982 was only eight per million. By 1996, the rate had reached twenty-six per million (MOTTEP, 2000). If the trend of organ donation among African Americans remains constant, that number will have increased to only thirty-six per million by the end of 2004. This trend must significantly increase if more African Americans lives are to be saved.

Another concern of the African American community is that their donated organs will be given to non-African American recipients. Studies have confirmed that donors of African descendants tend to be more compatible with racially similar recipients. African

American organ or tissue recipients have a 20 percent higher incident of organ rejection, irrespective of the donor source. Because of the antigens unique to African ancestry, African Americans are less likely to reject the organ of a donor of African descent (MOTTEP, 2000). However, research continues and great strides have been made to overcome the antigen barrier. With the ultimate success of conquering the challenges of antigens, organ donation will become more universal and the race of the donor/receiver will eventually become irrelevant.

The Minority Organ Tissue Transplant Education Program (MOTTEP) has been actively working to solve the primary problem of shortage of organ and tissue donors. As of 2000, the organization had established fifteen educational sites across the country. The first program of its kind, it is designed to educate minorities on facts about organ and tissue transplantation; empower minority communities to develop transplant education programs and become involved in addressing the shortage of organ/tissue donors; and increase the number of minorities who sign organ donor cards, have family discussions and eventually become organ/tissue donors (MOTTEP, 2000).

Socioeconomic Status of Minorities and Health Care

Numerous studies have determined that race is not just a biological category. One such study by D. R. Williams and C. Collins defined race as “a societally constructed taxonomy that reflects the intersection of biological, cultural, socioeconomic, political, and legal determinants, as well as racism” (Williams, 1993). The overwhelming societal factors of social status, politics, and economics affect health through cultural practices, stress factors, and medical care.

Genetic factors alone cannot explain trends in racial and ethnic differences in health. More than 90 percent of genetic diversity occurs within racial and ethnic groups rather than between groups. In diseases in which genetic factors play a role, these trends

may often be explained by differing environmental factors, which then have their greatest impact on persons who are at greatest risk genetically (Osborne, 1992). Public health research into the reasons for racial and ethnic health disparities has focused largely on differences in socioeconomic status. Although lower socioeconomic status is probably the most powerful single contributor to premature morbidity and mortality, the association between race and ethnicity and socioeconomic status is complex and cannot be expected to fully explain differentials in health status (Lantz, 1998).

Racial and ethnic minority groups have experienced substantial improvements in social and economic well being during the second half of the twentieth century. Yet, health care disparities between groups persist and in some cases, have widened. African Americans, Hispanics, Asian, Native Americans, and other minorities (especially new immigrants and refugees) continue to experience social and economic disadvantages in many arenas including health care (Council, 1998).

Health insurance coverage, either public or private (usually employment-based), is a key indicator of access to medical care and is linked to income and employment status. Hispanics and Native Americans have the highest uninsured rates for every income level (Williams, 1995). However, having health insurance is not a guarantee to access to quality health care. African Americans and other minorities are more likely to be hospitalized for amputations, kidney failure, and other ailments associated with acute diabetes, suggesting that poor quality of care is received especially by poorer minorities (especially Native Americans) with diabetes prior to the more serious complications of the disease (Gornick, 1996).

Linguistically appropriate services are essential to quality of care for racial and ethnic minorities with chronic illnesses or who are at risk of developing chronic illnesses. Approximately 4 million Hispanics; 1.6 million Asians; 282 thousand African Americans; and 77 thousand Native Americans had language communication constraints

according to the recent United States Census (US Census, 2000). The scarcity of health care providers skilled in both language and cultural competency also has had a negative influence on the quality of care available to racial and ethnic minorities. Public opinion polls have found that knowledge about transplantation, knowledge about the specific need for transplantable organs for African American patients, and understanding the usefulness of donated organs have been slower to diffuse into the African American and other minority communities (ASIM, 1999).

Although UNOS is the national system ensuring fair distribution of organs and tissues, the ethics of organ and tissue donation examines two major subjects in transplantation. The first is the ethics of living donor transplants. The second issue is the more controversial issue of xenotransplantation.

Ethics of Organ Donation

During the last two decades, an intensive discussion has taken place in the field of medical ethics, which has led to a reawakening of interest in the subject of living organ transplantation, xenotransplantation, and the re-evaluation of the moral problems related to both. In this process, traditional professional ethics have, to a large extent, been replaced by more complex modes of moral reasoning. The ethical principles of respect for the autonomy of persons have proven to be of prime importance in this field (Daar, 1997).

Moral reasoning and approaches to medical ethics are as pluralistic as societies are and different types of ethical theories start from different, partly incompatible sets of premises and intuitions, consisting of varied strengths and weaknesses. To create a common ground for moral discussion, mainstream medical ethics work at the level of principles as a process of reasoning. The most relevant of these principles are (a) respect for person, including their autonomous choices and actions; (b) beneficence, including

both the obligation to benefit others (positive beneficence) and to maximize good consequences, to do the greatest good for the greatest number (utility); (c) justice, the principle of fair and equitable distribution of benefits and burdens, and finally (d) non-maleficence, the obligation not to inflict harm. In the case of conflict, these principles have to be applied to specific circumstances and balanced against each other (Beauchamp, 1994).

The risk-benefit ratio of any proposed living donor transplant is determined not only by medical (or psychological) facts, but ultimately by personal value judgments and that these judgments should generally be made by the one most affected by the outcome. This assessment also implies the general rule that the removal of organs from living donors, shall only be admissible if a suitable organ from a postmortem donor is not available when the organ removal takes place. There is no moral sound reason for pushing donors and patients to postmortem grafts against their will when living donor grafts are available. The basis for this assessment is to be found in an ethical principle which is still more crucial for the question of living organ donation than the question of harm-benefit-ratio (Childress, 1992). Persons have an interest to decide for themselves how to live their lives. The ethical principle of respect for autonomy underlies the requirement of the patient's informed consent to medical treatment.

Most importantly, the living donor must be competent to decide about donation and the act must be purely voluntary. An organ or tissue may be removed from a living donor only after the person has given free, informed and specific consent (Gutmann, 1997). A transplant physician has the moral and legal duty to make sure of the conditions of the patient's valid consent to be fulfilled, and must make reasonable efforts to establish the motives and reasons for the donor's wish (Caplan, 1992). In this respect, the physician encounters personal legal risks, and therefore can rightfully demand from the

concluded, that those considering donations from living related donors (i.e. spouses and

potential donor to cooperate in a reasonable evaluation procedure of the decision to donate.

A unique problem related to the principle of autonomy is living organ donations by minors and incompetents. This ethical problem generally is dealt with in transplant law. There should at least be a very heavy presumption against using children (especially preadolescent children) and mentally retarded persons as sources of non-regenerative organs (Daar, 1997).

To be able to give valid consent, the competent donor must beforehand be given appropriate information as to the purpose and nature of the removal as well as on its consequences and risks, and the patient's consent must be voluntary. Although medical ethicists in general are very reluctant to acknowledge a genuine moral obligation to donate an organ while alive, many donors do feel the responsibility to restore a close person to good health (Sells, 1994). If it is the general goal to ensure that the donor's consent is voluntarily given, it must be taken into account that family members probably are more vulnerable to undue pressure than friends or strangers. The myth of informed consent must always be questioned, including the cases of living organ donation between genetic relatives (Land, 1989).

In principle, the use of living donors is unanimously accepted all over the world. The World Health Organization (WHO) rule states that even though living adults may donate, it is preferable that donors are genetically related. However, "exceptions may be made in the case of transplantation of bone marrow and other acceptable regenerative tissues" (WHO, 1987).

From an ethical point of view, the principal objections to non-related donation are misdirected. There is no conclusive argument that could justify a general exclusion of unrelated donors (Thiel, 1997). The President's Task Force on Organ Transplantation concluded, that those considering donations from living related donors (i.e. spouses and

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friends) that "special care should be taken to ensure that the decision to donate is informed, voluntary, and altruistic" (Task Force, 1986). Concern for an emotionally close person as one kind of basic motivation for altruistic organ donation is not restricted to genetic relatives. The bonds motivating emotionally related donors may well be as strong as those between genetically related donors (Land, 1991).

The proposals to introduce commerce in organ transplantation have been unanimously rejected by national and international medical organizations and parliaments (WHO, 1987). The WHO has published reviews of national and international legislation, codes and other measures to resist the commercialization of human organs and tissues for therapeutic purposes. Exploitation does not depend on whether there is free consent of the exploited or not. Disparities in wealth and chances predict whether lifting the ban on market solutions would undermine the public trust. And without the essential element of public trust, the transplantation system is subject to unwarranted public scrutiny (Hylton, 1996).

The question of whether or not a living donor has the right to sell an organ constitutes one of the most controversial problems in the current ethical discussion of living organ donation (Daar, 1991). The controversial and experimental organ/tissue alternative, xenotransplantation (cross-species transplantation) offers a possible source for organs and tissues to human beings without the risk posed on living donors and without the wait of cadaver donor. However, xenotransplantation has not presently been accepted as a viable means of alternative transplantation because of numerous medical concerns and other ethical concerns.

Xenotransplantation, like many high tech medical procedures, raises a series of ethical issues, including not only the rights of patients, but also the rights of animals. Within a few years, a growing number of surgeons expect to be able to transplant cells, tissues, and organs from baboons, pigs, and other animals into humans as accepted

therapy for a number of life-threatening conditions and diseases. Driven by scientific innovation and powerful medical need, the field of xenotransplantation is moving ahead. At the same time, some scientists and surgeons are calling for caution and restraint as the pace of progress accelerates (Platt, 1996).

Infectious disease experts have raised public health warnings about new viruses with epidemic potential that may center on the transfers from animals to humans (DHHS, 1997). As xenotransplantation nears clinical reality, clearly a number of scientific postulates integrating biomedical, social, and ethical questions will demand answers. Researchers have concluded that the current scientific base is insufficient to support experimental xenotransplantation involving humans (Dorling, 1997). The fear is unless those in the medical community can demonstrate self-control, it may needlessly invite burdensome federal regulations.

If xenotransplantation can become an exact science, it has a number of potential advantages over allotransplantation (Warden, 1998). Animals and their organs can be prepared beforehand and their deaths scheduled, both of which would be unethical in the case of human donors. Also, animals are resistant to some human diseases. For example baboons and their livers are resistant to hepatitis-B. The virus can destroy a human liver and then do the same to a human organ transplanted into the patient to replace the original liver (Philbey, 1998). However, the issues of animal rights similarly to those regarding the raising of animals for human consumption, will probably become a new agenda for animal advocates.

Presently pigs are the only animals being seriously considered as a future source of organs for transplantation to humans (Weiss, 1998). Pigs grow quickly to about the right size, produce large litters, and can be reared in specific conditions. Also, pigs can be genetically manipulated to produce organs less likely to be rejected on transplantation to humans.

The ethical issues about using pigs seem less than those about the use of primates. The argument maintains that pigs have been domesticated for thousands of years, they are routinely reared and slaughtered for human consumption, and the medical use of pig heart valves have not raised serious objections from those religions that disapprove of the consumption of pork. Transgenic mice have become a common tool in medical research, and transgenic pigs are not different in principle or practice (Platt, 1996). However, for the Jewish and Islamic cultures whose dietary laws prohibit the consumption of pork, this poses a possible dilemma for minority health care in the field of organ transplantation.

Some proponents of xenotransplantation argue that, as pigs have lived alongside humans for so long, humans would have by now picked up any of their microbes capable of infecting humans. But xenotransplantation also affords a much easier passage for animal viruses (Philbey, 1998). According to researchers, pig viruses may not be recognized if they do not cause disease in pigs. Designer pigs, genetically modified to allow organs to survive as xenografts, may allow pig viruses to infect humans more readily. However, besides the risk of infection, the goal of allotransplantation and xenotransplantation is to prolong the life of the human patient. Therefore, despite the risks, xenografts might still be used as "bridging" organs to keep patients alive until human organs become available (DHHS, 1997).

The routine preservation of blood stem cells from umbilical cords is being debated, as these could later be used to treat the person from whom they came. In addition, cloning from mature cells, as was done with Dolly the sheep, might allow functional human tissues and, eventually, organs to be regenerated from cells. With advances in reprogramming cellular differentiation, patients may themselves become donors for autografts, making xenografts superfluous. However, these developments in cell therapy are likely to be farther away than xenotransplantation (Butler, 1998). But, as

the interest in xenotransplantation grows, clear ethical, safety, and monitoring guidelines will be absolutely necessary to control the development of xenotransplantation.

The goals of this research will be accomplished through an evaluation of electronic, mail questionnaires, and media generated surveys. In this case, 276 surveys were completed by a control group of educators and high school seniors. The survey design is exploratory (Kerlinger, 1936). This is the method that is generally used in the stages of relatively new research. By analyzing this type of data, new postulates can lead to phenomena previously unknown. Further, this type of exploratory research is aimed at the explanation of prominent issues. New discoveries may include the insight of a subject group which may be directly, indirectly, or unrelated to the initial study.

Exploratory research is devoted to finding probable relationships among variables. It does so from theory-based expectations on how and why variables should be related and because the investigator has no prior knowledge of the outcome. The goal of this survey is to gather preliminary data, which in turn, may lead to a refining of data indicators (Dominick, 1987). Hypotheses could be basic (i.e., relationships exist) or could be directional (i.e., positive or negative). Results are then interpreted and in turn, contribute to theory development.

In this research, data are recorded first by socio-economic indicators, followed by descriptive indicators. The socio-economic indicators are gender, age, ethnic/cultural background, and economics. The descriptive indicators are organ donor/donation questions of interests such as family/medical notification, most needed organs, diseases causing organ failure, and voluntary personal information.

While the organ donation mainstream community has been very active in implementing diverse approaches for increasing organ and tissue donation, there has not been a concerted effort to determine the best methodologies for conveying this importance to minority communities. In the minority community, this is further

complicated with the necessity of tissue matching, phobias, and myths. In order to better inform minority communities about organ donor benefits and recipient causes, culturally sensitive communication strategies will need to be developed and administered very carefully.

For example, measuring the changes in public awareness of organ donation activities may not ultimately provide insight on the impact the activity had on donation rates. Because of the inability to predict who might become a potential organ donor before the occurrence of a traumatic event, any activity targeted at the general public must cast a wide net in order to reach those few people who will become potential organ donors. It is difficult to attribute any measured change in organs retrieved to a given population-based program with acceptable levels of certainty. The evaluation of population-based programs requires careful selection of performance indicators based on the goals and resources of the organization conducting the evaluation.

Utilizing measures previously discussed, accurate measurement of good intentions, and actual donation are not reliable data. Because human beings practice free-will and the choice to change one's mind at any time regarding transplantation or donation, any measures would be subjective. Measuring changes in public awareness of organ donation activities may not ultimately provide insight on the impact the activity has on donation rates (Gornick, 1996).

To develop this model for organ donation in the African American and minority communities, a survey questionnaire has been structured to interview potential donors who either have or have not considered organ donation. The survey was designed to measure initial interest, decisional balance, and potential processes of change.

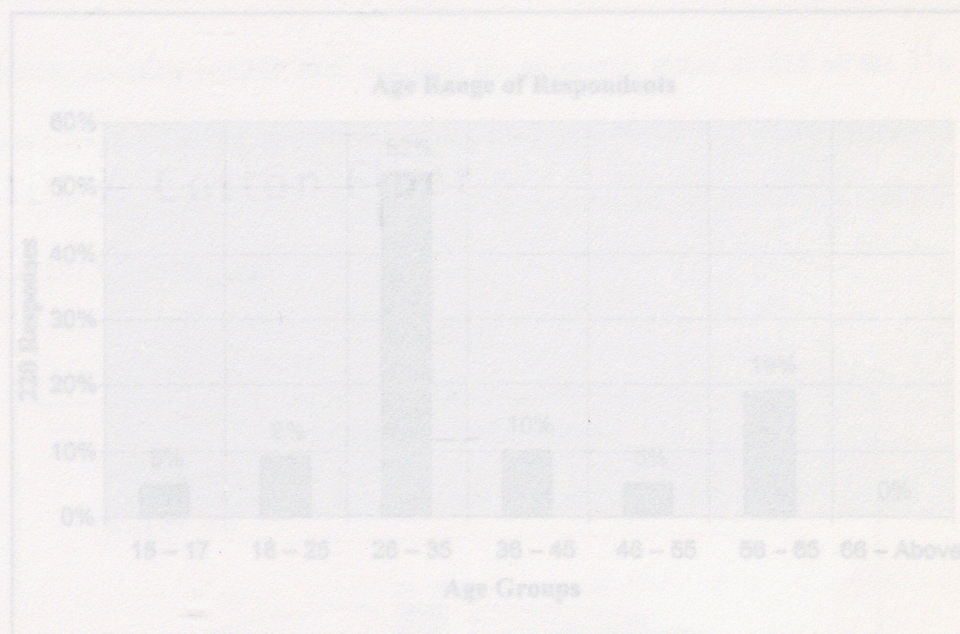
The information from the survey can be used to target specific processes of change to promote advances towards the action phase and, ultimately, to increase the likelihood of consenting to donate. One limitation of this survey is its potential to have

the characteristics of a narrow scope of potential donors and its small size of non-donor families. The current study determines baseline understanding and attitudes towards organ donation and any issues and concerns about organ donation in general.

indicated the respondent's demographic data; the remaining questions ascertained the respondent's general knowledge of donor/recipient organ transplantation and methods of possible communicating the benefits of organ donation. Two hundred seventy participants completed the survey. Sixty-two percent were female, thirty-eight percent male. The bold print in the survey questions indicates the correct answer for the reader of this research.

There were seven age brackets from which respondents could chose, with the largest response coming from the age group of 26 to 35. Graph I indicates the percentage of respondents according to age.

Graph I



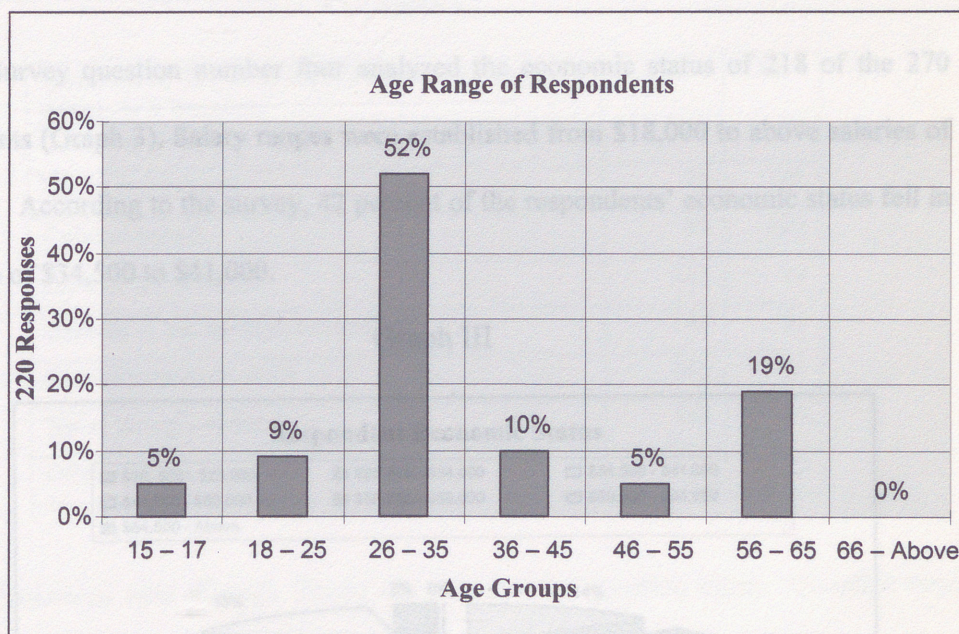
CHAPTER 4

RESULTS AND DISCUSSION

The survey consisted of twenty-three questions. The first four questions indicated the respondent's demographic data; the remaining questions ascertained the respondent's general knowledge of donor/recipient organ transplantation and methods of possible communicating the benefits of organ donation. Two hundred seventy participants completed the survey. Sixty-two percent were female, thirty-eight percent male. The bold print in the survey questions indicates the correct answer for the reader of this research.

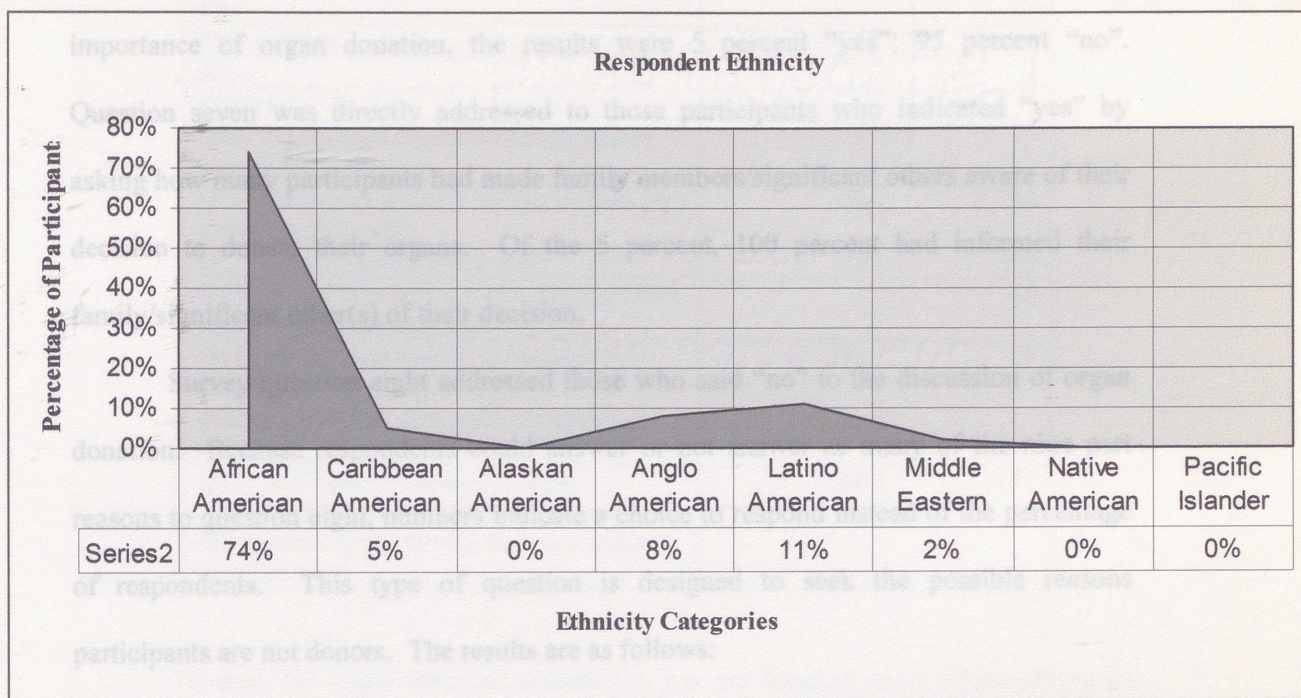
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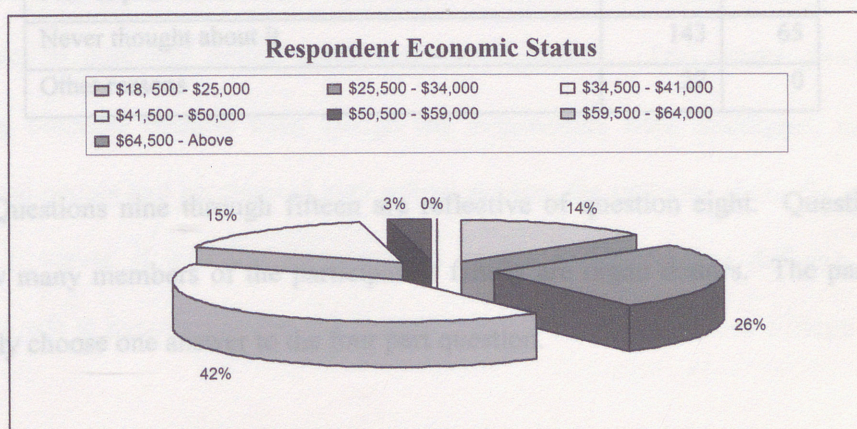
The ethnic/cultural category of the survey had eight choices. Graph II indicates the ethnic groups who participated in the survey.

Graph II



Survey question number four analyzed the economic status of 218 of the 270 respondents (Graph 3). Salary ranges were established from \$18,000 to above salaries of \$64,500. According to the survey, 42 percent of the respondents' economic status fell in the range of \$34,500 to \$41,000.

Graph III



Questions five through fifteen were “yes” or “no” choices. When asked if the respondent was a registered organ donor, the results were 10 percent “yes”; 90 percent “no”. Regarding discussion with significant others and/or family members regarding the importance of organ donation, the results were 5 percent “yes”; 95 percent “no”. Question seven was directly addressed to those participants who indicated “yes” by asking how many participants had made family members/significant others aware of their decision to donate their organs. Of the 5 percent, 100 percent had informed their family/significant other(s) of their decision.

Survey question eight addressed those who said “no” to the discussion of organ donation. Because respondents could answer or not answer as many of the nine part reasons to question eight, numbers indicate a choice to respond instead of the percentage of respondents. This type of question is designed to seek the possible reasons participants are not donors. The results are as follows:

Table 1

Question 8: If you are not a registered organ donor, is it because:	Yes	No
Religious Beliefs	111	57
Myths and hearsay	76	102
Cultural beliefs	85	120
Lack of information	153	14
Distrust of the medical community	182	22
Fear of premature death	165	37
Never thought about it	143	65
Other reasons	27	0

Questions nine through fifteen are reflective of question eight. Question nine asks how many members of the participant’s family are organ donors. The participant could only choose one answer to the four part question.

Table 2

Question 9: How many members of your family are registered organ donors?		
None		216
One		47
Two or more		7
All		0
Questions 10 – 15:	Yes	No
Q10: If you are a registered donor, do you carry a donor card?	25	15
Q11: Does your driver's license indicate you are an organ donor?	20	20
Q12: Do you have a living will?	15	255
Q13: If you have a living will, did you make an organ donation request?	1	14
Q14: Do you fear that if the hospital staff knows you are an organ donor that your quality of medical care will be negatively affected?	193	77
Q15: Although the National Organ Transplant Act of 1984 makes it illegal to sell human organs, do you feel your organs could be sold?	169	101

To date, the organ donation community has not focused much of its efforts on activities designed to educate and increase public awareness of organ and tissue donation, especially in the minority community. Consequently, the respondents' answers validate this statement.

Questions sixteen through twenty-two evaluate the respondent's general knowledge of organ donation. These questions were not created to indicate the respondent's religion, race, or to persuade decision. Question sixteen asks the respondents to clinically define death based on opinion. The results provided an interesting outcome because even though the respondents were intelligent, educated, professional people and accelerated high school seniors, the majority chose the incorrect answer. However, if informed persons were having a difficult time defining clinical death, it is safe to hypothesize that the general public would have a more difficult time in

doing the same. Respondents could only choose one answer, but they were not required to answer.

Table 3

Question 16: In your opinion, what is the clinical definition of death?	
Even with life support, circulation and breathing functions stop.	87
All functions of the entire brain stop (brain dead), including the brain stem	20
Both	23
Other	17

Question seventeen requests the communicative preference of the respondents regarding organ donation information. Like question eight, survey question seventeen allows respondents to answer or not answer as many of the eight part question as applies. Again, numbers indicate a choice to respond instead of the percentage of respondents. The results are as follows:

Table 4

Question 17: Through which of the following methods would you prefer to hear about the life saving benefits of organ donation? Please indicate as many as apply.	
Church, Mosque, Synagogue, Temple	158
Media (television, radio, newspaper)	171
Educational facilities	182
Endorsement by community leaders	108
Endorsement by organ recipients	136
Endorsement by national leaders	92
Endorsement by "famous" personalities and/or athletes	75
The medical community	203

Questions eighteen and nineteen ask the respondents to consider the percentage of the more than 87,000 waiting a transplant, how many are non-minority and how many are minority patients. The number of respondents indicated what percentage non-minority and minority patients they thought were on the transplantation list:

Table 5

Questions 18 and 19: Of the more than 87,000 Americans on the waiting list for an organ transplant, how many do you think (percentage) are:		
Answer Choices	Respondent Answers	
	Q18: Non-minority patients	Q19: Minority patients
8 %	21	31
12%	16	20
25%	71	33
More than 30%	109	122
More than 50%	53	64

Questions twenty and twenty-one ask the respondents to judge which organ is needed more by non-minority and minority patients. Because respondents were not required to choose an organ(s), the number of respondents does not equal the number of choices each responded indicated for both groups:

Table 6

Questions 20 and 21: Which of the following organs are most needed by non-minority and minority patients?		
Organs	Q20: Non-minority Patients	Q21: Minority Patients
Heart	105	186
Heart/Lung	127	95
Liver	66	105
Kidney	87	98

Question twenty-two asks the respondents to indicate which of the five diseases (diabetes, hypertension, alcohol abuse, drug abuse, obesity) is the major cause for organ transplantation. Respondents indicated the following:

Table 7

Question 22: Which of the following diseases do you think is the leading cause of organ transplants?	
Diabetes	49
Hypertension (High Blood Pressure)	35
Alcohol Abuse	81
Drug Abuse	68
Obesity (Overweight by 30 pounds or more)	38

The last question requested personal information of the respondent, which was also optional. Only thirty-one respondents completed this part of the survey.

To date, the organ donation community has focused much of its efforts on activities designed to educate and increase public awareness of organ and tissue donation, especially in the minority community. The thorough evaluation of activities like the ones discussed in this research can better equip organizations like MOTTEP and UNOS in disseminating information to the minority community if programs are designed to specifically meet their needs.

Research has determined that contemporary campaigns in minority communities have marginally been successful in increasing the level of organ/tissue education. However, the margin of acceptance in the minority community has not nearly reached the level of acceptance as that in the White community. Therefore, future intervention and prevention programs must attract minorities to not only promote organ/tissue donation but also to prevent minorities from becoming dependent on the organ/tissue waiting list.

One method of education about organ and tissue donation is to target grade school students with age appropriate materials. Television programs such as MTV, drivers' education classes, and health classes are perfect venues to inform this audience of prevention methods and the benefits of not being an organ/tissue recipient. This researcher proposes a media blitz that would be more direct and therefore, more effective.

Information commercials utilizing patients who are willing to talk about how they became a candidate for organ and/or tissue transplantation would bring to the forefront the importance of prevention.

This researcher believes graphic information such as the example previously stated would be more effective than the "be heart smart" commercials and other such media and printed information presently inundating the general public. Prior to the development of the commercial, a simple survey should be available for health professionals to gauge the effectiveness of the commercial (i.e. a few questions could be asked as part of the physician's examination routine and noted in the medical records) over an established time frame. In the field of communications, 75 percent of what is seen is retained. If this idea is supported by the medical community, federal and state officials, preventive measures in the minority community could conceivably experience a significant increase.

Two possible concerns regarding the testing methods and results should be noted. First, awareness does not necessarily correlate with eventual outcomes. Follow-up and correlation of increased awareness with actual donation is necessary to determine if the program has any direct impact on organ donation rates. Secondly, ruling out confounding factors in these activities is very difficult. Because individuals assimilate information from many sources and in various ways, it is difficult to use a pre-test/post-test assessment to determine whether changes in attitudes towards organ donation are due to the education program or some other factor.

To improve study designs, a contemporaneous control group must be identified. A viable and measurable means of collecting data must be established to verify the differences in donation rates versus donation awareness between the White community and the minority communities. Utilizing the medical community would be one way to gather this type of authentic data.

CHAPTER 5

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

An intensified commitment to research health disparities in minority communities and to develop new diagnostic, treatment, and prevention strategies to overcome them is a sound investment for the health and well-being of all citizens. However, there is compelling evidence that the United States minority populations suffer from increasing differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions. Health disparities heightened in minority communities include shorter overall life expectancy, higher rates of cardiovascular disease, cancer, infant mortality, birth defects, asthma, diabetes, stroke and other abnormalities. Most vividly is the disproportionate number of minorities listed as waiting for a life saving transplantation and the disparities in the selection process.

For example, a major health care issue in the United States revealed in this thesis is end-stage renal disease. There are striking racial and ethnic differences in the incidence and prevalence of this disease. In 1997, the incidence rates were 218 per million in Whites as compared to 873 per million in African Americans, and 586 per million in Native Americans and Alaska Natives (NIH Strategic Research Plan, 2001).

Diabetes is also the leading cause of end stage kidney disease, adult blindness, and amputation. Diabetes affects nearly 16 million Americans and leads to more than 300 thousand deaths annually. More than 90 percent of those affected have Type 2 diabetes, which is disproportionately manifested in minority groups. The prevalence of diabetes in African Americans is nearly 70 percent higher than in Whites. Native Americans, Hispanics, African Americans, and some Asian Americans are at particularly high risk of development of Type 2 diabetes. Most remarkably, diabetes prevalence rates among Native Americans are two to five times those of Whites (Haan, 1985).

Although observations and anecdotes can provide clues about health disparities, it is only through rigorous population research that the health care community can discern where disparities exist, define the scope of the problem, and then identify and evaluate new approaches to reduce, and eliminate them. With such glaring information as health care disparities, limited available organs and tissue transplants, and the socioeconomic disadvantages particularly inherited by minorities, it is imperative that organ/tissue information is designed to address the particular needs of the minority community. Severe educational preventive measures and the regeneration of these measures may be the primary base to saving many future minority lives.

Presently, xenotransplantation is not a viable option and may not be necessary if minorities are educated at an early age on the prevention of being an organ transplant recipient. Educating minorities will not only mean encompassing the standard methods of disbursing information, but the creativity of those health care professionals, government officials and organizations like UNOS, MOTTEP, LOLA, and others. If partnering with Fortune 500 and 100 companies is to be truly successful and not just a "feel good" gesture, than organizations like NAACP, LULAC, and other minority groups must be an active part of the program.

Finally, minorities are the ultimate creators of their destiny. Minorities must become more physically involved and cognizant about their future and health care, if they do not want to continue to be victimized by the present health care system. A comprehensive national effort to prevent disease, promote health, and deliver appropriate care to racial and ethnic minorities – all of which are necessary to achieve the goal of reducing and perhaps eliminating these disparities – cannot, however, be accomplished by these and other entities alone. Minority patients, potential patients and their families must become a committee of one to deliberately become more health conscious and more informed about preventive health care measures and resolution of health care disparity.

Sixteen persons die each day waiting for a life saving organ and/or tissue transplantation. Every fourteen minutes a new name is added to the national waiting list. More than half of both these figures represent minorities, with African Americans included the following occupying 50 percent of the minority number.

Type of Transplant	Patients Waiting for Transplant
Kidney transplant	60,525
Liver transplant	17,626
Pancreas transplant	1,776
Kidney-pancreas transplant	2,415
Intestine transplant	193
Heart transplant	3,253
Heart-lung transplant	170
Lung transplant	3,896
Total	87,297

NOTE: UNOS policies allow patients to be listed with more than one transplant center, causing registrations to be greater than the actual number of patients. Some patients are waiting for multi-organs, causing the number of patients to be less than those patients waiting for each organ.

Number of Transplant Performed in 2004*	
Type of Transplant	Number
Kidney alone transplants (5,536 were living donors)	10,798
Liver transplants	5,528
Pancreas alone transplants	1,715
Kidney-pancreas transplants	911
Intestine transplants	144
Heart transplants	1,777
Heart-lung transplants	48
Lung transplants	921
Total	21,842

Number of Donors Recovered in 2004*	
Type of Donor Recovered	Number
Cadaveric	5,933
Living	5,827
Total	11,760

NOTE: Data subject to change due to future data submission or correction.

*Based on OPTN data as of October, 2004. Double kidney, double lung, and heart-lung transplants are counted as one transplant.

APPENDIX A

National Patient Waiting List As Of October, 2004

On October, 2004, the UNOS national patient waiting list for organ/tissue transplant included the following:

Type of Transplant	Patients Waiting for Transplant
Kidney transplant	60,525
Liver transplant	17,626
Pancreas transplant	1,776
Kidney-pancreas transplant	2,415
Intestine transplant	193
Heart transplant	3,255
Heart-lung transplant	170
Lung transplant	3,896
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APPENDIX B

Donor Survey

In 1996, there were more than 50,000 Americans waiting for transplants. Since October 2004, the number of those waiting for donor organs has increased to over 87,000 – a 43% increase since 1996. This survey is designed to discover a practical method of communicating the benefits of organ donation for everyone. Thank you for your participation.

1. Are you female () or male ()?

2. What age bracket best describes you?

() 15 – 17

() 18 – 25

() 26 – 35

() 36 – 45

() 46 – 55

() 56 – 65

() 66 – above

3. What ethnic/cultural category best describes you?

() African America

() African/Caribbean American

() Alaskan American

() Anglo American

() Asian American

() Latino American

() Native American

() Pacific Islander American

() Other

4. What economic structure best describes you?

() \$0 – \$9,000

() \$9,500 – \$18,000

() \$18,500 – \$25,000

() \$25,500 – \$34,000

() \$34,500 – \$41,000

() \$41,500 – \$50,000

() \$50,500 – \$59,000

() \$59,500 – \$64,000

() \$64,500 – Above

5. Are you a registered organ donor?

() Yes () No

6. Have you discussed organ donation with your significant other and/or other immediate family member(s)?

() Yes () No

() Church, Mosque, Synagogue, Temple

() Media (television, radio, newspaper)

7. If yes, are your significant other and/or family member(s) aware of your decision to donate your organs?

☐ Yes ☐ No

8. If you are not a registered organ donor, why? Please check as many as apply.

☐ Religious beliefs

☐ Myths and "hearsay"

☐ Cultural beliefs

☐ Lack of information

☐ Distrust of the medical community

☐ Fear of premature death

☐ Fear organs will be given to a recipient not of your choice

☐ Never thought about it

☐ Other

9. How many members of your family are registered organ donors?

☐ None

☐ One

☐ Two or more

10. If you are a registered donor, do you carry a donor card?

☐ Yes ☐ No

11. If you are an organ donor and you have a driver's license, have you indicated your decision to donate your organs on the back of your driver's license?

☐ Yes ☐ No

12. Do you have a living will?

☐ Yes ☐ No

13. If you have a living will, is organ donation one of your requests?

☐ Yes ☐ No

14. Do you fear that if the hospital staff knows you are an organ donor that your quality of medical care will be negatively affected?

☐ Yes ☐ No

15. Although the National Organ Transplant Act makes it illegal to sell human organs, do you feel your organs could be sold?

☐ Yes ☐ No

16. In your opinion, what is the clinical definition of death?

☐ Even with life support, circulation and breathing functions stop.

☐ All functions of the entire brain stop (brain dead), including the brain stem.

☐ Both

☐ Other

17. Through which of the following methods would you prefer to hear about the life saving benefits of organ donation? Please indicate as many as apply.

☐ Church, Mosque, Synagogue, Temple

☐ Media (television, radio, newspaper)

- ☐ Educational facilities
- ☐ Endorsement by community leaders
- ☐ Endorsement by organ receivers
- ☐ Endorsement by national leaders
- ☐ Endorsement by "famous" personalities and/or athletes
- ☐ The medical community

18. Of the more than 87,000 Americans on the waiting list for an organ transplant, how many do you think are minority patients?

- ☐ 8%
- ☐ 12%
- ☐ 25%
- ☐ More than 30%
- ☐ More than 50%

19. Of the more than 87,000 Americans on the waiting list for an organ transplant, how many do you think are non-minority patients?

- ☐ 8%
- ☐ 12%
- ☐ 25%
- ☐ More than 30%
- ☐ More than 50%

20. Which of the following organs are most needed by non-minority patients?

- ☐ Heart
- ☐ Heart/Lung
- ☐ Liver
- ☐ Kidney

21. Which of the following organs are most needed by minority patients?

- ☐ Heart
- ☐ Heart/Lung
- ☐ Liver
- ☐ Kidney

22. Which of the following diseases do you think is the leading cause of transplantation?

- ☐ Diabetes
- ☐ Hypertension (High Blood Pressure)
- ☐ Alcohol Abuse
- ☐ Drug Abuse
- ☐ Obesity (Overweight by 30 pounds or more)

23. Optional Information:

Name: _____

Address: _____

E-mail address: _____

Thank you for participating in this important potentially lifesaving survey.

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