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The failure of altruism: Alternatives to improve the donor rate in organ transplantation

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THE FAILURE OF ALTRUISM: ALTERNATIVES
TO IMPROVE THE DONOR RATE IN
ORGAN TRANSPLANTATION

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A thesis submitted in partial fulfillment
of the requirements for the

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Ethics and Policy Studies
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**Graduate College
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ABSTRACT

The Failure of Altruism: Alternatives to Improve the Donor Rate in Organ Transplantation

by

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Ethical and moral issues facing potential organ donors, their families or agents, and the medical community are created and driven by the rapidly expanding demand for the life-giving resource (ever more successfully utilized) – a factor coupled with the persistently scarce and relatively constant low level of supply. The serious nature of the shortage of compatible organs has prompted medical, ethical, and legal scholars to consider alternatives to altruistic donation. This approach has never been able to keep up with the demand – indeed, it falls further behind each year. One set of alternatives involves (currently banned) financial incentives for organ donors. I will argue that some form of incentive, or other policy-type recommendation is the only possible method of catching up with the technological innovations, that while incredible, serve to exacerbate the demand/supply dis-equilibrium. The thesis will examine the ethical and moral issues that pertain to this dilemma and recommend policies targeted at alternatives for resolving the supply problems.

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CHAPTER ONE

INTRODUCTION

Medicine and surgery in the late twentieth century are filled with ethical and policy dilemmas: the field of organ transplantation is no exception. Economic scarcity of donor organs for transplant is a large contributor to this dilemma. Many questions inevitably involve the underlying ethical principles of respecting the self determination of patients with decision making capacity (*autonomy*), acting to protect the patients' well-being (*societal intervention or qualitative benefit*), and acting in a manner that promotes fairness and equity to all involved (*justice*). I will examine ethically defensible alternatives to altruistic donation and/or procurement of these scarce resources – specifically recommending alternatives to failed altruistic methods.

I will begin by detailing the extent of the problem. According to the United Network for Organ Sharing (UNOS), the number of organ transplants performed throughout the United States in 1997 (1998 data is not yet fully available) remained virtually unchanged from the 1996 total (See Appendix A - Table 1). While transplants from living donors increased approximately 5%, transplants from cadaveric (non-living) donors stayed nearly the same. “While we were able to save and enhance thousands of lives through transplantation last year, we are disappointed that we could not do more,” said UNOS president James F. Burdick, M.D., “Tens of thousands of people continue to await a transplant, and about ten die each day because an organ was not available for

them. The single greatest challenge we face in increasing organ transplantation is getting more personal commitments to organ donation.”¹ While Dr. Burdick made his statement in 1997, the issues are exactly the same in 1999.

A total of 20,935 transplants were recorded in 1997, as opposed to 20,499 in 1996. (See Appendix A – Table 1) There were 5,478 people who donated one or more organs upon death in 1997, an increase of about 1% over the 1996 total. Counting living donors there was a total of 9,298 human donors who contributed one or more organs during 1997. (See Appendix A - Table 2) Although the registration list varies throughout any given year, there were 65,733 people waiting as early March 1999, an increase of approximately 16% over the end of the year 1997. (See Appendix A - Table 3) Of those waiting on the list in 1997, a total of 4,855 died prior to getting a transplant, an increase of 12.6% over the prior year. (See Appendix A - Table 4) Organ transplants are being performed in the United States at a rate of growth such that the extent of the scarcity of donor organs for transplantation is so great that it would take almost the combined total of transplants performed in the last three years to meet the need of patients now waiting. Despite the obvious need, the supply of donor organs has remained fairly constant notwithstanding national and local efforts to increase donations.

Major breakthroughs in scientific, technical, and medical areas of transplantation are responsible for the advances of the past three decades. Improvements in the surgical techniques of transplantation, the ability to preserve organs outside the body for brief periods of time, the capacity for maintaining bodily functions on artificial life support technologies, the ability to determine antibody and blood types from small tissue samples, the growing confidence with which physicians can diagnose brain death and the

emergence of powerful immuno-suppressive drugs – especially cyclosporine – have been responsible for the rapid expansion in both the number and kind of transplants that are now being performed.

The ability of transplantation teams at many medical centers in the United States, and around the world, to succeed in extending life beyond the onset of organ failure has commanded a great deal of attention from those outside the field of transplantation. Difficult questions persist concerning the need to advance further the art of transplantation, e.g. the importance of providing equitable access to existing transplant centers, the criteria that ought to be used in determining who should receive transplants as well as a number of other issues have occupied a prominent and growing place in both legislatures and the media. Perhaps the most pressing policy issue facing both those within and outside of the field concerns the shortage of organs available for transplantation to those with end stage organ failure. A great deal of debate, discussion, legislation, and regulation among many different elements within U.S. society has been directed at the question of how to increase the supply of organs for transplantation. Because the number of organs available is presently determined largely by the number of cadaver donors, and because the need for organs has grown and continues to grow at an exponential pace with thousands wanting a kidney, heart, liver, etc. It has become apparent that moral, ethical and policy issues related to organ procurement are extremely visible among the many issues raised by organ transplantation today.

Historical Perspectives

The earliest days of transplantation involving human subjects were characterized by the inability of transplant surgeons to overcome the problems of organ rejection. Many approaches to the problem were tried, including various drugs and even massive exposure to total body irradiation, but none proved effective. Many physicians, knowing that little could be done about rejection, felt that it was morally objectionable to offer kidney transplants to patients.² Others within and outside medicine worried about the advisability of developing transplantation as the intervention of choice for kidney failure. Some favored putting social resources in to the development of artificial kidneys. Still others argued for prevention or for the use of public monies for other purposes (dialysis) for which established therapies already existed.³ Although these concepts were discussed and written about twenty and thirty years ago, the issues are still with us today.

During this early period, U.S. courts indicated that it was permissible for a competent adult to decide to give a kidney to a family member. The possibility of providing a life saving “gift” to a family member seemed to outweigh the risks to personal health that were involved in the donation of a kidney. In a landmark case, *Strunk v. Strunk*, the Kentucky Supreme Court ruled in favor of a brother with kidney failure in a case brought by the state on behalf of his mentally incompetent younger brother. This allowed a transplant which saved the sick brother’s life and did not harm the donor. This case has been cited with great frequency in nearly all fifty states, and indeed appears to meet all the legitimacy tests: rules, justification, and consent.⁴ Also, during this era, surgeons were almost entirely dependent upon live donations in order to attempt kidney transplants. One of the major concerns of courts and government was to

assure that the interests and welfare of prospective donors were adequately considered by those involved in or seeking transplants. Even though the chances of the operation's succeeding were small, during this period, the courts were of the view that a decision to help a family member ought to be respected as long as that decision was based upon an informed, voluntary choice on the part of the donor.

Courts of this era (the late 1960s through the late 1970s), were particularly concerned about the voluntary nature of decisions to donate. This was a result of three factors. First, there were serious if small risks associated with the surgery to remove a kidney. Second, in some cases children or adults afflicted with certain physical or mental impairments that might adversely limit their decision-making capacities were asked to consider donation. Third, those making donations seemed particularly vulnerable to coercion in that the people who needed the organs were biological relatives. In another landmark case, *McFall v. Shimp*, the legitimacy of autonomy and consent was upheld. In the summer of 1978, McFall developed a rare and terminal blood disease, which as it turned out would require a bone marrow transplant to save his life. An exhaustive search eliminated a large number of family members who had *volunteered*, yet to no avail. Finally near death, a distant cousin (Shimp) agreed to be tested. He was a perfect match. However, his wife objected and he in turn refused to go through with the painful but essentially low risk procedure. McFall's family sued in the Pennsylvania courts, where in a series of remarkably fast decisions, appeals, reversals, more and more appeals, the State Court of Appeals finally ruled that Shimp could not be compelled to donate as it would be a violation of his rights of self determination and autonomy. McFall died three

weeks after this ruling, prior to being heard in the Pennsylvania Supreme Court. Here the rules of law were clearly present and consent was absolutely upheld.⁵

Transplant Law Legitimacy

As stated earlier, tens of thousands of individuals are waiting for properly matched organs for transplantation. At the same time, thousands are dying while waiting. In such an environment, moral and ethical issues related to doing the right thing often are in pragmatic conflict with legislation and regulations. This is where the concept of legal legitimacy becomes crucial to the process. Are the laws and regulations actually legitimate when to a great measure (while beneficially coordinating screening and waiting lists), they mostly perpetuate the scarcity by prohibiting alternative proposals which could alleviate the shortages and thus the sufferings and certain death of those with end stage organ failure?

The concept of legitimacy, is based on three underlying precepts. First, legitimacy which (can) give authority to power, emanates from *rules*. Rules in a democracy can be verbal (unwritten) or formalized as laws, codes, statutes etc. Nevertheless, they tend to be precise and enforceable. When adhered to, society is respecting the power/authority vested in the rules. When authority is forced or acquired in contravention of the rules, that authority is illegitimate. Second, just having authority is insufficient for a law with possession of power to be legitimate. *Legitimacy requires common beliefs in the validity of laws* that are shared by both the dominant and the subordinate - as in those who enforce/uphold laws and those who obey them. Third, legitimacy requires an *expressed consent* of those who are subordinate to the laws or to

those who hold power. Without consent, there can be no legitimacy. While some may argue that the three precepts may in some societies exist in different forms or may not be as “absolute” as stated briefly above, legitimacy would be eroded if laws were not absolutely so grounded.

Given the circumstances that have evolved in the field of transplantation, where the existing laws are mostly grounded in altruistic morality, the question must be asked – are transplant laws really legitimate or are they lacking one or more of the precepts of legitimacy? It is not surprising, therefore, that the legal system during this era based solid organ donation on the individual’s autonomous choice. The courts believed and insisted that the welfare of those confronted with the option of donating a kidney could best be protected by demanding that decisions be made in an informed, uncoerced manner by those competent to do so. Autonomy and volunteerism became the ethical and moral linchpins of organ procurement and have remained so.

Legislative and Regulatory Background

Legal systems are different among countries. Some have systems based on judge-made law, reflecting a region’s customs and prioritization of values. This may be supplemented, consolidated or amended by politically-inspired legislation. Those conditions exist in the United States today. Often those systems are described as common law systems. In contrast, others have defined all prevailing rights and duties in a single code, legislated at the highest level of authority, so that a presumed right or duty must be derived from language in the code. Judges interpret what the code means, but are not themselves an original source of the law. These systems are often described as

civil law systems. Further, systems of religious law also apply in many countries. These are based on authoritative interpretations of sacred texts. In religious law systems, sacred texts are usually interpreted to prevail over other expressions of law in case of conflict.

Not every country has legislation specifically addressing the taking of organs or tissues from living persons, from persons after death, or from either. Issues at death, respect for and disposal of dead bodies, and preservation of the integrity of the bodies of the living are, however, almost invariably of spiritual and religious concern.

Few if any countries have legislation that deals exhaustively or comprehensively with organ or tissue acquisition from bodies of living or deceased persons and transplantation into bodies of recipients. Although almost every country has laws regarding organ transplantation, they are not normally exhaustive or comprehensive. Indeed, the legislation in itself will not usually tell medical, ethical, and legal practitioners all that they need to know about the legal environment in which practitioners are acting or about to act. Usually, practitioners within the field of transplantation find little more than generalized direction, and those individuals have to find answers to deep questions not so much from the specific language of the law, but often by previous interpretation and/or precedents.

In the United States, issues related to laws about transplantation have evolved into a formalized context only within the last thirty years. Legal issues relating to transplantation had been incorporated into several annotated forms of policy, all of which are a subset to the broader national health policy concerns. Many of these specific issues will be developed and expanded upon in a following chapter. The development of organ transplantation policy has been driven by a philosophical or ideological perspective that

is grounded in autonomy and fundamentally different from the utilitarian perspective that has driven other facets of health policy in the last two decades.

But at the most basic level, organ transplantation policy deals with the problem of coping with the costs of catastrophic disease. For years, there has been a debate in health policy circles about the best way to conceptualize the very special problems posed by catastrophic disease.⁶ Should the nature and effect of an illness – e.g., whether it is life threatening – guide our thinking? Or should the financial consequences of an illness – whether it be an acute life threatening episode, or a long-term chronic problem be determinate?

Although far from comprehensive, Congress did enact the Medicare Catastrophic Coverage Act of 1988 which reflects adherence to the financial consequences definition. More on this subject will also be covered in a subsequent chapter.

Transplantation law, like most others in the United States, has grown incrementally. However, unlike many laws, the rapid advances in medical and pharmacological technology have forced many incremental adjustments to the thirty year old body of transplantation law. In the U.S., transplant law has grown by analogy, that is, by accommodating to new questions by using concepts already articulated and accepted as law, for example, “object of personal property.” The Uniform Anatomical Gift Act (UAGA), first codified in 1968, originated as an analogous compilation of judicial decisions, statutes, customs, or practices developed in all fifty states. In the U.S., many “uniform” ideas and/or laws are a compilation of state customs, that are consolidated at some point into a “uniform” context. Once consolidate, they are sent to the states for ratification; a process that could take years. It is analogous to the constitutional

amendment process. In 1968 UAGA (which was not ratified by all 50 states until 1973), had a harmonizing effect among the competing interests, who in the first decade of transplantation had often come up against the pure legality of transplantation. The UAGA established that the body and its parts were property. The owner of that property, therefore, had the right to make a gift of any or all of those parts. Previously there had been a number of competing interests regarding the physical disposition of the potential donor's body, as well as with any legal questions which covered a large range of property and personal rights.

The principal competing interests regarding the physical disposition are:

1. The wishes of the deceased during his lifetime concerning the disposition of his body.
2. The desires of the surviving spouse or next of kin.
3. The interests of the state in determining by autopsy, the cause of death in cases involving crime or violence.
4. The need of autopsy to determine the cause of death when private legal rights are dependent on such cause.
5. The need of society for bodies, tissues and organs for medical education, research, therapy and transplantation.

Prior to UAGA, the principal legal questions were:

1. Who may during his lifetime make a legally effective gift of his body or a part thereof?
2. What is the right of the next of kin, either to set aside the decedent's expressed wishes, for themselves to make the anatomical gifts from the dead body?

3. Who may legally become donors of anatomical gifts?
4. For what purposes may such gifts be made?
5. How may gifts be made, can it be done by will, by writing, by a card carried on the person, or by telegraphic or recorded telephonic communication?

UAGA in harmonizing the competing interests and answering the legal questions, stated that donation was a legal gift. It was the voluntary act of an individual in writing, before two witnesses, giving some or all of one's body at death for transplantation, therapy, education, or research. Delivery of the document of gift was not required, nor was it necessary to name a donee.

Other sections of the 1968 UAGA specified the manner of making the gift, amending or revoking the gift, the rights and duties at death, and the immunity from civil or criminal liability of persons who acted in good faith in accord with the provisions of the act. The medical profession soon considered the UAGA the Holy Grail of organ procurement.

The UAGA is still on the books. For its time, it served to alleviate medical, ethical, and legal problems that had arisen during the first decade of organ transplantation. In the late 1960s, issues over contraception, abortion, sterilization, health care allocation/availability, and transplantation were just beginning to surface. Now priorities and viewpoints have changed, such that advances in technology issues and greater legal recognition of patient autonomy are frequently aired in the press and even on television. It is useful to look at UAGA in terms of Congressional intent and content. The intent of Congress was to deal legally with several problems that piece-meal legislation enacted by the states did not solve. For example, an individual who executes a

donor statement in one state, then moves to another, and dies in a state with different laws; the rights of surviving spouses and/or family in the absence of the donor's explicit instructions; the absence of clear orders of priority among survivors to carry out the decedent's expressed intention; and the protection of physicians from civil or criminal liability for organ removal. These and a host of other thorny issues had sprung up during the 1960s since the first successful transplants. Most of the state legislatures had created such a hodgepodge of often conflicting laws, that many of the participants did not know what the controlling authority really was. Hence, judicial law-making in the field of transplantation had developed throughout the 1960s. Unfortunately, while gathering all of their then-known categories of problems in one bundle, Congress to a large extent left cohesive enforcement vague and ambiguous. Therefore, we now have some *rules* that for the first time were formalized; however, the *justification* problem remained, for most of the states had laws that were almost universally grounded in altruistic mores in which not all participants had a common or even majority belief. Thus validity and acceptance of authority became an immediate and continuing issue. Without common beliefs in the justification process, for most practical purposes, judicial law-making continued. *Consent* occurred because Americans by and large accept judicial rulings at least when the Supreme Court finally rules. Aggregating over the passage of time, UAGA is not truly legitimate.

UAGA was not a failure, it just did not live up to the 1968 intent - on the other hand, how could it? Near the end of the 1970s decade, medical and surgical technology began rocketing forward, forcing reconsideration of many if not most of the altruistic ethics that had guided and constrained the development of transplantation law so far.

UAGA did establish several regulations/procedures that survive today, including two concepts relating to death. Only the patient's attending physician can determine and pronounce death and that physician cannot be part of the harvesting or transplantation team, thus avoiding conflicts of interest. Further, other physicians also are prohibited from participating on both harvesting and transplantation teams, thus avoiding conflicts of interest. While still in effect, the definition of death has undergone transformation – it is no longer cessation of heartbeat and respiration (as in 1968), but the determination of “brain death” that is now accepted. Brain death includes the cessation of heartbeat and respiration, but also further includes the cessation of all functions of the total brain – no valid electro-encephalographic impulses.

The late 1970s and early '80s saw a medical/pharmacological breakthrough that changed the science, the ethics, and the law in one astounding development – the implementation of the miracle drug cyclosporine. Cyclosporine had and continues to have the ability to fight off rejection. This meant, quite simply, that transplantation was not tied to related living donors, in that for the first time well-matched cadavers could be used with a greatly increased probability of success. Throughout the 1980s, demand for transplantation began to grow exponentially. Matching the supply of organs with the demand had always yielded a shortage. However, now (by the mid 1980s) hearts, lungs, livers, the stomach, and pancreas were either being experimented upon or were (in the case of livers) becoming fairly commonplace. With cyclosporine indeed becoming a miracle drug, and saving thousands of lives by the mid-eighties, new ethical and legal problems began to arise.

In 1984 the National Organ Transplant Act (NOTA) was enacted establishing rules for obtaining organs. Although not addressing resource allocation problems, NOTA did establish legitimacy on the donor's side of the equation. It created rules that specified how and in which circumstances organs could be legally secured from living and cadaver donors. It made illegal some forms of procurement, such as sales or other types of financial compensation. It created more of a level playing field (although not perfectly level) it has not proved to be terribly efficient. But in the rising national optimism over the opportunities for living a restored healthy life, most people accepted NOTA's validity.

By 1984 we had formalized *rules* that if not universally right, most transplant community participants felt that it represented most of their commonly held beliefs. so we also had *justification*. Finally, although the constraints keep the supply well under the ever increasing demand - mostly for ethical reasons, as patients who are desperate would likely pay for their organs - the general population reacting in outrage to that prospect has *consented* to the laws covering organ procurement.

Summarizing briefly, UAGA and NOTA still rule transplantation today (there have been periodic amendments). UAGA was not very efficient and not legitimate, while NOTA is not very efficient but was at least legitimate by the decade of the 1980s standards.

Hypothesis

The advent and implementation of the immuno-suppressive drug cyclosporine, in the late 70s/early 1980s, significantly changed the patterns of survivability of organs for

transplant. With the earlier, near-absolute necessity of requiring a close relative to donate a kidney as a living donor, the newly available use of cadaveric organs opened the possibilities for transplants of a number of different solid organs. While cadaveric organs now represent approximately three of every four of the kidneys being transplanted today, for other solid organs (hearts, lungs, whole livers, pancreas, intestines, bone, etc.), cadaveric resources represent 100% of the scarce resources for transplant. A small portion of the number of liver transplants, for specific conditions, are carried out via the removal of a small “lobe” section from the living donor. Nevertheless, nearly all non-kidney transplants are sourced from cadaveric donors.

Given the current and potential future demand for cadaver organs, there may be no way to avoid the problem of rationing for most forms of transplantation. Therefore, it is both morally and ethically sensible to examine current public policies with respect to the procurement of organs for transplantation to determine whether legal or regulatory changes might be effected that would help maximize the supply of tissues/organs available to those in need.

Although many of those involved in organ procurement are making some efforts to increase the supply of organs from cadaveric donors, there are a number of factors that severely inhibit the ability of the present system to take advantage of the supply (potentially) available from cadavers. Both economic and legal obstacles impede the present system of voluntary donation. Further, there is a real probability that unless something is done to improve the efficacy/efficiency of the volunteer system, the free market responding to the overwhelming demand will present a potential solution which

might include the possible establishment of a for-profit or financial incentive solution in order to meet the overwhelming scarcity dilemma.

There would appear to be a number of obstacles that work against the efficacy of the current volunteerism policy in obtaining cadaver organs. First, many people find that the subject of death and organ donation upsetting and distasteful. Although surveys show that the public is willing to support organ donation, it is difficult to transform willingness into concrete realization on a donor card or driver's license.⁷

Second, most physicians and nurses do not want to inquire about organ donation. The highly emotional circumstances under which such requests are made make it uncomfortable for both families and medical personnel to communicate about the subject of donation.

The research problem of this thesis is wrapped around several conflicting variables. The variables themselves – medical, ethical and legal – are complex in their own right, such that when stirred into the cauldron of a relatively young medical and scientific specialty, it is difficult to generate a formula that can solve the dilemma of the altruistic donor supply and still be acceptable to society. It is my hypothesis that a successful solution to the dilemma can be approached and implemented. In subsequent chapters, I will lay the groundwork concerning the economic, ethical, and policy issues that can combine to form a positive solution to the problem.

In the following chapters, I will lay the groundwork for analyzing how altruism has failed to motivate enough potential donors to provide organs to satisfy the desperate needs of those with end-stage organ failure. In Chapter Two, I will empirically examine the supply problem. The first place to look is how society views and deals with

healthcare issues on a macroallocative basis. This requires an examination of costs and benefits, as well as, factors pertaining to the expenditures of scarce societal resources at what are (in the field of medicine) often diminishing returns. The economics of organ transplantation essentially deal with a priceless form of scarcity – organs are extremely limited in their availability and simultaneously the most perishable goods on the planet – there is no inventory. Chapter Two will discuss these issues and conclude with a listing and brief description of a number of practical “market” type solutions, as well as, a preview of several non-financial alternatives. A more detailed examination of alternatives, per se, will be conducted in Chapter Four.

In Chapter Three, I make the claim that the organ shortage failure is not so much the fault of altruism, but society’s failure to recognize the problem as a duty or obligation to assist their fellows when in need. Perhaps that comes close to altruism or volunteerism not working, however, the argument will be made via moral theory and practical examples that if we collectively recognized our obligations, the organ supply problem would not be a practical one. Chapter Three also critically assesses the minority donation issues in American society. Minorities, who typically represent a large proportion of those needing transplants, just as typically, refuse or are reluctant to donate. This chapter examines the moral, cultural, psychological, religious, and racial factors that contribute to their under-participation as donors.

Chapter Four goes straight to the point of incentives (financial and non-financial), offering market-type solutions to the donor supply problem. Incentives have been looked at and considered previously, but, they are currently not permitted in the U.S. Any ultimate adoption of an incentive would have to surmount a high ethical and legal

threshold prior to any implementation. I will examine several proposals that have been discussed in the literature and offer current reasons for their reasonableness and ethical validity. Some will fall short of the threshold. I will also offer a compromise plan that could meet pragmatic as well as ethical criteria.

In Chapter Five, I summarize the analysis undertaken in the previous sections, and specify why, I think certain of my intermediate conclusions will work, if given a chance.

Endnotes

¹ United Network for Organ Sharing press release April 18, 1997, "U.S. organ transplants in 1996 show little increase, organ shortage continues" UNOS is the federally chartered organization that serves as the clearinghouse for all transplant waiting lists, and medical, clinical, policy, and ethical issues.

² Moore, F. . "Medical Responsibility For the Prolongation of Life," Journal of the American Medical Association vol. 206; 1968, pp. 384-386.

³ Fox, Renee C., and Swazey, Judith P., *The Courage To Fail*, 2nd Edition (University of Chicago Press, Chicago, IL), 1978

⁴ Cited in Scott, Russell, *The Body As Property*, Viking Press, New York, 1991, *Strunk v. Strunk* citation, pp. 105-110.

⁵ Ibid Scott, *McFall v. Shimp* citation, pp. 127-138.

⁶ Congressional Record, June 17, 1988, pp. 58095-96; In an interesting statement on this issue, Senator Quayle (soon to be vice-president) inserted a speech concerning a proposed grant program for immuno-suppressive drugs. Quayle objected to the creation of a disease-specific program because he could not justify "singling out immuno-suppressive drugs when there are other expensive drugs needed by many individuals with life threatening illnesses."

⁷ The Gallup Organization. "Attitudes and Opinions of the American Public Towards Kidney Donations." Prepared for the National Kidney Foundation, Washington D.C., 1993.

CHAPTER TWO

THE SUPPLY PROBLEM

Health Care Scarcity

There appears to be a fairly broad consensus among health economists that in most instances, Adam Smith's Invisible Hand of the market works very badly to allocate resources for health care. Health economics, faced with market failure, appears to be only involved as a sub-field of research and study, aimed at creating public policy tools which can achieve some form of optimum distribution of the scarce resource of health care.

The concept of scarcity tells us that in general there will never be enough resources to provide every health-related service to every person who might want or need that service. Having MRI machines on every corner available for anyone who needed that service might be desirable and occasionally even handy, but at this extreme no society could afford a health care system where resources were essentially un-rationed.

Many citizens would argue that at a given level of investment in health care, other needs (housing, education, leisure, consumption of other goods, etc.) have an equal or greater priority. Therefore, it is not really a great surprise that when weighing the cost and benefits of health interventions, citizens, providers and others in the medical sector

may come to the conclusion that a particular marginal benefit is not worth the cost – which, of course, is also a value judgement with ethical impacts. By providing information about the relative cost of achieving health benefits (an organ transplant versus years of expensive and invasive dialysis treatments), health economics is able to provide data and focused analysis, but ultimately the decision that one intervention is valuable and another is not, cannot be made solely on economic grounds.

For several reasons it is difficult to be precise about transplant health care costs. First, an individual patient's medical course is complicated and unpredictable; it depends on the patient's initial condition, and the skill of the transplant team and support staff. Second, reported cost figures are generally incomplete. Often they include surgeon's fees, organ procurement cost, capital cost, and the cost of screening patients not accepted as candidates. These costs may be omitted because they are not available or more typically because the focus of those compiling them is only on the budget of a particular institution or program (e.g., the transplant center or Medicare), as opposed to complete medical care costs. Finally, the figures that are available, especially those for hospital care, generally reflect arbitrary accounting standards rather than true economic costs. Nevertheless, given the emergence of economics as the policy science over the past several decades, health economists are under considerable pressure to create technical tools, which disguise political responsibility, and thus evade the ethical responsibility for health care rationing. This occurs when empirical analyses are used to obfuscate political and ethical responsibility.

Complicating health economists' approach to real policy problems is the ethical principle underlining health economics – utilitarianism. Utilitarians assume that health

care systems exist to maximize total health output, that is, to provide the greatest health for the greatest number of people. For the individual, however, utility can be defined as a function of one's preferences for health state satisfaction, well-being, and/or life expectancy.

To evaluate health-related quality of life, one must consider all of the different ways that illness and its treatment affect outcomes. Health concerns can be reduced to two categories: life duration and quality of life. Individuals are concerned about illness, disability, and effects of treatment because they can affect life expectancy and quality of life. The assessment of a particular transplant candidate should consider the following basic questions. Does the illness or its treatment make life last a shorter duration of time? Does the condition or its treatment make life less desirable and if so, how much less desirable? What are the duration effects: how much life is lost or how long is the period of undesirable health effects? Determining how illness or treatment affects desirability of life is a matter of preference or utility. Such evaluations require that health states be compared to one another.

The balance of Chapter Two looks at how health economics considers health care generally and organ transplants in greater specific detail. Economics as a policy science addressing health care issues, takes more of a positive empirical viewpoint than a normative subjective approach. That said, Chapter Two will deal more in the arena of a cost/benefit analysis approach from the macro or top-down viewpoint. That is, when economics studies healthcare issues, it is examining the global perspective of diseases, cures, research and development, and budgets etc. Accordingly, in Chapter Two I've discussed costs/benefit approaches as well as a unique measurement device created

especially for health economics. That is the concept of QALYs, a measurement protocol for converting total resources expended with the number of qualitative life years per dollar of expenditure.

In the second part of Chapter Two, I'll examine a number of alternative proposals to the current altruistic volunteer system for donating organs. Several will be introduced, and a few incentive alternatives will be graduated on to Chapter Four, for a more intense analysis. The purpose of this chapter is to provide an overview of an empirical reality check with absolutely practical applications, and compare it to the more normative discussion which follows in Chapter Three and deals with ethical and moral questions regarding donation.

Monetary Evaluation of Length and Quality of Life

The idea of assigning to human life a value measured in monetary units may meet with widespread disapproval. The objections raised are two different kinds. A principal attitude is that any attempt in trying to compare life and money is morally reprehensible. On a more pragmatic level, such a comparison would be accepted, but any other result than that of an infinite value of life would be called into question.

The weighing of life and freedom from bodily harm on one side and money on the other is considered profane by moral rigorists, whether inspired by Christian belief, the oath of Hippocrates, or a humanistic philosophy of life. Some would say that economic approaches to these evaluations are put on a par with the euthanasia programs of the Third Reich. Does such a valuation not imply that it is acceptable to kill those whose "value" does not cover the cost of living, such as food and medical treatment?

First, this argument fails to take into consideration the “morally relevant difference” between actively intervening and letting nature run its course. that is. between the act of killing incurables and making do without life-support devices. This distinction plays a major role in the discussion on “dying and dignity.” Of course it can be said that refusing to give a person essential food for free is morally equivalent to killing that person, however, the greater the efforts required to save a human life, the less valid this argument is. For example, assume that rescuing a group of miners buried in a pit would cost thousands of billions of dollars, causing the rest of the country to survive in misery. Can a refusal to rescue the miners then be treated as equivalent to killing them?

Second, we have to keep in mind that most public decisions do not affect “identified” but “statistical lives.” If life-threatening dangers of personally identified individuals are involved, politicians usually are expected to do everything possible to save the lives of the victims, probably because the public is aware that even a maximum effort would only consume a very small percentage of the Gross Domestic Product. For example, assume it would take ten million dollars for saving each miner buried in the pit. This does not imply that the public would consent to the government spending the same amount on averting a risk of being buried of one in a thousand, for one thousand miners. “Statistical” lives tend to cause less emotion than “identified” lives.

Realizing that the issue is not so much weighing life against money, but rather length of the life span against money could help to de-emotionalize the subject. When thinking of medical treatment or public security measures, we usually think of lives actually saved. In reality, however, life is prolonged only (often) with some heroic performances of high-tech medicine resulting in a gain of a few months, for in the long

run everybody has to die. So actually the measurement of an extended life span against a better quality of life is most germane, since more money purchased resources means permitting a higher quality of life. Therefore, the moral argument of an inadmissible valuation of life in terms of money is not as convincing as it appears at first sight.¹

However, the main justification for elaborating and applying an economic approach is based on the simple observation that political decisions involving such valuations have to be made regularly. The mere fact that some action is undertaken (or refrained from) implicitly means that a weighing of prolonged statistical lives against money has occurred. The economic calculus facilitates awareness of this fact, helping to make policies more consistent.

Conversely, doing without an economic valuation of “life” entails risks of its own. A country may introduce a measure (such as introducing new medical technology) resulting in costs of one million dollars for avoiding premature deaths, yet fail to take into account alternative measures (for example public road works) that could do the same for only fifty thousand dollars. Society as a whole will be deprived of a longer life expectation.

For decades now, parliaments and legislatures in many countries have usually approved public projects only after a thorough evaluation of all of their costs and benefits. But when it comes to human lives, there has been a lack of approved procedure to evaluate them in monetary units. As a substitute, it has become customary to mention such costs and benefits known as “intangibles,” without, however, considering them as net benefits in the actual evaluation process. Consequently, projects such as transplantation with high risk factors in terms of human lives are easily approved, while

those with a lower risk tend to be rejected. Ironically, those who are against a valuation of life in monetary units thus obtain the exact opposite of what they intend.

Public policies in a democracy should not only be consistent in the above-mentioned sense, but also capable of reflecting the preferences of the citizens involved. Since permitting affected citizens to express their preferences is a prerequisite of democracy, the moral condemnation of weighing money against life is at odds with the democratic principle. By determining the preferences of citizens regarding life span and quality of life, economic analysis thus also serves to enhance the process of democratic decision making. These considerations make clear that expressing the value of human life in monetary terms is not the same as estimating its market or financial value. Rather it amounts to describing the preferences of the individual concerned or of society at large among mutually exclusive alternatives.

The QALY Concept

Within the past few years interest has been growing in using quality of life data to help evaluate the benefits of health care programs. In cost-effective analysis, the benefits of medical care can be expressed in terms of “well years.” Many have chosen to describe outcomes in quality-adjusted life years (QALYs). The term “QALY” has become generalized and is now in widespread use. QALYs integrate the value of quality-of-life with a value of length of life into a single index number, which may then be used as a currency in which the benefits of health care interventions can be expressed. In the simplest case, in which a person remains in the same health state for a number of years, QALYs (assuming no discounting) are calculated according to the following formula:

$$QALY = H \times Y$$

Where H is the relative weight attached to a particular health state and Y is the number of years spent in that health state.² Although QALYs can be used to measure the benefit derived from different therapies by an individual patient, for the purposes of the goals of this paper, they are discussed in the context of their use in the allocation of scarce health resources among different potential transplant patients.

Nord (1994) suggests that although the number of QALYs gained from different interventions only represent the (unweighted) sum of gains and individual utility, they have been used to represent social value, whereby they are seen as a measure of society's preferences over different health care outcomes.³ Nord also cites a paper by Weinstein and Stason (1977) as evidence that such evaluations have been used in this wider sense: "alternative programs for services are then ranked from the lowest value to the highest, and selected from the top until available resources are exhausted" (Nord, et. al., 1993).⁴

According to Weinstein and Stason, this ranking of alternatives takes place according to the aggregate unweighted number of QALYs obtained, i.e., those that yield more QALYs are ranked higher than those that yield fewer. This defines the objectives of the health care system in terms of the maximization of health gain, and is consistent with defining need in terms of capacity to benefit. In other words, an allocation of resources that maximizes the number of QALYs gained is defined as an efficient one. Of course, it is possible that people would want decision-makers when choosing between alternatives, and be also concerned with how those QALYs are distributed, and again different definitions of and approaches toward the need are relevant. For example, if need is defined in terms of ill health – those in the worst health states are those most in

need of treatment – then pretreatment health status becomes the most important consideration in determining priorities. Alternatively, if need is defined in terms of final health status, then post-treatment status is more important.

Despite the differences in approach, some important assumptions are similar. All approaches set one completely healthy year of life at an index of 1. Years of life at less than optimal health are scored at less than 1. The basic assumption is that 2 years scored as 0.5 add up to the equivalent of 1 year of complete wellness. Similarly, 4 years scored as 0.25 are equivalent to 1 completely well year of life. A treatment that boosts a patient's health from 0.5 to 0.75 produces the equivalent of 0.25 QALYs. If applied to four individuals and the duration of the treatment effect is one year, the effect of the treatment would be equivalent to one completely well year of life. Economists disagree not over the QALY concept, but rather over how the weights for cases between 0 and 1 are obtained.

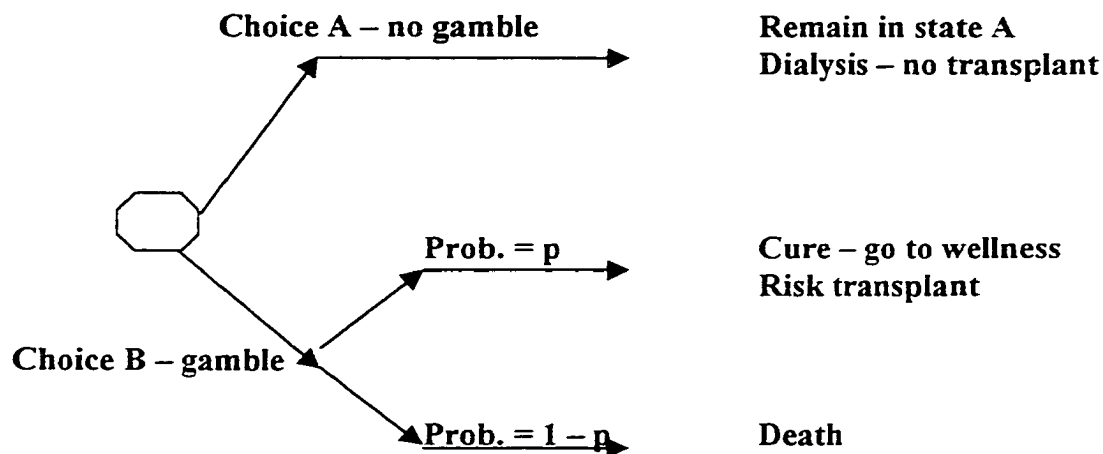
Different techniques have been used to assess utilities for health states. Some analysts do not measure utilities directly. Instead, they evaluate health outcome by simply assigning a reasonable utility.⁵ However, most current approaches have respondents assign weights to different health states on a scale ranging from 0 (for dead) to 1 (for wellness). The most common techniques include category rating scales, magnitude estimations, the standard gamble, the time trade-off, and the person trade-off.

- **Rating Scales** – rating scales provide simple techniques for assigning numerical values to objects. The category scale is a method in which subjects are requested to assign a number to each case selected from a set of numbered categories representing equal intervals. This method, exemplified by the familiar ten-point rating scale, is

efficient, easy to use, and applicable in a large number of situations. Typically, the subject reads the description of a particular case, and rates it on a scale ranging from 0 for dead to 10 for an optimum health state function.

- **Magnitude Estimation** – a specific case is selected as a standard and assigned a particular number. Then other cases are rated in relation to the standard. For example, if the standard is assigned the number 10, a case regarded as half as desirable as the standard, is given the number 5. If it is regarded as twice as desirable, it is given the number 20. Ratings are then aggregated using a geometric mean.
- **The Standard Gamble** – a method which explicitly considers decisions and choices made under uncertainty. The standard gamble offers the choice between two alternatives: living in health state A with certainty or taking a gamble on treatment for which the outcome is uncertain. The respondent is told that treatment will lead to perfect health with the probability of p or immediate death with the probability of $1-p$ (the choice health state B). The health state described in A is intermediate between wellness and death (analogous to end stage kidney failure with certain treatment available via dialysis). The probability (p) is varied until the subject is indifferent between choices A and B. An attractive feature (for economists) of the standard gamble is that it is based on axioms of microeconomic utility theory.

Standard Gamble



- **Time Trade-off** – an alternative to the standard gamble yet consistent with the concepts of opportunity and choices, uses a trade-off in time. Here, the subject is offered a choice of living for a defined amount of time in perfect health or a variable amount of time in an alternative state that is less desirable. Presumably, all subjects would choose a year of wellness versus a year with some health problems. However, by reducing the time of wellness and leaving the time in the sub-optimal health state fixed (such as one year), an indifference time can be determined. For example, a patient may rate living in a wheel chair for two years as equivalent to perfect wellness for one year. The Time Trade-off (TTO) is theoretically appealing because it asks subjects to explicitly state their preferences in terms of quality life year equivalence.
- **Person Trade-off** – allows comparisons of the numbers of people helped in different health states. Patients might be asked how many persons in state B must be helped to provide a benefit equivalent to helping one person in health state A. From a policy perspective, the Person Trade-off (PTO) directly seeks information similar to that required as a basis for policy decisions.

Several articles reviewed by Nord (1993), have compared utilities or health states as captured by different methods.⁶ Most health care economists examining the above methods, have proposed the standard gamble or time trade-off methods as having more validity criteria than various rating scale methods or the magnitude estimation formats. However, Nord suggests that we move away from methods based on the assessment of individual utility, such as the Standard Gamble (SG) or the Time Trade-off (TTO), towards methods based on the assessment of social preferences, such as the Person Trade-off (PTO). Using this approach, Nord posits that respondents indicate the number of people in one health state, as mentioned above, which they would need to be able to treat (with a specified outcome) to make them indifferent to treating a given number in another health state (again with a specified outcome). Valuations from this technique can be seen as representing the trade-off's that people are prepared to make between gains in (length and) quality of life, and number of persons treated.

There are some problems with Nord's proposal. Responses to PTO questions contain relative weights a respondent attaches to at least four subsets: (1) the severity of the pre-intervention health state; (2) the severity of the post-intervention health state; (3) the health gain as a result of intervening; and (4) the number of persons treated. It would be impossible from answers to PTO questions to determine/distinguish what are the relative weights attached to each of these considerations. While all four are likely to be important, different weights attached to each may have quite different implications for resource allocation decisions.

Paul Dolan (1997) has suggested an alternative approach. Using a particular class of health-related social welfare functions (HRSWF),⁷ he allows efficiency and equity to

be considered independently. Dolan's central theme is that it is possible to characterize social welfare by a vector of individual welfares. Economists have typically argued that individuals are the best judges of their own well-being and that social welfare depends only on the welfare of persons in society. For Dolan, it was necessary to assume that it is possible to make interpersonal comparisons of utility. For example, while it is known that different HRSWFs have different types or comparability, maximizing the sum of individual utilities requires that the differences in utilities can be compared.

The application of a utilitarian HRSWF to health care implies that HRSW is maximized when the total number of QALYs gained (subject to a budget constraint) is maximized. But the utilitarian approach is only one approach to deriving a HRSWF from individual utilities. Another might be to adopt a decision rule that gives greater weight to one individual's utility than to another's. For example, a "maximin" approach would require giving greatest weight to the treatment of the more seriously ill individual (as often happens in transplantation ethics).

Notwithstanding the concepts and issues brought to health care economics generally and transplant economics specifically, utility and social welfare are not the only analysis method components that measure efficiency and the effectiveness of health alternatives. When considering a comparison of costs and benefits in an overview of health economics, the use of marginal benefit analysis for health policy could be useful. By this analysis is meant the way in which economics conceptualizes questions of relative cost and benefits for different health interventions. In particular, it is the use of *average* marginal benefit in health policy, which has ethical dimensions not often considered when policy prescriptions for (e.g.) "outcome based funding" are advanced.

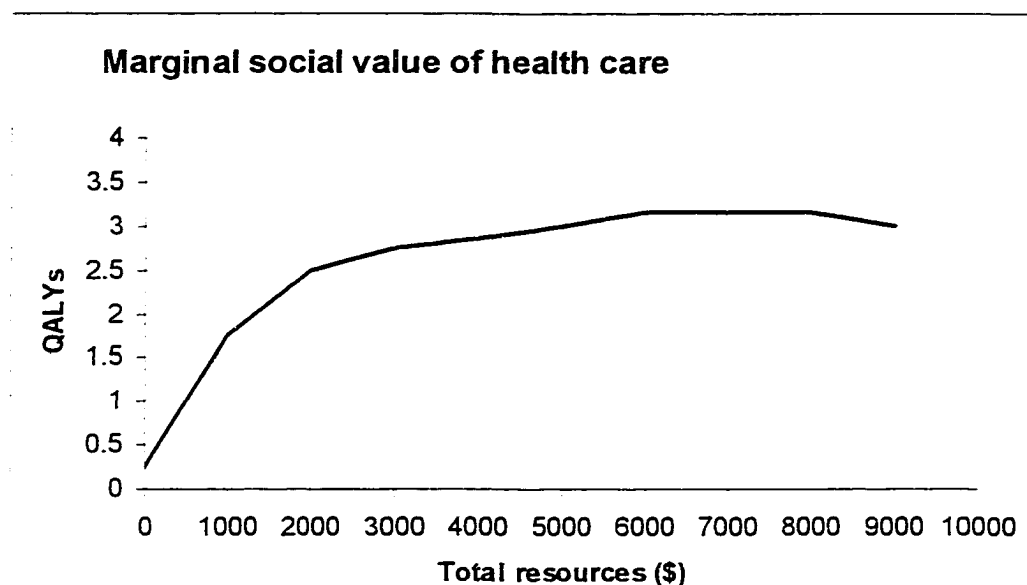


Figure 1 This figure is a graph of Marginal social value of health care

Marginal benefit, on the graph above, with quality adjusted life years (QALYS) – one of the tools designed to capture both quantity and quality gains in a single measure -- on the vertical axis and total resource dollars available on the horizontal, can be applied to a number of different levels of our health system. Indeed, diminishing marginal returns (benefits) is the essence of the argument about appropriate levels of decision making for health care, which leads to having ethical implications of various proposals relating to health care, e.g. transplants versus dialysis. The curve suggests that the first dollars spent on health care buy great improvements in patients' survival time and/or quality of life. The first \$1,000 dollars buys almost two QALYS, the second \$1,000 dollars almost an additional year, etc. In concert with diminishing returns, as the expenditures get higher the vertical lines get shorter as smaller and smaller increments of health gain result. When looking at an individual's treatment, the marginal curve leads to decision making that is relatively free of problems. As more dollars are spent at the

beginning of an individual's treatment process, higher gains and quality are the natural result. However, towards the end of an individual's hospital stay when he presumably is getting well, the last incremental blood tests or x-rays are yielding considerably less benefit per dollar spent. Health economists and medical professionals term this "flat of the curve medicine".⁸

Another application of the marginal benefits curve is to consider how much of any particular treatment should be provided – and thus, given scarcity, how many people will be treated. Predicting an individual's ability to benefit is, of course, not an exact science, and predictions based on medical/disease characteristics shared with other patients raise problems when considering average benefit as discussed above. In our society, it is not one central planner making decisions about how much treatment should be provided or to how many; but rather it is a function of a marketplace wherein a combination of patients, doctors, providers, hospitals and insurance plans are making those politically sensitive decisions. Therefore when using marginal benefit analysis to prioritize access to health care, there will be ethical implications. A third use of the curve is in setting of priorities among disease conditions or treatment protocols. For instance, in some managed care plans/HMOs certain procedures are placed either higher or lower on the curve. Thus prenatal care might be at position one while organ transplants conceivably could be in position four or five yielding less marginal benefit – not to the individual, of course, but to society's allocation of resources. The ethical problem with using the curve in this way is that no account is taken of the individual patient's potential to benefit.

Scarcity of Organs for Transplant

Continuing with the themes raised above, the scarcity of the supply of organs for transplant is the dominant factor driving both medical criteria and the many ethical considerations involved in recipient selection. Intuitively, everyone knows organ transplantation is a costly technology that benefits a relatively small number of people. Therefore, a relevant question to ask is how big a demand on societies' resources is at stake? In other words, what does a transplant cost and how many are needed? Medical need is something of a difficult issue to precisely define. In fact there is no hard and fast definition of medical necessity. Patients who now need transplants began with the onset of some medical condition for which transplantation becomes a "reasonable option", but this depends directly on the strictness of the medical criteria applied in each case. Decisions about appropriate medical criteria are always difficult value judgments and generally individualized in nature.

When considering scarce resources and need, restrictions like age of potential recipients is fairly universally applied in the United States. Patients may be considered either too old or too young to benefit from organ transplants. While medical criteria can be used to defend the use of age restrictions, applications of age discrimination laws and policies in the United States create something of a fine line if cutoff points are to be observed. If technology improved and age discrimination/age restrictions were removed, the scarcity issues currently affecting the organ transplantation universe would have dramatic positive demand side impacts.

As stated above in a discussion on health care and society in general, most believe that society has an obligation that some level of health care be available to everyone.

There is a great deal of evidence of this shared feeling of social responsibility in the numerous public and private programs that are devoted to increasing access to care. However, critics of many of those programs, especially in this decade, have become concerned about the extent of society's obligation. Again, as mentioned above, health care is important but so are other social and private goods. To provide everyone with all possible beneficial medical care would be very costly and would require that other important needs go unmet. It seems obvious that society's obligation cannot be unlimited. But if this is the case then how much care should a person expect to receive?

The President's Commission for the Study of Ethical Problems in Medicine, addressed these issues in a report (now dated but still contextually meaningful) entitled "*Securing Access to Health Care.*"⁹ The goal was to provide a consistent ethical framework for thinking about the allocation of scarce resources in health care. A central concept in the commission's final report was that our society is morally obligated to provide access to "an adequate level" of health care – but not an unlimited level.

In the ensuing years, when considering transplantation, medical professionals and providers as well as patients are often asked, is it part of an adequate level of care? Since there is no consensus on what an adequate level really is, society has been somewhat reluctant to face the issue squarely and decide definitively how to allocate organs as a scarce resource in an equitable manner. Health officials (across many spectra) who have for years promoted organ transplantation apparently have succeeded in getting most transplants categorized under the adequate level standard. This has essentially been accomplished by piggybacking on the End Stage Renal Disease Program (ESRD) which is basically paid for by Medicare. If dialysis which is a remedy, but not a cure for ESRD

is considered an adequate level, the Task Force on Organ Transplantation reasoned from the ESRD experience in its conclusion that organ transplants should be available to all without regard to ability to pay with the cost born by the federal government if necessary.¹⁰ The message has become somewhat muddled. As the ESRD program (dialysis) has proven to be very expensive, Congress has been unexpectedly firm in refusing to extend the same treatment to other transplants and other health conditions. While more than kidneys are now covered by Medicare, blanket coverage for any type of transplantation (under Medicare,) is far from reality. There is no real consensus, at least in the federal government, that organ transplantations are part of an adequate level.

A fair question at this point might be, what does the cost of the transplant have to do with finding and developing methodologies by which the supply of these scarce resources can be increased? The enormous dollar cost of transplants has always been part of the transplant community's dialogue among all of the players and indeed the public. As a point of interest at this junction, a significant part of the cost (in the United States at least) has been the level of cost associated with trained and experienced transplant surgeons and transplant team members. As a subset of this overall scarcity issue, the number within the United States of such professionals is quite limited, hence their ability to command high professional fees in the marketplace. From personal experience, having had discussions and conducted interviews with a number of transplant surgeons, a quickly obvious conclusion is that a somewhat disproportionate number of that fraternity are foreign born/trained. In a universal consensus their opinion is that the transplant cost structure in the United States is somewhat a function of the slowness with which transplantation technology developed and evolved from the experimental stages to

accepted medical practice. In contrast, surgeons from Canada, Britain, the European Continent, and Japan, have dealt with far less restrictive regulatory restrictions than still exist in the United States. That slow evolution has enabled many foreign-trained transplant surgeons to take advantage of market forces and thus command the lofty fees that we see in evidence today. Nonetheless, over the years a significant number of remedies, proposals, and incentives have been put forth in order to stimulate the general public into alleviating the chronic shortage by appealing to rational self interest.

A June 1993 white paper report of the UNOS ethics committee (payment sub-committee) addressed this issue directly:

The concept that financial incentives be offered as a potential solution to the on-going organ donor shortage has been previously considered and debated among experts in the fields of transplantation, ethics, law, and economics (1), the background for this proposal remains the ever-growing need for increased organ acquisition and the undeniable fact that the current system despite 30 years of experience based on altruistic donation has yet to meet this need. Historically, the current system of organ donation based on altruism evolved during the 1960s and 1970s when issues such as the definition of brain death, the use of donor cards, and public attitudes towards donation were only just evolving. Based on the Uniform Anatomical Gift Act and the National Organ Transplant Act of 1984, the buying and selling of organs has been specifically prohibited (2), in the late 1980's required request legislation was adopted but has yet to demonstrate a significant effect in the rate of organ donation.

An accompanying 1993 UNOS sub-committee report identifying potential financial incentive alternatives for increasing the national supply of donor organs has not exactly been "pocket-vetoed", but nevertheless, remains waiting for action. There is, however, wide-ranging public dissatisfaction with the current system inadvertently fostering an imbalance between the need for and supply of organs for transplantation. Consequently, that public dissatisfaction has fostered a great deal of independent thought and a

multitude of proposals to reform the system. Current proposals for alleviating scarcity tend to fall into the below-listed seven categories:

1. A reliance on the market mechanism (direct payment to donors or donor families)
2. Encouraged volunteerism through indirect payments (tax credits to donor families, in-kind reward payment of funeral expenses)
3. Encouraged volunteerism through preferred status (persons who declare a willingness to be organ donors would in exchange receive preferential status on the waiting list for organs themselves)
4. Altering professional behavior (“required request” legislation). This has indeed happened and is now law in all states wherein people admitted to hospitals are required to officially answer a request for organ donation should they succumb.
5. Increasing the organizational efficiency of organ recovery (consolidating organ procurement networks)
6. Change the basic in-hospital admission form from “explicit” to “presumed” consent
7. “Routine salvaging” of suitable organs after death (with or without a provision for patients “opting out”)

Following is a more detailed description and in some cases definition of the mostly market-based alternatives – all of which have been given at least some analytical investigation:

1. A reliance on the market mechanism (direct payment to donors or donor families)

A definition of terms is probably necessary prior to a discussion of the concept of financial incentives for organ donation. Financial incentives, or payments as discussed here do not mean additional money spent for public or professional

education or recognition and counseling of organ donor families. Because the concept of financial incentives fundamentally changes the process of organ procurement, it is argued that the term “donor” would no longer be applicable and would need to be replaced by a term such as “vendor”. The existing term “gift” under conditions of any financial considerations might be renamed “rewarded gift”, however this appears to be something of an oxymoron. Of significance is the distinction between “incentive” and “payment” since a system of financial incentives may be a viable option if, “incentives” do not amount to “purchases” (as interpreted by law), and “donors” are therefore not transformed into “vendors”.

For purposes of definition, financial incentives should be considered as any material gain or consideration obtained by those directly consenting to the process of organ procurement, whether it be the organ donor himself in advance of his death, the donor’s estate, or the donor’s family. As a substitute for direct payments, which has been ethically criticized, a form of “donor insurance” has been suggested whereby an individual would agree in advance to donation with payment to his beneficiaries or his estate taking place only after donation. This proposal would allow individuals to “opt in” to the donation process while still living and their families or estate get compensated at the time they actually become donors. For any financial incentive plan or proposal to actually take effect, federal and state laws would have to be changed which currently prohibit any such payment for anatomical parts.

2. Encouraged volunteerism through indirect payments (tax credits to donor families, in-kind reward payment of funeral expenses)

As a somewhat “softer” proposal, the idea of tax credits or prepaid and/or reimbursement for funeral expenses has also been suggested, although to the ethically pure, it amounts to the same thing as a straight financial incentive.

3. Encouraged volunteerism through preferred status (persons who declare a willingness to be organ donors would in exchange receive preferential status on the waiting list for organs themselves)

“Encouraged volunteerism”, which is a term that describes the current state of persuading potential donors to be altruistic, can be described as an “opting-in” system that requires the direct expressed consent of the donor and, almost always, the donor’s family. Therefore in this particular proposal, where payments do not change hands, a donor would still be classified as altruistic in that the potential donor in exchange for his gift, receives or has some greater status on a waiting list if he were ever to need a transplant himself - notwithstanding, of course, any medical criteria that would preclude him to be placed on the list in the first place.¹¹

4. Altering professional behavior (“required request” legislation). This has indeed happened and is now law in all states wherein people admitted to hospitals are required to officially answer a request for organ donation should they succumb.

“Required request” offers the opportunity for higher probabilities of organs being donated, by virtue of simply asking all admitted patients whether they would consent to making the gift should they expire during their stay. There are any number of analogies that would suggest that increasing the frequency of asking for the donation would ultimately lead to an increased number of patients responding in the affirmative. The reality, however, is that although “on the books” in all 50 states,

there is very little explanation, education, counseling or guidance. The result is that generally the question simply does not get asked.

5. Increasing the organizational efficiency of organ recovery (consolidating organ procurement networks)

Although organizational efficiency has steadily improved in the three decades since the first transplantations, and via UNOS there is a central clearinghouse, there are still probably far too many local and regional procurement networks operating within the United States. This increases redundancy and sets up undesirable and time-consuming competitive situations for the scarce and perishable donor organ. While regional geographic proximity through local transplant centers is extremely important, there are economies of scale that could be gained if more information regarding donor organ characteristics matching with recipient requirements were not as wide spread and diluted as currently exist.

6. Change the basic in-hospital admission form from “explicit” to “presumed” consent

“Presumed consent” public policies have been described in the literature, and have already been implemented in Belgium, Austria, Finland, France, Norway, Denmark, and Singapore. Their positive impact on organ supply has attracted significant attention in the U.S. The most celebrated and successful of these experiences has been Belgium where organ recovery has more than doubled following implementation of its policy of “presumed consent.” Objections to such recovery policies tend to be based on ethical arguments, which ignore efficiency.

Those who advocate presumed consent, in the literature,¹² advance the following as its ethical justification: (1) Efficiency is good, increasing the supply of organs is a

worthwhile goal. It is sufficiently important to collect more organs, that other goals and values within limits may be compromised; (2) Delay in asking for consent can be cruel – presumed consent would eliminate the need to ask the donor’s family for consent at a time when the family is grieving; (3) Individual conscience can be respected – presumed consent respects the principle of individual choice by giving objectors to organ donation an opportunity to empower their anti-donation preference by affirmatively objecting and registering it publicly; (4) Individuals owe society the effort to register their objection – those who object to decedent donation should be burdened with the task of registering their preference with authorities, because organ donation is socially desirable although some have claimed this is a “taking,” if an individual has had the opportunity to choose either way, he is “presumed” to have actually made a choice. (5) Presumed consent, combines the principles of supply side efficiency, respect for individual conscience, and an individual’s positive yet qualified duty to promote the good of society.

Opponents of presumed consent base their position on the following ethical considerations: (1) there will be false positives, that is, persons who were “presumed” to consent but who in fact objected to donation – for a variety of reasons such as individuals on the margins of society who did not learn of their option or simply failed to register with public authorities their objection; (2) The mechanism for registering and transmitting objection status is likely to be inadequate, again harming those who in principle object but fail to have their wishes transmitted; (3) Individual autonomy speaks to a core value – asking individuals to publicly express their

objection to donation does not respect that individual's right not to choose; (4)

Individual's should have the right to delegate the decision to family members.

While presumed consent legislation is pending in several states in more or less similar versions, there is by no means a national consensus on public policy approving such a concept. Given the ethical considerations for and against the proposal, presumed consent in the United States is likely to be a long drawn out process. Meanwhile, the scarcity of organs in the United States remains a fixture on the landscape, unlike the aforementioned countries, which have these enabling regulations already in place.

7. "Routine salvaging" of suitable organs after death (with or without a provision for patients "opting out")

Routine salvaging is a policy that is somewhat similar to procurement based on presumed consent.¹³ The ethical underpinnings, however, are quite different. The policy of routine salvaging is inconsistent with liberal individualism. Liberal societies assume that the individual, not the state, should control his or her physical disposition – a liberal society respects this principle by asking for the consent of the donor before organs are recovered.

In the United States, reforming the organ donation system on the basis of routine salvaging would give more authority to the national transplant community than public opinion would allow at the present time. Such a reform would require abandoning the current commitment to the importance of the individual at least for matters of determining how the body is to be treated after death.

Finally, it is obvious that everyone does not have equitable access to treatments that are already standard medical practice. Many citizens in the United States do have serious difficulty obtaining health care that is of significant, sometimes even lifesaving importance. In fact, kidney dialysis and kidney transplantation are the only expensive high technology medical procedures to which access is virtually universally guaranteed. While the access may be guaranteed, the shortage continues to plague those in most desperate need, and those in need of other organs and/or other high technology procedures do not even as yet have the access. The existing organ supply, therefore, is clearly inadequate to meet the current and future needs in this country. Donor organs are a genuinely scarce resource, and questions of fairness in their procurement and distribution are inevitable. It is still speculative to presume that increased educational programs, new legal approaches, or financial or other incentives can increase the supply of living and/or cadaveric organs.

While they may be speculative, a few of these incentive alternatives are worth greater analysis. Futures contracts, presumed consent, required response, and preferred status will show up again in Chapter Four in a more complete discussion of these alternatives.

We now move to Chapter Three, where, as stated in the introduction, we look at the moral, psychological, behavioral, cultural, and racial implications of the decision to donate. These and some other factors have throughout the entire history of transplantation, significantly impacted the decision to donate by various segments of society. Of particular interest, will be an analysis of society's moral obligation, to be followed by a discussion of why minorities are reluctant to donate. As stated in the

introduction, the linchpin of this thesis is the necessity for a paradigm shift from an absolute reliance on altruistic volunteerism, toward a more straightforward recognition of an obligation owed by individuals in a society.

Endnotes

¹ Williams, A. H., 1992, "Cost-effectiveness Analysis: is it ethical?", *Journal of Medical Ethics*, Vol. 18, pp. 7-11.

² When H changes over time, the QALY algorithm assumes that the utility derived from the whole individual profile is equal to the sum of the QALYs derived from each health state. In other words, it is assumed that each individual's utility function is strongly separable on the time dimension.

³ Nord, E., "The QALY: A measure of social value rather than individual utility," *Health Economics*, 1994 vol. 3, pp. 89-93

⁴ Nord, E., Richardson, J. "Social Evaluation of Health Care vs. Personal Evaluation of Health States: evidence on the validity of poor health state scaling instruments," *International Journal of Technology Assessment*, 1993, vol. 9, pp. 463-478.

⁵ Weinstein, Milton, and Stason, William, "Foundations of Cost Effectiveness Analysis for Health and Medical Practices," *New England Journal of Medicine*, 1983, vol. 296, pp. 716-21.

⁶ Nord (1993), *ibid*.

⁷ Dolan, Paul, "The Measurement of Individual Utility and Social Welfare," *Journal of Health Economics*, February 1997, pp. 39-52.

⁸ Ethical Intersections, edited by Daly, Jeanne, Jackson, Terri, "Health Economics and Policy: Ethical Dilemmas in the Science of Scarcity," Westview Press, Boulder Colorado, 1996

⁹ The Presidents Commission for the Study of Ethical Problems in Medicine, *Securing Access to Health Care* (Washington D.C.; Government Printing Office, 1983), Chapter 1

¹⁰ Task Force on Organ Transplantation, Health Resources and Services Administration, *Organ Transplantation: Issues and Recommendations*, (Washington D.C.; Government Printing Office, 1986)

¹¹ *Wall Street Journal*, Editorial, "To Get an Organ, Offer to Give One," October 8th 1998.

¹² Hull, Allen R., "Dwindling Donations Make Presumed Consent a Proposal Worthy of Consideration," *Nephrology News and Issues*, (October 1990), p. 28.

¹³ Dukeminier, Jesse and Sanders, David. "Organ Transplantation, a Proposal For Routine Salvaging of Cadaver Organs," *New England Journal of Medicine* 1968 Volume 279 pp. 413-419

CHAPTER THREE

THE FAILURE OF ALTRUISM

The U.S. organ transplant system is in crisis. At a time when transplant survival rates are at an all-time high, the waiting list for organs grows longer every day.

Approximately 60,000 individuals are now on waiting lists to receive transplantable organs. As mentioned in Chapter One, for over five years, only approximately 20,000 organs (of all types) have been successfully transplanted annually in the United States. At the same time, the numbers of those who die while on waiting lists also continues to grow each year. It has been estimated by UNOS that there are thousands of individuals who remain uncouncted because they never make it to a waiting list. At the same time, surely there are other thousands of individuals who die with an end-stage organ failure who also remain uncouncted because they never made it to a list.

For many persons, organ transplantation holds out the only hope of survival; for many others, it promises the only hope of survival with a good quality of life.

Tremendous pressure exists to reform the present organ transplantation system, which has been faulted for failing to tap the potential pool of transplantable organs as well as for failing to allocate fairly the organs that become available. Although legislation has been proposed to address the allocation issues, the underlying problem – the shortage of

available organs – cannot be addressed until our society rethinks its approach to organ donation. This will require that we stop treating organ donation purely as an act of individual altruism and begin viewing it as a societal and/or a community obligation.

The purpose of Chapter Three is essentially twofold. The primary aim is to look deeper into the reasons that individuals, when it comes right down to making choices about the ultimate disposition of their bodies, often refuse to seriously consider organ donation. This is despite the fact that approximately 80% of the population support the concept. So why are most people reluctant to prearrange the event or failing a personal decision, why do families veto the life-giving/life-saving gift at an extraordinarily high rate? Getting to a moral, ethical, cultural and even racial understanding of the attitudes and behaviors of potential donors and their families is the principal task for Chapter Three. The second goal for Chapter Three is to sift further the financial and non-financial alternatives to altruism listed in Chapter Two. The questions of how they can work pragmatically, as well as, the credibility of establishing a compatibility with society's ethical norms will be asked and answered. Several of the suggested free-market alternatives will never be implemented, given the general abhorrence society has long maintained against (analogously) selling body parts. Yet, in the struggle to improve the donor rate, financially compensating donors, may ultimately become part of the solution. Therefore, this chapter intends to analyze, discuss and construct moral arguments, with the ultimate goal of empowering a policy, that can positively impact the problems/issues, while remaining within the bounds of ethical criteria.

Societal Attitudes Toward Altruistic Organ Donation

Society's attitudes toward donation are complicated by many factors, which are reflected in public opinion polls conducted throughout the past three decades.

Comparisons are difficult because of a lack of standardization in sampling methods, question formats, and polling techniques. Nevertheless, these polls have consistently shown that awareness of organ transplantation is very high among the general public and that organ donation is perceived as a socially desirable action.

Today, organ transplantation is no longer considered experimental and has been proven to increase greatly the quality and longevity of life for thousands of transplant patients. Currently, however, approximately sixty thousand patients are awaiting life-saving and life-enhancing organ transplants. Unfortunately, while medical and pharmacological advances make it possible for greater numbers of people to recover from formerly fatal diseases and to live longer lives once they have received organs, as discussed previously, the supply of organs has remained relatively static, thereby resulting in a critical shortage.

Societal attitudes including cultural values, religious beliefs and death anxiety that result in a reluctance to donate organs are among the reasons cited for the shortage. A greater understanding of the concerns and beliefs of the general public is necessary to effectively target public awareness efforts and ultimately, to stimulate altruism and reverse current trends thereby increasing donation. The success of organ donation explicitly depends on the altruism of the public. Research continues to show that the public, especially white and more highly educated survey respondents, support organ donation in broad terms. In addition, surveys of both the general public and actual donor

families indicate that family members are more likely not to donate organs and tissues if they do not know their relatives' wishes regarding donation and are asked to decide in the absence of this information.¹ The same researchers have concluded that organ donation goes more smoothly when the hospital attends to the needs of the donor family, because the family gives the gift of the organ, and they expect information, gratitude, or recognition in return.

In examining public attitudes towards altruism, one must look at the family. Thirty years of surveys pointing towards general broad acceptance of donation as a socially desirable action, does not explain the intensely personal decision process when it comes to one family's decision process regarding donating their beloved one's body parts. It has been shown that families will explain their decision to donate a member's organ as altruistic when they receive sufficient social support during the donation period. Three variables can lead to a positive social construction of altruistic motivation for donation: (1) greater personal resources, (2) higher social support, and (3) positive evaluations of the donation experience. Another set of variables predicts that reports of enhanced coping will be associated with altruistic accounts of donation motivation. Further, they will also be associated with these three variables, that is, where families have more resources, they will be likely to garner more social support and to report coping more effectively with the crisis of the death of the donor. Another set of variables predicts that family members who report fewer personal and social resources will be more likely to report conflict about the donation of a relative's organs. These family members are less likely to consider their motivation for donation as altruistic and to find fewer coping benefits from the donation.² In the spring of 1995, a questionnaire was

mailed to a sample of 396 families of cadaveric donors located in the Northeast, South, Midwest, and Southwest. The overall response rate was sixty-one percent (242 families completed and returned questionnaires). Altruistic motivation was the dependent variable studied. Although it is difficult to test empirically the connection between social values and altruism, a study of the motivation for organ donation may clarify this relation. In the present analysis, altruism was expected to correlate with higher socioeconomic status, greater social support, and a positive evaluation of the donation experience. In other words, altruism was predicted to be dependent upon the interactions of the other three variables. (Batten, 1995)³ Looking at the respondents' concepts of altruism, they were asked how important it was for them to want to help someone else and not to waste functioning organs. Between 85% and 90% reported wanting to help others, and 75% felt organs should not be wasted.

Personal Resources

As part of Batten's study, personal resources were hypothesized to be associated with reports of altruism. Six characteristics were used in this study to measure individual's personal resources. They are: (1) marital status, (2) income, (3) religious identification, (4) religiousness, (5) gender, and (6) age.

Demographic characteristics such as higher education and greater income levels are traditionally associated with socioeconomic status. However, because married women's socioeconomic status is more likely tied to their husband's educational levels than their own, the women's educational status was an inaccurate indicator of the

family's socioeconomic status. For that reason, household income was a better measure of the donor family member's socioeconomic status.

Marital status and religious identification were considered indirect measures of personal resources. Age may be related to levels of socioeconomic status through the connection of age to income. Younger people may have lower incomes because they are just beginning their careers. In addition those who are younger may have fewer social connections (personal resources), because they have not yet established extensive social networks.

Social Support

Social support systems may also influence the expression of altruism. Social support for donor family members can come from within the family itself, but it can also come from the hospital. Donor family members interact with the institution of the hospital and other representatives of the health care system during and following the donation.

Family support was measured by five indicators: (1) the number of people involved in the decision to donate, (2) whether or not the family initiated the request for donation, (3) how well the family accepted the fact that the donor was brain-dead at the time the donation was requested, (4) whether or not the family agreed to a multiorgan donation, and (5) whether they donated both the kidneys and the heart. The number of deciders was an indicator of the size of the respondent's support network at the time of the donation (Batten p. 87). Indeed, many in the medical ethics community have commented that greater social resources ameliorate stress in a crisis. The assumption is

that the more people are involved who agree with the decision, the higher the respondents' degree of social support will be.

When the survey reported that the family raised the option of organ donation and the family had accepted the donor's death when the subject of organ donation was broached, it was theorized that the family feels more in control of the donation events. The assumption here is that better-integrated families will have sufficient resources to maintain some control over a situation that is otherwise desperate.

The respondent's assessment of strong hospital support was hypothesized to be associated with altruistic motivation. Support provided to the donor family by nurses, physicians, and the organ donor coordinator in the hospital may be a reflection of family status. More cohesive families report more positive interaction with hospital staff and higher levels of hospital support (Batten p. 88).

Ethical Perspectives on Donation

Shifting the perspective from the quasi-empirical analysis of how altruistic motivations might be derived, an ethical and/or moral viewpoint is appropriate to the discussion. There are controversies in biomedical ethics that revolve around transfers and uses of human body parts. Developments in transplantation and in immuno-suppressive drug therapies have raised significant questions about the moral rights and obligations of individuals, families, health care professionals, and society at large in the transfer and use of human body parts, including: Who owns human body parts? What are the moral limits on treating human body parts as property?; and What are the practical implications on judgments about ownership in the context of relevant moral principles?

For purposes of offering an ethical assessment of policies for organ donation, we can look to several moral principles or values that have become commonplace in debates in biomedical ethics. Several have become widely accepted in the policy arena, and could be considered embedded in various policies and practices rather than as grounded in any particular moral theology (e.g. church teachings) or moral philosophy. Embedded principles are not immune to criticism from the standpoint of ethical theory, and it is crucial to be able to move between ethical theory and ordinary general and particular moral judgments. This approach to an embedded “common morality” is close to the approach of the common law.⁴ This approach can be assessed according to its capacity to illuminate debates about policies of organ procurement and donation.

The relevant imbedded moral principles are respect for persons, including their autonomous choices and actions; beneficence, including the obligation both to benefit others (positive beneficence) and to maximize good consequences – i.e., to do the greatest good for the greatest number (utility); nonmaleficence, the obligation not to inflict harm; and justice, the principle of fair and equitable distribution of benefits and burdens (President’s Commission, 1983).

In addition to disputes about conflicts among moral principles, our debates about public policies for organ procurement and donation involve disputes about the appropriateness of viewing human body parts as property. We often think about property only in commercial terms, but even the *donation* of human body presupposes some conception of property. Of course, there are different ways to view property. If we view property as a bundle of rights, then we must determine who the rights holders are and what rights they have.⁵ Much of the debate about the appropriateness of the language of

property, hinges on different conceptions of rights of ownership and different conceptions of owners. For example, the possible owners of human body parts after an individual's death could be those to whom the individual willed those parts, the family, or the community. Possible rights of ownership include the rights to possess, to use, to exclude, to destroy, and to transfer.

Do we own our own bodies? That seems like a silly question. Of course we do. But do we? Recall from the earlier discussion about the Pennsylvania case (*McFall v. Shimp*), in which a man needed a bone marrow transplant or he would die. The only person who had suitable bone marrow was his cousin. His cousin had nothing against McFall, the person who needed the marrow. In fact, he liked him. But he was scared. He refused to donate the marrow, and McFall did what any red-blooded American would do – he went to court. He sued for an injunction to order his cousin to give him the bone marrow. The court denied the injunction, stating that the precedents did not authorize it, as an equity court, to order the injunction. The court expressly made no comment on what would happen if the dying man sought damages from his cousin for failing to agree to the transplant. Nor, despite some very purple language indicating deep revulsion, would the court decide the constitutionality of a law requiring such transplants to be given, should one be enacted. As related in an earlier chapter, McFall died, forgiving his cousin.

The Pennsylvania lower court was probably right because our society is still based on an autonomistic, libertarian philosophy and this individualistic point of view remains at the root of much of our law. In other legal systems, there are elements of what is referred to as solidarity with others, communitarian or collectivist values. No one today

goes as far as Marx, who said, “from each according to his ability, to each according to his need.”⁶ In Marx’s terms, it is not what you possess that counts, because you do not own that. Rather it belongs to the state, or if the state determines, to someone else in need. In our society, however, there are relatively few of these Good Samaritan-type duties.

Although there are not many situations where we say that a person must do something to help out another, there are some. In a regime, which forbids abortion, ask any woman whether she owns her own body totally or whether, to some extent her body is owned by the state. The state then is commanding her to nurture the unborn child at least until birth. The point here is that: anti-abortion laws require, at least to some extent, that women be Good Samaritans.

Another possible precedent the Pennsylvania court could have used is the situation in which the state calls upon us for military service. In the case of conscription, our bodies are suddenly not our own anymore. We are obligated to go because our bodies belong to the collective. Whether it is for the common good or the common bad depends on one’s view of the particular situation in which one is called upon to fight.

The Pennsylvania court also could have looked to every-day experience to find a precedent. For example, every time we allow people to drive in ways that may kill us (driving while intoxicated), we are in a way saying that we do not really own our own bodies.

There are additional examples. We do not let people sell their bodies. We do not let people sell their kidneys. We frown on letting women sell their wombs in cases of surrogate motherhood. We do not let people sell their hearts. However, we do let them

sell their blood and we let them sell their hair and sperm. If people really owned their bodies in the same way that they own property, we would presumably allow people to sell all of their body parts.

What then of the constitutional issue? If a legislature passed a law saying that everyone that had good bone marrow must give it to people who needed it, would we hold that constitutional?

Interestingly several justices and judges have addressed this issue, although somewhat indirectly. Based on his discussions of privacy, Justice Brennan probably would say that such a law would not be constitutional. He should say that to force somebody to give his or her body to someone else would infringe on individual privacy and autonomy.⁷ On the other hand, Judge Robert Bork, if he were true to his position, should probably say that he had not read anything in the Constitution that would prohibit the forced donation of body parts, and if a legislature were to pass such a law that law would be constitutional. He should say that the due process clause talks about property and about life in the same terms. “We have allowed all sorts of laws shifting property, so why not the same with respect to life?” Thus, if he were true to his position, Judge Robert Bork should uphold the statute.⁸ Fortunately, there is a problem with his position. Bork does not take into account what would happen if, instead of a law that required everyone to give their bone marrow, the law required only those who have the most suitable marrow or kidneys, or livers to give them to people who needed them. If it turned out that the people who had the best marrow or kidneys or livers were, just by chance, women, or those who had recessive sickle cell anemia (i.e., those we call Blacks), or those who have recessive Tay-Sachs (i.e., those we call Jews), we might then be

concerned about such a law if, in practice, it required only people who had traditionally been discriminated against or inadequately represented in the legislature to donate their bodies. The law would be passed by the majority, not to discriminate or punish, but more insidiously to save those who needed the marrow, as long as those who had to bear the burden were not those who elected the legislators. In those circumstances, a law like this would have to be constitutionally suspect.

Now consider a communitarian-based law under which, even though women, Blacks, or Jews might still be the best donors, *everyone* would have to be donors because we wanted to show that we were all willing to take on the burden. The persecution issue would then be totally different. It is unlikely that our legislature would actually do this, which again says something about whether or not we as a society are sufficiently concerned about “life” to be *non-discriminating humanitarians*. If we were, that type of law might well be constitutional.

Returning to our society, we are not so libertarian or individualistic that a legislature would never pass a law giving body part rights to those who need them. But we are sufficiently libertarian, individualistic, and autonomistic so that a legislature would almost never pass such a law unless the law affected only those who were “outsiders.” Such a law could only be constitutional if the burden, in practice, was imposed on all of us, and not just on the convenient, traditional “losers.”

Should we be so libertarian with respect to body parts? What are the consequences in adopting a system in which the body parts belong to those who need them, rather than those who happen to possess them? The first consequence would be

distributional. Some people who are currently very well off would be harmed, while others who are currently in a very bad way would become much better off.

The Individual Libertarian Contract

A brief look at current procurement policy will reveal its libertarian underpinnings. The Uniform Anatomical Gift Act (UAGA), adopted by all fifty states between 1968 and 1973, requires explicit consent of the organ donor. The UAGA's policy of "encouraged voluntarism" ranks the principle of self-determination or respect for individual autonomy above all other moral principles. One of its key assumptions is that a "donor's" autonomy is duly respected only if an individual contract is negotiated. Any procurement policy that does not rest upon consent via a contract is seen by proponents of UAGA as riding roughshod over individual liberty, the most treasured possession of citizens in a liberal society.

In the context in which a patient's consent is seen as the deciding factor in treatment decisions, consent for obtaining cadaver organs for transplantation is taken to be the key condition. Of course, obtaining consent from deceased donors is somewhat more complicated than from living patients. The time for obtaining consent is past, once the donor is a cadaver and is in a position to "donate." This leaves society and procurement organizations with an up-front strategy and a fall-back position: encourage people to make decisions about these matters when they are still very much alive (for instance, have people sign donor cards); failing that, do what is normally done in therapeutic contexts with incompetent and comatose patients – ask their family for consent.

The starting point of current procurement policy is the individual and his or her rights to privacy (the right not to be interfered with) and property (the body viewed as property of the deceased) – the key principles of libertarianism. As mentioned briefly above, U.S. procurement policy, has its roots in libertarianism, an individualism that rejects the concept of the common good in favor of that of the public interest. Whereas the idea of the common good arises from vision of society as a community whose members are joined in a shared pursuit of common values and goals and in which each individual's good is bound up with the good of all, the idea of the public interest arises from the vision of society as an alliance of self-interested individuals who join together in the pursuit of mutual advantage. Therefore, any use of an individual's organs after death without that individual's (or his duly authorized representative's) express permission is seen as trespassing, and as infringing on the most basic rights of that individual.

Those who argue for fundamental change in organ donation/procurement policy must challenge the widely held conviction that explicit consent is a morally necessary condition. They must confront the perceived wisdom that any alternative policy that does not require explicit consent of the donor must be rejected on ethical grounds. Typically, respect for autonomy in organ procurement policy is identified with explicit consent. I think that any procurement policy that actually rides roughshod over autonomy must be rejected. The only way an alternative policy that does not require explicit consent can get a hearing is to challenge that identification.

In order to challenge the dominance of respect for autonomy and explicit consent views, we must consider the appropriateness of modeling organ procurement policy on that of patient's rights.

“Contract” Autonomy vs. “Citizen” Autonomy

In the clinical setting, we contract for a cure. But suppose that the procedures recommended for the cure require amputating my arm. I may not want that, and I may decide to take my chances without the operation. If I am not informed of my alternatives and allowed to choose, my autonomy has been violated.

Because people can want things and yet, with perfect rationality not want what those things turn out to entail, when we contract to bring about some general end, we cannot presume that whatever bringing about the general end requires, is also what is wanted. Typically, the clinical setting involves such “conceptual under-determination.” By knowing and understanding the general end, we do not necessarily know or understand the various means by which the end can be realized.

Not all relationships, however, are contractual. We live by all manner of restrictions and policies that are not products of one-to-one contracts. Yet we do not feel that our autonomy is being compromised. In a democratic society all manner of social policy is generated by legislatures and adopted by and through majority vote of citizens or their representatives. Many of these policies deeply and intimately affect individuals. With the exception of the extreme libertarians, most generally agree that such social policies do not infringe on our autonomy as citizens as long as the policies are enacted via the correct procedures for the formulation of social policy and, where necessary and/or possible, have “opt-out” clauses.

The question that must be asked is why organ procurement policy must meet the conditions of “contract” autonomy, as opposed to the “citizen” autonomy just described. Many of the advocates of current policy simply assume that “contract” conditions must

be satisfied, because they have (incorrectly) seen the postmortem removal of an organ as an analogue of therapy. Again, therapy in this context relates to conditions that must be observed with dealing with the incompetent or the comatose. If we free ourselves from that model, it is possible to devise a donation/procurement policy that meets the demands of autonomy yet does not rest upon explicit consent.

Implications of Nonexplicit Consent

The implications of such a policy are far-reaching. A policy that does not have to meet the condition of explicit consent by each donor holds the promise of making many more life-saving and life-enhancing organs available for transplantation. Such a policy, in contrast to the UAGA would not be dependent on the donor card.

That is not necessarily a bad thing, for unfortunately, a variety of problems have limited the effectiveness of UAGA. Despite intensive educational efforts, relatively few people consider donating their organs. Less than fifteen percent of the public sign and carry donor cards.⁹ Furthermore, while most donors are victims of motor vehicle accidents, when such accidents do occur, emergency personnel frequently fail to search for donor cards and even if a properly completed donor card is found, almost all organ procurement programs require additional approval from the next of kin, despite the provisions of UAGA. Additionally, of the possible fifteen percent of the population potentially carrying donor cards, only about twenty percent of that number meet medical criteria for donating organs. Finally of that increasingly smaller proportion, an average of approximately fifty percent of the remainder are rejected by family members. The number of eventual donors who start out carrying donor cards is a very small number.¹⁰

The attempt to obtain organs for transplantation using a method so solicitous of individual choice is certainly a noble one. Yet the fact that neither now nor in the future can we realistically anticipate an adequate supply of organs, if we remain with the current policy, certainly suggests that we should search for some alternative(s). Those who reject such a search are likely to say that, although the shortage is a tragedy, it is a lesser evil than would result from adoption of alternative policies.

Suppose, however, in opposition to those satisfied with current policy, it can be demonstrated that more effective policies can give sufficient weight to autonomy or individuals' freedom of choice. Would it not then be incumbent upon us to pursue such a policy?

Reluctance to sign a donor card is not the only problem with donor cards. Despite the efforts over many years to get people to sign cards and with the weight of the law behind them, an unanticipated problem has arisen: transplant teams hesitate to act on the basis of a signed donor card, deferring instead to the family of the deceased. Despite UAGAs attempt to make the wishes of the deceased controlling, it is the family's (wishes) that are. UAGA specifically stipulates that in case of conflict the expressed wishes of the deceased are to take priority. The family therefore, remains at the heart of the matter. Typically the family is consulted even if a donor card has been signed and if they object to the donation, its not likely that the organs will be removed. On the other hand, if there is no signed donor's card, the law states that the next-of-kin are to make the decision. Either way, the family is in the controlling position. It is they who, in their most intense moment of grief, are asked to grant permission to have their loved one's organs removed to possibly benefit someone else.

Moral Obligations

At this time we have no *legal* obligations to give our body's parts or products to another, but might we or our surviving family representatives have *moral* obligations to do this? Yes, under certain circumstances we may have moral obligations to give or donate body parts or products to another.

As examples, recently there have been cases where a mother gave a lobe of her liver to her child. It is known that the liver can regenerate itself, so the mother may not suffer any long-term harm from her donation, although the pain and the risk of the procedure should not be made light of. The hope is that the child's immune system would accept the mother's liver as a close match, and that the liver might grow with the child. In another recent case a mother donated a part of her lung to her child. This too was seen as an experiment with no benefit assured and with risks to both participants. Skeptics might ask: should parents even be permitted to do such a thing? Most people would say, of course, if a child were gravely ill and there was something, even though risky and painful, that a parent might do to save him or her, the parent should be allowed to do it. What reasons would one give to defend a choice to make such a gift? In the "libertarian, individualistic, and autonomistic" culture we inhabit, many are quick to cite a right to control one's own body, perhaps grounded on a legal right to privacy. Giving a piece of an organ seems dramatic perhaps, but not so different in kind from other things we are asked to do for our children's benefit. Should others be permitted to interfere with our fulfilling our moral obligations to our children?

The problem with talking about moral obligations in the two hypothetical extensions of realistic examples just mentioned, is that it is hard to imagine saying that

any parent is obliged to participate in such risky, desperate, long-shot attempts. But suppose that the costs of helping – the pain and risks – were reduced to a minimum, and that the potential benefits were made more probable and no less significant: might we then be willing to say that parents can indeed have a moral obligation to give some body part or product if it will almost surely save their child's life?

Parents have a range of moral obligations. We do not require them to do what is impossible or futile, nor do we require them to sacrifice completely their own interests or the interests of others for the sake of their children, but we do expect them to accept minor inconveniences and even a little pain if their children might benefit enormously from it.

In the case of organs for transplant, for many people the needs of others become the grounds of moral obligation. If we are selfish or indifferent toward the needs of others, while hoarding the resource we possibly let ourselves open to the same accusations leveled against the very wealthy that they should respond generously to others' needs. We should not be surprised that the accusation with respect to body parts is just now (within the last twenty years) being uttered. Until the time that body parts or substances actually could assist in another's need, it made no sense to accuse someone of holding back that which could not benefit another.

Understanding the need and accepting that obligation follows, does not mean that we must respond to every individual in need. And it most certainly does not mean that the state is justified in insisting that we satisfy such needs. But it does mean something.

Suppose the facts of the case were a bit different than those presented to the judge in *McFall v. Shimp*. Let us say that bone marrow transplantation for the particular

disease had advanced to the state where, when a well-matched donor could be found, a near-certain cure was the likely outcome and the alternative was death. The reluctant could-be marrow donor was the patient's son, whom the patient-father had raised lovingly and generously. The marrow extraction procedure was virtually pain - and risk free. The son nevertheless, refused.

This son has acted in an ungrateful and cowardly manner. His father's impending death will be further blighted by the knowledge that the son has failed to exhibit the moral virtues the father had exemplified and tried to impart. He not only dies, but dies knowing he failed as a parent, with his own preventable death the proof of that failure.

Did the son in this case fail utterly to do his moral duty? Yes, probably, however as the relationship between prospective donors and those in need grows more distant and anonymous, the case for a strong moral obligation becomes less compelling.

This should not be surprising. Judgments of moral obligation in complex circumstances share similar characteristics: a number of relevant moral considerations of varying weight including the consequences to the various parties, promises made, the strength and intimacy of relationships, and the like. As the circumstances change, moral judgments may become less certain until finally the balance tips in the other direction.

The law already supports the moral duty to give body parts to others in need. It does so with blood, other tissues and whole organs through the various statutes that permit donation from cadavers and occasionally living donors. Laws such as these support people's fulfillment of their moral duties, but do not force them to do so. Donating organs and other body parts has been described as a moral duty, because if one pays attention to the reasons people give for making such donations, they are frequently

couched in the language of obligation. Studies of living-related kidney donors show that the decision to donate is most often made immediately; people usually do not need a great deal of convincing when a sister, brother, mother, father, or child needs a kidney.¹¹ These actions are usually seen as evidence that people recognize their moral duty to donate in such circumstances.

The benefits of a system of gifts of organs or other body parts are subtle but far-reaching. Gifts of blood, other tissues, and whole organs attest to our connectedness with one another, our shared embodiment, and our always tenuous and threatened grasp on health. Especially in large impersonal societies where bureaucracies mediate between any one person's resources and the needs of others, gifts of the body are a symbolically rich way to reaffirm the value of solidarity, that we are in fact, members of one community, responsive to one another's needs (Murray, 1987).¹²

Following Murray's further reasoning (1991), I contend that there might well be circumstances in which we have moral obligations to give parts of our bodies to others. These moral obligations will grow more visible and compelling as the likely benefits to others grow more dramatic and certain and the risks to donors become minimal.¹³

Why People Are Reluctant to Donate

Behavioral change models and theories outline the complex process of individual change. Trial of a new behavior, such as family discussion and acceptance of organ donation intentions follows a sequence of events: awareness, understanding, interest, acceptance, personalization, and decision-making related to the issue. Fishbein and Ajzen's "Theory of Reasoned Action" is described as state of the art for predicting

specific behavior intention as well as personal decision-making in performing or not performing a behavior.¹⁴ Their six-step process can be used to explain virtually any behavior over which an individual has volitional control. Of course, this contemporary vision is not exactly new. Aristotle, writing in Nicomachean Ethics nearly 2400 years ago, espoused these same themes.¹⁵ Nevertheless, Fishbein and Ajzen's views address the organ donor issues rather well.

The Theory of Reasoned Action offers guidance to tracking the public's knowledge, attitudes, and behaviors to assess whether and what changes are occurring in organ donation. It permits modifications of motivational strategies as the public views change. These motivational strategies can lead to effective mass media campaigns to increase awareness of the shortage of organ donors and establishes it as a priority of concern. It is clear that while public education messages have been consistent in focusing on the beneficial and altruistic nature of donation and have been successful in reinforcing the value of donation to the white majority, they have failed to address the needs and concerns of substantial segments of the total population. Public education efforts can affect donation rates only if they are targeted at those who are not already committed, especially minorities or those with little formal education.

Currently, donor education falls dramatically short of this goal. Its messages revolve around slogans about the need for organs or the moral worth of donation – matters undisputed by, but uninteresting to, the key target populations. The challenge of public education is to convey the dual message that organ donation protects rather than endangers the interests of potential donors (via the creation of a nationwide advertising campaign focusing on the pre-death benefits that accrue by altruistically doing the right

thing). Globally, changes must be made both to the content of the messages conveyed and in the mechanisms used to transmit these messages to the appropriate target populations.

Reluctance of Minorities to Donate

As minority populations experience rapid growth in the United States, it becomes increasingly important to recognize and understand cultural differences that influence these segments of the population, particularly in relation to health matters. African Americans, Hispanics, Asian/Pacific Islanders and American Indians remain fairly *unaware* about organ and tissue donation even though data show an unabated need for donors from these subgroups.

In a review of common reasons for the reluctance of minorities to donate organs for transplantation, it was found that major barriers stand between many of the above listed minority groups and their willingness to donate.¹⁶ These barriers include:

- Distrust of the white majority group, of which most physicians and health care workers are a part.
- Cultural differences in communications between ethnic minorities and health care personnel.
- Belief that physicians would prematurely declare a minority patient dead in order to surgically remove an organ for transplantation to a patient of the majority group. This belief may be held more strongly by minority group members of low socioeconomic status, who also believe that the organ will likely be donated to an affluent patient.

- Religion and/or superstition, such as some Native American's belief that the body must remain intact after death in order to become part of the great ancestral society.
- Lack of awareness of the need for donated organs, which may be a result of the lack of exposure to information about organ donation and transplantation due to isolation from mainstream society.
- Lack of faith in the success of transplantation, probably more prevalent among members of groups with low socioeconomic status, regardless of race or ethnicity.
- Intense emotional state of the family, which may include hostility toward physicians or others who approach the family about donation. The frequency of this occurrence may be reduced if willing donors make their families aware of their wishes in advance.

Improving African-American Donation Rates

Blacks/African Americans are the largest racial minority group within the U.S. population, constituting approximately twelve percent of the total population. Like the other identifiable ethnic/racial groups, Blacks appear to have a predisposition for developing certain health problems. For example, Blacks have a greater risk (1.3 times) of dying from heart disease, have twice the chance of succumbing to the complications of diabetes, and are 3.2 times more likely to develop kidney failure than is the white population.¹⁷

Hypertension, a common health problem of many Blacks, is a major contributor to the development and/or complications of these diseases. Hypertension affects about

one-fourth of the Black population, whereas it is present in only about one-tenth of the White population (Funkhouser and Moser, 1990).

Another chronic condition that disproportionately affects the Black population is diabetes. Blacks develop diabetes at a higher rate (1.3 times) than do Whites, and this condition magnifies the clinical consequences of hypertension. Patients with both hypertension and diabetes have increased risks of developing heart disease, stroke, blindness, and kidney failure. As a group, Blacks constitute about twelve percent of the nation's population, yet account for approximately thirty percent of all treated end-stage renal disease (ESRD) patients.¹⁸ For those affected by ESRD, dialysis continues to be the most common treatment. Blacks account for nearly forty percent of this country's dialysis patients (Plawecki & Plawecki, 1992). Unfortunately, the number of Blacks on dialysis who are also on waiting lists for kidney transplantation continues to grow due to an insufficient number of available/suitable organs.

The number of Black patients on dialysis and on waiting lists for transplantation greatly exceeds the percentage of that same race who will donate organs. The reasons for the low levels of organ donation by the Black community (as a subset of the minority list stated above), have been identified as: (1) lack of information about kidney transplantation; (2) religious fears and superstitions; (3) distrust of health care providers; (4) fear that donors would be declared dead prematurely; and (5) racism (Blacks would prefer to give their organs to other Blacks).¹⁹

Other considerations that may negatively affect organ donation decisions include the characteristics of the facility. As a group, Blacks visit physicians' offices less frequently, relying on hospital clinics and emergency rooms for their health care (DHHS,

1985). The often chaotic, businesslike, depersonalized nature of care delivery in these facilities may interfere with the sensitivities of the organ procurement interchange and discourage potential Black donors. This factor is confirmed by data that demonstrate that the most likely locational source of organs for transplant were the inner-city hospitals, which serve large minority populations.²⁰

The lower organ donation rate for Blacks may decrease the likelihood that acceptable donor/recipient matching will occur. Lower donation rates also extend the patient's time on dialysis, progressively lengthen the list of potential recipients, and ultimately decrease the likelihood of success for transplantation.

The differences of frequency of ABO blood groups between the races is one factor that reduces the likelihood of Blacks' receiving a kidney transplant. Of Whites, forty percent have blood group A, whereas only approximately twenty-seven percent of Blacks have that same blood type. Proportionally, almost twice as many Blacks (twenty percent) have blood group B, whereas only eleven percent of Whites have that same blood group.²¹

There is another factor that influences recipient selection and it is extremely significant. That factor is the compatibility of human leucocyte antigens (HLA). The greater the HLA compatibility between the donor and recipient, the more likely that a patient will receive a transplant. "Blacks have a more diverse group of HLA molecules than Whites. This genetic diversity makes it difficult to find an HLA matched kidney for a Black recipient when the donor pool is predominantly White" (Plawecki & Plawecki, 1992).

HLA frequency differences between the races might affect an equitable distribution of kidneys when the allocation system is heavily weighted for matching – indeed, as it is.²² HLA matching correlates favorably with transplant outcome. “Blacks would benefit from well-matched kidneys if more donors of that race were available” (Lazda & Blessing, 1989). Of cadaver kidneys, seventy-five percent are recovered from non-Black donor groups. Based on HLA frequency, Blacks therefore, have less chance of favorable matching and, consequently of obtaining a kidney. “These results systematically and dramatically indicate the need for an increase in organ donation among the Black population” (Plawecki & Plawecki, 1992).

What can be done to improve the Black donation rate? Several matters must be taken into consideration:

- It is essential to keep Blacks/African-Americans involved in the planning as well as the implementation process of various strategies and activities within their communities. Their participation allows them to recognize that they are responsible for becoming a part of the solution to a national problem – a donor shortage.
- The utilization of key persons such as transplant recipients, donors, transplant candidates, and donor families as advocates for the cause must continue. Their personal experiences lend enormous credibility to the message that health professionals deliver.
- The public and private sector must share in the responsibility of educating the Black/African American community by pooling together resources which will

allow for the creation of additional marketing materials that can be disseminated and used to educate the community.

- The media must continue to project and target positive messages at the Black community regarding organ and tissue donation.

In a community-based, grass-roots effort, all of the above mentioned elements together hopefully, can and will make a difference in how the community responds to the need.

Hispanic Donor Attitudes

Documented Hispanics make up slightly less than ten percent of the American population in the United States, however, their numbers are rising fast and are expected by the end of the century to be the largest minority in the United States. Hispanics represent about six percent of donors, about 8.5 percent of recipients, and a similar number on dialysis and on transplantation waiting lists as of December 31, 1997.²³ Over the last fifteen years, there have been a number of studies that have pointed to the extremely low donation rates among both Blacks and Hispanics. Hispanic donation rates run even lower than those of the Black population. In Chicago, Pollak showed, in 1985, that family refusal rates of Hispanics were sixty percent vs. thirty percent in Whites.²⁴ In 1993, Prottas found a zero percent to twenty percent organ donation rate in Blacks, compared to a percentage for Hispanics that was rarely greater than five percent.²⁵ He concluded that, as far as the predilection for kidney failure and unwillingness to become organ and tissue donors, Blacks and Hispanics have much in common. The major difference is that Hispanics do as well after transplantation as do Whites, while Blacks have ten to twenty percent poorer graft survival rates. Conversely, Hispanics fair poorly

on dialysis, while Blacks fair better than all other ethnic groups as far as patient survival on dialysis.

The main contributor to the poor rate of donation among Hispanics, is that year in and year out more than fifty percent of potential donors are rejected because of family refusal. The following factors have been identified by UNOS as contributing reasons for family rejection:

- Hostility is invariably present in the dynamics of families with divorced parents or relatives, broken homes, and situations where both parents had argued about which one had given permission to their child for the particular activity where the accident or fatal trauma occurred.
- Fear of mutilation and suffering is frequently verbalized, although relatives can barely define the nature and cause of the fear. Relatives often do not accept the argument that the dead relative was not suffering because he was dead.
- Denial of death is a frequent rejection rationale, especially when the family can see the breathing movements caused by an artificial respirator, notwithstanding a verification of brain-death.
- Religion is occasionally a factor in family rejection. However, in most circumstances, religion works in favor of donation.
- A very important factor in refusal is “the extended family.” With Hispanics, decisions are frequently made at family reunions and discussions. Thus, even with the presence of the next-of-kin in the hospital, a family often prefers to wait for other relatives, either senior or prominent members of the family living elsewhere and who are considered to be the successful members of the family.

Also much weight and consideration is given to the opinion of the elders of the family, i.e., grandparents, even if they lack elements for adequate decision-making. The wait for all these members, as well as the frequently hostile, adamant, attitude of some of the extended family frequently influences the next-of-kin against donation.

- For Hispanics, the problem of “collective hysteria” is ever-present in the dynamics of organ procurement during the grieving process.

Religious Views on Organ Donation

While it is usually possible to find degrees of divergence of view within a particular religion, there are very few religions for which organ transplantation or organ donation conflicts with fundamental tenets. It is far more common for cultural (as discussed above for minorities), as opposed to religious, beliefs to conflict with donation. Often, over the preceding thirty years (of transplantation history), it has been difficult for the individual to interpret the view of their religion without some leadership. Failure to acknowledge the dilemmas and difficulties that modern medical therapies confront the individual with, would represent an abrogation of religious responsibility and most major religions have thus addressed the donation issue.

The definition of religious attitudes to organ donation has been tied to the progression of understanding of the potentials of transplantation. A therapy that is experimental, uncommon and of unproven benefit such as cardiac transplantation in the 1960's or baboon liver transplantation in the 1990's, attracts one level of religious analysis. A therapy that is standard, common and of proven benefit, joins the health

measures that together can be seen as a society's fulfillment of providing a right to health for its members. The rate at which the different religions have needed to address the theological issues has been partly dependent upon the stage and development of medical services. The converse of this is that interaction of religious stances, cultural views and medical technology has determined the delivery of service to each community. Where the religious and cultural views are not permissive, such as in Japan, lack of cadaveric organ donation has prevented delivery of transplantation therapies to large proportions of the community despite the technical ability to do so.

It is the approach to the dead body that provides most religions with the underlying principles that establish their viewpoints. In Japanese society the Shinto view of the dead body as an impure and dangerous object has been a basic concept for at least a thousand years. Injuring the dead body, for example by organ donation, has implications in the Japanese culture that are deeply imbedded in belief and ritual, that is aggravated by a general public misunderstanding of brain death.²⁶ While some religions draw on their understanding of human death to interpret the demands of organ donation and thus find broadly held views, other religions find diversity. Following are capsule summaries of several of the world's major religions' viewpoints on organ donation as discussed in the journal *Life Cycles* in its Summer 1987 edition:

- Amish – the Amish consent to transplantation if they know it is for the health and welfare of the transplant recipient. They are reluctant, however, to donate their organs if the recipient and/or the outcome are not identifiable.
- Buddhism – Buddhists believe that organ donation is a matter that should be left to an individual's conscience. There is no written resolution on the issue

- Catholicism – Catholics view organ donation as an act of charity, fraternal love and self-sacrifice. Transplants are ethically and morally acceptable to the Vatican. Pope John Paul II has expressed considerable concern about donor's psychological and physical integrity, but he has not taken any position against organ transplantation.
- The Church of Christ Scientist – Christian Scientists do not take a specific position on transplants or organ donation. Christian Scientists normally rely on spiritual, rather than medical means for healing. The question of organ donation is left to the individual church member.
- Hinduism – Hindus are not prohibited by religious law from donating their organs. The act is an individual decision.
- Islam – In 1983, the Moslem Religious Council originally rejected organ donation by followers of Islam, but it has reversed its position, provided donors consent in writing prior to their death.
- Judaism – Judaism teaches that saving a human life takes precedence over maintaining the sanctity of the human body. A direct transplant is preferred.
- Mormons – The Church of Jesus Christ of Latter Day Saints considers the decision to donate organs a personal one. Mormons must individually weigh the advantages and disadvantages of transplantation and choose the one that will give them peace and comfort. The Church does not interpose any objection to an individual decision in favor of organ donation.

- Protestantism – Protestants encourage and endorse organ donation. The Protestant faith respects an individual's conscience and a person's right to make decisions regarding his or her own body.

New Strategies and Frameworks

Signs are abundant that the current organizational and legal framework regulating donation is perceived as failing the needs of transplantation. The current framework, sometimes described as “encouraged volunteerism” may be characterized as an “opting-in” system that requires direct expressed consent of the donor and, almost always the donor's family. “Dissatisfaction with the current regime stems from a progressive widening of the tragic imbalance between the need for and supply of solid organs for transplantation.”²⁷ Consequently, a wide-ranging public discussion has focused on the imperative of reforming the laws governing organ recovery. In recent years, a multitude of ideas has been presented to alleviate the situation and reform the system. Although none of the following has been nationally implemented, given current law and lack of consensus on the best choice, the reform proposals fall into the following categories:

1. Reliance on market mechanisms – financial compensation of one sort or another, e.g., direct payments before death to donors, prepaid medical and life insurance, payment contracts to heirs, and “futures” contracts – financial arrangements made in the present for delivery at some future date.
2. Greater encouraged volunteerism through “indirect” payments – tax credits, in-kind rewards like funeral expenses.
3. Greater encouraged volunteerism through preferred status – an individual's expressed willingness to donate yields him/her a preference in the waiting queue for that individual (or in a further alternative a close relative)
4. Improving health care professional behavior – legislation strengthening the required request laws that already exist.
5. Increasing the efficiency of organ recovery organizations – although UNOS is the federally chartered national clearinghouse for all transplantation, medical/surgical information, pharmacology research, as well as a bioethical

focal point – actual procurement is done regionally and even locally at transplant centers (hospitals) around the country. The current structure grew out of the perishability issues relating to the survivability of organs themselves. However, there is some inefficiency and under-allocation of these scarce resources. Since April, 1998, reports of the establishment of a single national waiting list for the various organs suitable for transplantation have gained renewed credibility. That is when U.S. Department of Health and Human Services (HHS) announced new policy initiatives.

6. Changing of the basis from “explicit” to “presumed” consent. This would have major ramifications and dramatically impact the quantity of donated organs.
7. Routine “salvaging” of suitable organs with or without provision for “opting out” or having to request consent.
8. Eliciting and empowering donor preferences by “requiring/mandating their response/choice” – a reciprocal situation with required request, in that the respondent is required to make a choice either for or against donation” prior to receiving e.g. a drivers license, registering to vote, or filing a will etc. (Childress, 1989).
9. Organ sales – the classic oxymoron of “rewarded gifting”

As stated - all of the above proposals have been studied previously and yet none to date have gained a consensus in any important arena. However, as explored throughout this thesis, and as referenced by Deborah Stone,²⁸ the sheer numbers/statistics involved in the transplant universe – operations performed, people waiting on lists, people dying while waiting on lists – all of which, of course, relate to donor shortage, shout out for some very near-term action review of these proposed policy solutions. In conducting my research for this thesis, I have looked at and evaluated all of the above. I shall now turn to two of the most viable.

Two Strategies

What politically courageous solution can be implemented to head off the impending crises in transplantation? It is clear that altruism has failed to even closely match the tremendous advances in transplantation technology. And clearly, the shortage

of organs for transplantation results in an unacceptably large number of potentially preventable deaths. I will now proceed to examine two proposals that appear to have the highest propensity for success while still incorporating high levels of respect for individual's rights and preferences.

Under *presumed consent*, it would be assumed that consent to remove the cadaveric organs has been given by donors unless they or their families pre-register an objection. In contrast, the current system affords people the opportunity to "opt in" to the organ donation system by signing a donor card or otherwise expressing their desire to be organ donors. Again, under presumed consent, individuals would be in the system unless they decide to "opt out" by pre-registering their refusal to donate.

Presumed consent raises important ethical concerns that preclude its use when there is no effective mechanism for documenting and honoring decisions to "opt out" of the system. However, when there is an effective "opting-out" system, presumed consent may be ethically acceptable. Actually, presumed consent currently exists in several states. Most states have laws which permit coroners or medical examiners to remove corneas, pituitary glands, and other tissues specified by statutes from cadavers where there is no knowledge of objection to removal from the decedent or the decedent's family. In some states, these laws have been challenged on Constitutional grounds. Complainant's have claimed that removing organs in the absence of any objections, rather than with the donor's or the family's express consent, violates the Fifth Amendment's prohibition on the taking of private property without due process and just compensation. Recent court decisions²⁹ suggest that any constitutionality of presumed consent may be in doubt when there is not an effective system for documenting and

honoring objections to donations. However, “when there is an effective opting out system, most legal commentators agree that presumed consent is constitutional.”³⁰ In 1993 both Maryland and Pennsylvania passed limited presumed consent laws/statutes according to earlier preferences stated by the donor, which have been ruled as effective and requiring no further consent upon death. Texas is the first state allowing retrieval of organs without explicit consent, albeit in limited circumstances. Texas law allows the retrieval of organs if the decedent's next of kin cannot be reached for a consultation after reasonable efforts have been made. After the donor’s family is contacted, the wishes of the next-of-kin are respected unless the potential donor had expressed a preference for donation during his or her lifetime. According to the law, preferences for donation are to be elicited in a manner that anticipates the policy of “required response”.

Presumed consent may do a better job than a system of expressed consent in making more organs available for transplantation. A comparison of six European countries in 1993 showed significantly higher rates of organ transplantation in Belgium, France, and Austria, which operate under presumed consent, than in the United Kingdom, Germany, and the Netherlands which operate under an “opting in” system.³¹ Belgium experienced a reported 140% increase in the total numbers available for transplantation after it moved from an expressed-consent system to a system of presumed consent. (L. Roels, et.al. pg. 2078).

Presumed consent may be effective by changing the consent process in ways that at first, many Americans might find undesirable. For instance, the way in which presumed consent facilitates organ procurement, thereby reducing the role of family input in the decision-making process actually might be objectionable. In fact, in some

European countries operating under presumed consent, family input is eliminated (L. Roels, et. al., pg. 2078). According to the Roels paper, many Europeans argue that it is more humane not to discuss the issue of organ donation with the family because such discussions only add an extra burden to their grief. This appears to be an ethically troublesome sub-issue of presumed consent. Consulting with the donor's family, imposes an obstacle to effective and increased donation rates, but is nearly an absolute requirement in American transplant centers. In America, when the prospective donor's views are in doubt, family input is viewed as ethically required to provide additional insight into the donor's probable wishes. The family's decision-making authority derives from its knowledge of the deceased's values and beliefs and in its general right to make decisions for a family member who lacks decision-making capacity. Again, as stated earlier in this paper, in America, asking for permission is a difficult proposition both for the hospital and procurement staff personnel as well as the grief stricken families.

Thus, presumed consent is actually more likely than systems of expressed consent to harvest organs against the true wishes of individuals and their families. More organs would certainly be procured under presumed consent, but only because it takes advantage of the public's general reluctance to directly dissent (taking advantage of the grief stricken's temporary confusion whereby those who may not wish to donate, nevertheless, fail to register their objection). If one goal of the organ procurement system is to avoid organ harvesting against the individual's true preferences, a better approach would be to encourage or even require individuals to make their preferences clearly known in advance.

Mandated Choice/Required Response

Transplantation literature refers to the above two sub-titles synonymously. Henceforth in this thesis I will use the term *required response* in the discussion. Under required response, individuals would be required to state their preferences regarding organ donation when they renew their driver's licenses, file tax forms, or perform some other task mandated by the state. Requiring a decision regarding donation would overcome a major obstacle to organ donation – the reluctance of individuals to contemplate their own death and the disposition of their bodies after death – nevertheless, individual autonomy would be protected.

Public opinion polls have shown that one major reason why people currently do not sign donor cards (or otherwise indicate a desire to be donors), even when they support the concept of organ donation, “is a wide-spread reluctance to consider one's own death and the prospect of bodily mutilation that organ harvesting would entail.”³² Under required response, individuals who feel this reluctance would have to confront it thereby removing it as a barrier to donation.

Requiring individuals to make a choice about organ donation may be considered to be coercive or an invasion of privacy. When the costs of required response are compared with the social benefits of such a policy, this objection appears to hold little weight. Required response could be carried out in conjunction with many other state-mandated tasks, such as renewing a driver's license, and would not require additional expenditures of time and energy by the individual or personnel receiving the response. Given the pressing need for organs, requiring merely that a choice be made seems a small price to pay for the possibility of saving more lives. Just by definition, coercion involves

narrowing options for the coerced, requiring a response is in no way coercive, in that individuals who do not want to donate are free to say no.

In the opening paragraph of this thesis, I mentioned the importance of individual autonomy. That brief reference is meant to convey an importance that is recognized throughout the transplant universe. Requiring that competent adults making donation decisions for themselves, in advance of illness, promotes individual autonomy. The importance of individual responsibility in medical decision-making is well established and rests on a fundamental right to self-determination on matters of great personal importance. Under most circumstances, the course of action that will best promote a person's well-being rests on subjective judgments that only the person is in the position to make. Individual autonomy also reflects Western society's additional respect for the unique worth of the individual.

An individual's interest in controlling the disposition of his/her own body and property after death suggest that it is ethically preferable for the individual, rather than the family, to decide to donate organs. This view is supported in the law as well. It is specifically stated in the UAGA act referred to in Chapter One.

By requiring that individuals make their preferences clear, required response would reduce the stress the current system places on the families and physicians of dead or dying patients whose organs could be suitable for harvesting. Under the current system, "required request" laws mandate that physicians or hospital staff ask the decedent's family for permission to remove organs when the decedent's own preferences are unknown. Grieving families may resent the timing of such request, which usually must be answered within a few hours for the organs to remain viable for transplantation.

As stated earlier, hospital staff are often quite reluctant to confront grieving families with this request, resulting in organs not donated.

Digressing slightly to a related concept, a reference to existing policy issues related to the donor card is appropriate. The policy status quo is a state-centered approach relying on driver's licenses and other official documentation. The approach is uncoordinated across the states. Not only is there no centralized collection of donation preferences, but not even the same relevant data points are collected (decisions made by donors relating to all or which organs they consent to donate). A policy of required response would replace wasteful uncoordinated state level programs with a uniform method of collecting and disseminating donation preferences, most likely through UNOS. A national approach is needed to assure the routine and uniform collection of donation preference data and its further distribution to organ procurement centers – located regionally around the country.

Donation preferences likely should be recorded in a UNOS database accessible by Organ Procurement Organizations (OPO). These preferences will carry a legal weight. Following death declarations, the OPO will have the legal authority to excise organs from a deceased person who had expressed a pro-donation preference. The recorded preference would be shown to the donor's family in order to acquire their cooperation. Required response would increase the supply of donated organs by decreasing the frequency of refusal by donor families and by granting additional legal protection to OPOs. Although required response may not completely suppress the efforts of some families to overrule decedents' preferences regarding donation, it could discourage most "family vetoes" by making the decedent's wishes indisputably clear.

There is also empirical evidence that required response would be acceptable to the public and therefore exponentially effective in increasing the organ supply. In a survey of public opinion, approximately “90% of respondents indicated that they would support such a program. Support for presumed consent, the other policy proposal studied in this survey, was only 60%.”³³

Given the high likelihood of public acceptance of required response and its reliance on voluntary choices of autonomous individuals, required response is a promising strategy for increasing the supply of organs for transplantation and should continue to be pursued.

For many years, proponents of the current organ-donation system have argued that all that is needed to create an adequate supply of transplantable organs is to educate the public and to a lesser extent, health care professionals, about the need for organ donation. As I have pointed out in this chapter, however, this approach has not been sufficient.

Some proponents of presumed consent, reject the traditional emphasis on individual autonomy in donation decisions. Placing too great an emphasis on individual rights and autonomy ignores fundamental moral obligations incurred by individuals as members of a society. And “opting-out” systems that assume people would be willing to donate reflects a more communitarian outlook that respects the needs of the larger community as well as those of the individual. The communitarian view holds that individuals have a moral duty to help others when the cost to the individual of helping is very low. Since cadaveric organ donation can save the lives of others and causes no significant harm to the decedent or the family, individuals who do not object on religious

grounds have a moral duty to donate their organs, according to this viewpoint. The opting-out provision in a presumed consent system recognizes this moral duty by making consent to donation the norm – those opposed to donation would have the burden of making their objections known. The communitarian argument should be considered, for it directly challenges basic assumptions of the current system – that consent to donation should be considered an act of volunteerism as well as an issue of individual rights. Currently, the legal system sees the duty to help others as a moral duty properly left to the individual's own conscience. While the communitarian viewpoint sounds interesting, and is worth considering, the overwhelming consensus of thought relating to organ donation remains grounded in the concept that control over the disposition of the dead should remain governed by individual and familial values rather than by a communitarian ethic.

The ethical advantage of required response is its undiluted loyalty to the value of individual autonomy. By giving the adult the opportunity to opt-out of the donation system, required response respects the individual's right to stand apart from society. On this dimension, required response is distinct from presumed consent because the latter offers less protection against the risk of collecting organs from persons who hold reservations toward organ donation. This distinction held by required response is also the source of its major limitation, because it is uncertain what percentage of the adult population would elect to opt-out of the system. If not accompanied by an effective public education process, required response could backfire by empowering a potential bloc of anti-donation attitudes.

In summary, the efficacy of required response would come about as the result of reducing uncertainty of the donor's wishes by (1) recording the donor's preferences routinely and (2) making those preferences available nationally to OPOs which have a need to know this information on a timely basis.

The policy of required response should be implemented as the first part of a largely reformed strategy. Over time, demographics (numbers, as Stone would put it) will likely force the legal system regulating organ donation to approach the policy of "presumed consent" and if my scenario is correct, implementing a required response system first can yield an exponential set of benefits (in terms of increased donations), as adults increasingly "opt-in" to the donation system by expressing "yes" as their required response. As required response evolves, favorable probabilities of the societal consensus on transplant donation will almost certainly emerge, as recorded through required response, so that in time, by custom, consent may be more safely "presumed" because of the (greater) universal approval of organ donation.

As discussed earlier, setting up an administration of required response systems, e.g. driver's license notation, could actually be inexpensively implemented. Required response, furthermore, respects individual rights and autonomy, specifically allowing for individuals to "opt-out", while building a much larger base of citizens who are directly expressing their willingness to donate. If nothing further happens, this system alone should reap great benefits for tens of thousands who are now waiting to die. If societal attitudes do change over time, "normalizing" the effects of presumed consent in tandem with required response, would dramatically impact the capabilities of the transplant

community to not only save but provide a better quality of life for the thousands of people suffering from some form of end stage organ failure.

Notwithstanding the above arguments, the shortage crisis is now and reforms postponed until moralities change, means lives wasted and/or lost now. In the next chapter, I will examine policy reforms that are currently being considered. Their short-term potential for pragmatic reform could have far reaching impacts on improving donation and procurement.

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CHAPTER FOUR

MARKET SOLUTIONS AND RECENT POLICY INITIATIVES

Financial Incentives

The concept that financial incentives be offered as a potential solution to the ongoing organ donor shortage has been previously considered and debated among experts in the fields of transplantation, ethics, law, and economics. The background for these proposals remains the ever-growing need for increased organ acquisition and the undeniable fact that the current system, despite thirty years of experience based on altruistic donation, has yet to meet this need. Historically, the current system of organ donation based on altruism, as discussed previously, evolved during the 1960s and 1970s when issues such as the definition of brain death, the use of donor cards, and public attitudes toward donation were conceptually immature. Based on the Uniform Anatomical Gift Act (UAGA) and the National Organ Transplant Act (NOTA), the buying and selling of organs has been specifically prohibited. In the late 1980s, required request legislation was adopted in all fifty states, but has yet to demonstrate a significant impact on the rate of organ donation.

This chapter examines the use of financial incentives to encourage cadaveric organ donation. Proponents of financial incentives argue that incentives to donate would increase the supply of organs and extend individuals' control over their own bodies.

Proposals involving financial incentives vary widely in their provisions for the use of living donors vs. cadaveric donors, the size and type of any financial incentive, the recommended degree of market regulation, and other areas. Some proposals favor an open, unregulated market governing the supply and distribution of organs. In an open market, those needing transplants would be able to buy organs directly from living donors or the families of cadaveric donors. The price would be determined by the law of supply and demand. Others have suggested using financial incentives to encourage donations while outlawing the outright purchase of organs by needy individuals. In this scheme, the supply of organs would increase but transplant recipients would continue to be selected according to ethically appropriate criteria related to medical need, not ability to pay.

Digressing, it is interesting to note that the 1984 NOTA was somewhat rushed into enactment as a result of an innovative financial incentive proposal. In 1983 an entrepreneurial physician named Jacobs invited 7,500 U.S. hospitals to participate in his plan to buy and sell kidneys through an international brokerage company. The uproar from this proposal – public as it was – was so loud and immediate that Congress passed (by early 1984), the National Organ Transplant Act which further tightened UAGA and went on to prohibit the sale of human organs (including very stiff penalties for such activities). It is perhaps an interesting rhetorical question if one were to ask why it so often takes a moral outrage on the part of the public to get protective legislation passed and enacted. While our moral pulses were quickened by Dr. Jacobs' business enterprise proposal – harvesting and brokering organs internationally for gain – the 1983-84 NOTA legislation also established the President's Task Force on Organ Transplantation which was empowered to investigate the medical, legal, ethical, social, and not least the

economic/financial implications of transplantation dynamics.¹ What is clear from the final passage and enactment of NOTA in 1984 is that the use of financial incentives to encourage organ donation would require a major departure from the moral sense of American society as expressed in both federal and state law.

A definition of terms is necessary prior to a discussion of the concept of financial incentives or organ donation. First, financial incentives as discussed here, do not mean additional monies spent for public or professional education or recognition in the counseling of prospective organ donor families. Because the concept of financial incentives fundamentally changes the process of organ procurement, it has been argued that the term “donor” is no longer applicable and would need to be replaced by a term such as “vendor.” Of latest practical significance is the distinction between “incentive” and “payment” since a system of financial incentives may indeed be a viable option if, as interpreted by law, “incentives” do not amount to “purchases” and “donors” are therefore not transformed into “vendors.”

To many, the idea of any kind of incentive for donation is subject to serious ethical abuses. Many fear that financial incentives to donate would undermine altruism in society, be coercive to the poor, jeopardize the equality of the organ supply, and dehumanize society by viewing human beings and their parts as mere commodities. All of these concerns are important, but it is not clear that they justify a ban on all forms of financial incentives. It may be that the possible risks of certain kinds of incentives would be outweighed by the incentive’s effectiveness in increasing the organ supply and saving lives. In addition, many of the objections to a market for organs do not apply equally to all forms of financial incentives - some types of incentives could be effective

and relatively free of moral risk. As Childress writes, “it may be possible to accommodate some types of transfer of some kinds of tissues for valuable consideration without major ethical costs.”² Some financial incentives, such as future contracts for cadaver donors, may be effective in saving lives while avoiding the ethical pitfalls of other forms of incentives.

Incentive Alternatives

Perhaps the most promising form of financial incentive for organ donation is a modest payment for cadaveric donation at the time the organs are retrieved. In this type of plan, an adult could agree while still competent to donate his or her organs after death in return, a state agency, an insurance company or other third party would agree to some financial remuneration to the donor’s family, estate, or beneficiary at the time of actual donation. Thus, under such an agreement, called a *future contract*, the financial benefit from donation would go to the family after the donor’s death, when organs are retrieved. However, the decision to donate would have been made by the competent donor while still living. Decisions to accept financial incentives would not be made by the decedent’s family or other third party.

Several incentive proposals have evolved since the late 1980s and early 1990s. One of the earliest proposals actually allowed living individuals to contract for future delivery of their organs and yet receive compensation before death. This concept was originally put forward by Richard Schwindt and Aidan Vining in 1986 who suggested that a “public purchase market with forward delivery” be established and operated by the federal government. In this proposal, a government buyer/broker would execute a

“contingent-forward” contract (like a commodity market futures contract) with an individual for the delivery of organs upon death. In Schwindt and Vining’s proposal a pure market price would not exist, rather the government would adjust the price based upon fluctuating organ inventory requirements and of course, demand.³

This type of an arrangement is called a monopsony – a situation which is the opposite of a monopoly, where there is one seller. A monopsony environment has only one buyer. There are a number of purely practical and problematic issues with Schwindt and Vining’s proposal. From a practical standpoint, efficiency would be a large problem. For example, not everyone who might engage in a “futures” contract would be able to deliver his organs upon death. Some would die with organs unsuitable for transplantation (for a variety of reasons), others would die under circumstances where it simply became logistically impossible to recover the organs previously contracted and paid for. Therefore it is highly likely that a relatively large proportion of paid for organs would not be recovered.

From an economic standpoint, the monopsony situation represents unique problems for the buyer (in this case, likely the government). The problem arises in the need to very accurately predict demand requirements for the future organs. Further, these commodities are without question the most perishable goods on the planet. As such, there is no such thing as inventory. Another issue facing the monopsonist is analogous also to the “futures” market. Once contracted for, (like corn, soybeans or cattle), the organs will be deliverable in the future. The sole buyer in the future likely will be dealing with improvements in medical/surgical procedures, better preventative medicine

protocols, and even the likely development of artificial organs. All of the above would impact the need for delivery of organs contracted for in the past.

A second proposal featuring a financial incentive for donation was developed in 1990 by Henry Hansmann. His proposal was actually a variation on the Schwindt-Vining system discussed above. This proposal also involved the type of a futures contract purchased from a potential donor while he was still alive. However, the Hansmann variation was not a lifetime contract, rather it was renewable and renegotiable on an annual basis. Hansmann also suggested that this contract could be managed by health insurance companies rather than the government, and that the insurance companies would compensate the donors by reducing insurance premiums.⁴ This proposal suffers some of the same practical problems as above, while offering a few new benefits. Practically, the problem of death occurring and organ suitability remains the same as under the Schwindt-Vining proposal. On the cost side, however, the aggregate financial exposure from the buyer (in this case, likely, insurance companies), could be controlled more efficiently. Hansmann's proposal suggested that pricing for the future organ donations could be set and established by the market or by government edict. Hansmann's proposal raises significant moral questions, if not outright problems. If prices were established by free market actions, any spot shortages would obviously have the impact of bidding prices up, depending of course, on the absolute parameters of the negotiated price elements of the future contract. If the prices were set by the government, they would most likely be lower than any market price, possibly however, forcing a situation where the incentive did not propel enough potential donors to make the donation decision. This method runs the typical market risks of high prices eliminating some potential recipients

who need the organ but cannot afford them, contrasted with the opposite circumstances with the incentive not being high enough to induce enough donors to contribute. A further problem with the Hansmann proposal involves the high level of transaction costs that would, of necessity, be allocated to this method. For instance, significant monitoring of future donors would probably be necessary to ensure that they did not resell (for an additional payment) their organs to other procurement agencies. The Schwindt-Vining proposal also suffers from this weakness. In addition, neither proposal has actually accounted for the airline ticket sales analogy – that is, as airlines routinely overbook on the probability that not everyone booked or sold a ticket will actually show up for the flight, transplant procurement agencies (due to the variables involved in matching antigens) must of necessity buy/contract for higher numbers of donor organs than they will actually need in the future.

A third futures market plan has been proposed by Lloyd Cohen. This plan probably achieves greater efficiency because it avoids many unnecessary costs. The Cohen plan compensates the estate or the beneficiary rather than (in advance) the potential donors, and only for the organs actually recovered at death.⁵ Although appearing efficient in terms of cost, it might still be ultimately inefficient in that it relies on a traditional altruistic motive on the part of the donor since he/she won't be getting a compensation benefit. Given that altruistic foundation, these are concerns that aggregate donor procurement would still be subject to altruistic motives and that donor gifting may or may not be statistically improved.

A fourth incentive plan is one authored by Thomas Peters. Peters does not consider a futures market, rather he suggested making outright payments to survivors

only if the recovered organs will be useful and actually recovered at death. This method could project large cost savings into its narrow focus and not having to pay in advance for something that might not be useful or never actually delivered.⁶

Arguments in Favor of Future Contracts

Arguments in favor of financial incentives/future contracts for organ donation are grounded in the hope that such a system would increase the supply of organs and thereby secure the basic ethical concern of saving lives that would otherwise be lost due to a lack of this resource. The fact that the current altruistic system of donation has been in place for thirty years without modification or change despite the different organs now available (heart, liver, lung, pancreas) and the increased transplant activity today, has been cited as justification to consider a new approach. Specifically, because the current organ procurement system is based on financial gain for all concerned (physicians, surgeons, coordinators, social workers, hospitals, etc.), the altruistic “gift” upon which so many recipients depend has been described as unfair and insensitive to donor families and the source of basic distrust of the system by the public. It has been argued that the donor and the family are the only participants not directly benefiting from the process and therefore, some form of compensation is the right thing to do, even if the number of donors and cadaveric organs does not appreciably increase.

One point in favor of future contracts is that they address all of the usual factors involved in organ donation: the individual donor, the family, and the physicians and hospital personnel involved. Future contracts could overcome the psychological costs of agreeing to donate, reduce the need for bedside requests to grieving families to consent to

the harvesting of their loved one's organs, enhance donor autonomy, and meet the requirements of justice. Each of these advantages is discussed in some detail below.

Overcoming Psychological Costs of Organ Donation

As discussed previously, many supporters of organ donation do not sign donor cards because of their reluctance to consider their own mortality and the idea of being operated on after death. Although the adoption of required response, in which individuals would be required to make a decision regarding donation, might help address this issue, it in itself would provide no motivation to respond affirmatively. For individuals who favor organ donation but are uneasy or reluctant about identifying themselves as donors, an additional incentive may be all it takes to convince them to donate.

The success of a system of future contracts in encouraging an individual to face the donation decision and make an affirmative choice has been described as related to the length of the individual's reluctance to consider issues related to his own mortality. Although individuals will vary in their feelings in this area, there is reason to believe that this reluctance is generally not very deep. For instance, in a 1993 Gallup Poll, 85% of respondents supported the donation of organs for transplantation, and 69% of respondents indicated that they are likely to want to donate their own organs after death. At the same time, only 42% of respondents indicated that they have made a personal decision about donating their own organs.⁷ Limited financial incentives could be successful in many cases in translating this general support into a greater individual commitment to donate organs after death.

Easing Pressure on Physicians and Families of Cadaveric Organ Donors

In most cases, potential organ donors have not made their preferences regarding donation clear before death. The passage of required request laws to obtain the donor 's and/or family's permission for donation has created a stressful situation for physicians and other hospital personnel, who must make the requests, and for families who may resent having to make such a decision in the midst of their grief.

Future contracts for cadaveric donation can ease this situation by encouraging individuals to become donors and to discuss their decision with their families, who would usually be the designated beneficiaries of future contracts. Future contracts, therefore, would benefit families primarily removing the need that often arises under the current regime of required request for families to make a decision regarding donation during their time of grief. When the deceased had already entered into a future contract, the family would either already know or be made aware by the public nature of the contract system – thus the need for family permission would not arise. Future contracts can help ease the pressure on families and physicians created by required request laws.

Enhancement of Donor Autonomy

Future contracts can help ensure that individuals control whether their organs are used for transplantation. Under generally accepted principles of personal autonomy, patients have the right to decide what happens to their bodies. Individual autonomy also reflects our society's traditional respect for the unique worth of the individual. We acknowledge and respect human dignity when we grant individuals the freedom to make choices in accordance with their own values. It is important for individuals to control not

only what happens to them in the present but also to direct their future course in life and after death. The individual's interest in controlling the disposition of his or her own body and property after death suggest that it is ethically preferable for the individual, rather than the family, to make the decision to donate organs. This view is prevalent in the law as well. Under UAGA, the individual has the right to decide to donate organs after death.

As mentioned previously, despite the legal and ethical arguments in favor of obtaining consent for donation directly from the prospective donor, in advance of illness or injury, the current system relies heavily on permission from the next-of-kin at the time of the prospective donor's death. Notwithstanding any pre-consent, physicians generally require permission from the decedent's family before proceeding with organ retrieval. There is no guarantee, however, that the families will conform with the actual (although possibly unexpressed) wishes of the donor. Furthermore, when the deceased had expressed a desire to donate organs, requiring further approval from the family gives the family the ability to effectively veto the donor's decision.

Future contracts, by encouraging individuals to identify themselves as organ donors, would promote individual autonomy and lessen the possibility of a family veto. Thus, by encouraging the individual to make his or her desire to donate known in advance (via a future contract), it becomes more difficult to oppose or ignore the individual's wishes, a future contract transfers decision-making power from the family back to the individual donor.

It might be argued that deference to the decedent's wishes over possible objections from the family *may* cause psychological harm to the family, increase the physician's risk of liability, or foster a negative perception among the public of over-

zealous physicians who seize organs without family permission. These objections, however, have little validation. As discussed above, the ethical justification of respecting the donor's decision is firmly grounded in the principle of autonomy.

Respecting the wishes of the donor is not incompatible with the view that the family has a legitimate interest in the care of their loved one's body. Although the family generally has the right to make decisions for a family member who lacks decision-making capacity, the family's ethical obligation is to act as the executor of the patient's wishes and to make decisions in accordance with what the patient would have wanted, not according to their own values.

Recognizing the major role played by the family under the current organ donation system, some advocate offering financial incentives directly to families of decedents rather than to individuals in advance of death.⁸ While such an approach might be effective in encouraging families to donate the organs of their loved ones, it misses the point and is ethically problematic. Allowing the family to decide to donate in return for payment clearly emphasizes the family's decision-making power over the preferences of the individual, serving as the source of the organs, thereby suggesting that the family has proprietary rights over the relative's body. Futures contracts, in contrast, would encourage individuals to make the donation decision early and by themselves and would increase the likelihood that those decisions would be respected.

Justice

Advocates of future contracts and other financial incentives point out that under the current system, the donor is the only party involved in transplantation who does *not*

benefit from the procedure. The recipients of donated organs clearly benefit the most of all the parties involved, and transplant teams are well paid for their services. It seems unfair that the donor, who makes the whole process possible, is the only one who is not financially rewarded, and yet is expected to act out of altruism alone. I think it can be argued, therefore, that justice requires that financial remuneration for the donor or the donor's family be allowed to reward the party most responsible for the transplant procedure.

Objections to Financial Incentives

Any course of action that would entail providing financial compensation to organ donors or their family for the donation of organs for transplant purposes must first confront current federal laws making it a felony to buy or sell human organs for the purpose of transplantation. Since passage of the National Organ Transplant Act of 1984 (NOTA), federal law has provided that:

“It shall be unlawful for any person to knowingly acquire, receive or otherwise transfer any human organ for valuable consideration for use in human transplantation if the transplant affects interstate commerce.”

As discussed, there have been several different proposals for using financial incentives to increase organ donation. To understand how Congress might react to such approaches – whether as a pilot program or otherwise – one has to understand the federal prohibition's origins.

While some have said this prohibition was adopted without serious consideration by Congress (see the discussion regarding Dr. Jacobs, who in 1983 proposed the establishment of an international brokerage exchange for organs for transplant), the

legislative history of this provision reveals four basic concerns underlying the enactment of this section of NOTA: (1) a concern that a system of organ procurement based upon organ sales would destroy the existing system of voluntary donation; (2) concern that indigents and “Third World” individuals would become the vast majority of the donor pool; (3) concern for safeguarding the health of living donors; and (4) concern that a payment-based procurement system would increase the likelihood of transmitting disease in transplanted organs. As discussed in the earlier mention of Dr. Jacobs and his organ sales scheme, the national outrage that his proposal evoked, undeniably galvanized moral conservatives into an intense lobbying of Congress which then rushed to legislate NOTA.

Although the debate on using financial incentives to increase organ donation is not new, it has taken on new life recently as waiting lists have lengthened and deaths while waiting have increased. Congress, however, has not spoken to this issue since the initial passage (in 1984) of the prohibition. Obviously, the appropriate time for it to do so would be during the reauthorization of NOTA, which is supposed to occur every three years. However, as will be discussed in much greater detail in Chapter Five, Congress has not formally re-authorized NOTA since 1990. It is not only the ethical questions that have begun to pile up over the succeeding nine years since the last reauthorization, but dozens of medical, surgical, technical, and pharmacological advancements have Congress quite far behind the curve. Given all of those listed advancements, and their (in some cases) correlated ethical dilemmas, it is clear that Congress has virtually abdicated its social responsibility in terms of organ transplantation issues.

Notwithstanding legal and policy issues that currently stand in the way of any consensus approval of financial incentives for organ donors, there are a number of ethical

pitfalls facing proposals involving the use of financial incentives. In general: (1) the dilution of altruism in society; (2) the risk that the quality of donated organs would decrease; (3) doubts about the volunteerism of those who accept financial incentives for donation; and (4) the treatment of human beings and their parts as commodities.

Diluting Altruism

Under the existing organ procurement system, the *only* motivation for donating one's organs is altruism. Many commentators identify altruism as an important end in itself, worthy of protection from encroachment.⁹ Financial incentives, it is argued would spell the end of altruistic gift giving and add to the fragmentation of society.

Although it is indisputably an important social virtue, society's interest in the ethic of altruism must be weighed against the pressing claims of individuals to life itself. However, altruism in society is not expressed exclusively through organ donation.

Quality Concerns of Donated Organs

Some fears have been expressed that financial incentives could encourage individuals to donate organs even if they are of questionable quality. The closest analogy that is drawn has to do with the practice of selling blood. Evidence suggests that paying blood donors may actually *decrease* the overall quality of the blood supply because it encourages prospective donors to conceal disease, drug use, or other factors that would make their blood medically unacceptable.¹⁰ In recent years, routine donor and laboratory screening tests have largely eliminated quality differences in blood plasma from unpaid vs. paid donors (Strauss et. al. 1994).

While inferior quality may still be a concern with paid blood donation, it is much less likely to be a problem with organ donation under a system of future contracts. Unlike paid blood donors who might conceal risk factors because of the prospect of receiving quick cash for donation, organ donors who may have entered into future contracts are dead and incapable of such deception. While it is conceivable that the family of the deceased might withhold relevant information about their relative's health history or risk factors to collect the modest payment from the future contract, the chances that a family would behave in such a manner in the midst of their grief, and the further chances that laboratory tests and physical inspection of the organ would fail to identify a defect in the organ are very slight.

Incentives could even enhance the quality of the organ supply if payments were made *only* after the organs had been judged medically suitable. Payers (government agencies) of incentives would have a strong interest in making certain donated organs were in good shape before payment was made.

Summarizing, quality concerns most likely can be avoided with appropriate regulations concerning the use of the incentives. Quality concerns do arise with other forms of financial incentives. For instance, an open market for organs from living donors could result in a large number of private, unregulated exchanges of organs for dollars. Quality control in such a scenario would be extremely questionable.

Volunteering

Financial incentives could be unduly influential on the poor, who because of their dire financial need could be induced/coerced into making undesirable choices. Further,

financial incentives that result in the poor becoming the majority of organ donors and the rich the majority of recipients would seriously undermine our society's egalitarian ideals. (Pellegrino, 1991; Dougherty, 1987). Although, this is a formidable problem for proposals offering financial incentives to living donors, it is much less of a problem for future contracts for cadaveric donors.

When discussing voluntarism, concerns rise regarding paternalism. Proponents of incentives argue that the poor are already disadvantaged in our society and have few options for raising their standard of living. Further, it would be unjust to deny the poor one of the few options that they do have – accepting money for organ donation – mainly because others (usually in more comfortable positions) feel uneasy about it. The paternalism argument is probably defeated again in the area of risks undertaken. For living donors, although significant, risks are probably not as great as those attending other situations for which payment is expected and appropriate, such as employment in the military or police force. If society is willing to pay people to accept the risks of hazardous jobs, then it should tolerate payment for accepting the risks of organ donation.

Notwithstanding minimized (in the United States) concerns regarding exploitation and coercion of the poor, there is still a strong possibility that the poor could be made even more vulnerable by the pressure to donate created by incentives. This concern is one of the most convincing arguments for continuing to prohibit the offering of financial incentives to living donors. However, the potential for exploitation of the poor is greatly minimized if financial incentives are limited to future contracts for cadaveric donors only.

Human Beings As Commodities

This objection to financial incentives holds that organs and perhaps human body parts in general, are simply not the kinds of things that should be bought or sold. This observer believes that offering financial incentives would in effect make organ donation just another economic activity. Thus, it is argued, it would “cheapen the gift of life and fundamentally alter the social meaning of organ donation altogether.”¹¹

Although there is no consensus on the exact nature of an individual’s property interest in his or her own body, it is true that our attitudes toward donated organs are substantially different from our attitudes toward traditional goods on the market. The system of future contracts could be carefully designed and regulated to minimize commercialization of the donation process. Nevertheless, it seems likely to always be argued by some that any introduction of incentives for donation inappropriately treats the body as a commodity, even if the incentive falls short of creating full property rights in one’s own body. This view, however, appears to overlook that some “donor-ship” rights in the body are already a part of society’s legal and ethical traditions. Donation itself depends on some notion of ownership rights, that presumably one cannot give away what one does not own anymore than one can sell it. The important question is not which account of property or ownership rights in the body is more convincing, but whether financial incentives can be designed to encourage donation while protecting donors from exploitation.

Would A Market Approach Work?

A properly designed and regulated system of future contracts could avoid the ethical pitfalls attributed to the use of financial incentives. The system that financial incentives (i.e., the market) would replace or supplement is the current system based almost solely on altruism. How do altruism and markets compare in other contexts as devices to induce people to provide for strangers? A transplant organ is for its recipient a necessity of life. In the case of necessities such as food, clothing, and shelter, we permit markets to operate side-by-side with altruism. If this were not so, life would be vastly different than it is today, for all but a trivial quantity of necessities comes to us by way market actions rather than by gift. If with respect to the very essentials of life, self-interest dominates altruism as a motive for people to provide for strangers, what reason is there to believe that the motivations to donate cadaveric organs are any different? Perhaps because unlike those other necessities, which require much effort and sacrifice to produce and supply, cadaveric donation requires no sacrifice. The dead gain nothing by retaining their organs, and therefore sacrifice nothing by supplying them. Markets are most effective at transferring goods from low valued uses to high valued uses. I can think of no good that fits this bill better than a cadaveric organ. But if the organ is of no value to the dead, then why does altruism not work? Perhaps the organ does have a value (spiritual, psychological, or otherwise). Could it be that the value is so great that those who refuse consent are simply irrevocably opposed to donation? That seems highly unlikely. Polling data over the last thirty years continue to repeat and reaffirm that next-of-kin can often be persuaded to donate. Further, the many signed organ donor cards, the

absence of any movement protesting cadaveric organ donation, all strongly suggest that there is no widespread deeply felt objection to donation.

So again, why are we not getting more organs? In Chapter Two and Chapter Three I elaborated on the many reasons: fear of over-eager doctors; aesthetic, cultural, and religious concerns; and an unwillingness to confront one's own mortality (among many others).

No one would argue that there has not been a lot of effort expended in an attempt to discover the root of people's reluctance to donate. I submit that much of this effort misconceives the problem and obscures it with too much detail. Although social, religious, medical, and psychological issues are all at play, the uneasiness about organ donation does not operationally distinguish it from a host of other activities in which people engage despite deep-seated antipathy. From a different view than much of the existing literature, the objections reported by thirty years of public polling are costs that prospective donors must incur. They are and have been unwilling to donate because they are being asked to assume those costs without being offered a sufficient compensating benefit.

A successful futures market requires that the supply of cadaveric organs be like the supply of almost all other goods and respond to price. What evidence is there on the shape of the organ donors supply curve? At present we know but one point on the curve. The price currently paid to organ donors is \$0. At that price we have a substantial but less than satisfactory amount of organ donation. Imagine that we do not raise the price, but lower it instead. Would anyone doubt that if donors were charged a fee of, for example, \$500 for donating that the currently supply would dry up? If on one side of the

\$0 price the supply curve is highly responsive to price, is there any reason to think that on the other side of the \$0 price supply is totally unresponsive?

Although an open, unregulated market for organs would be potentially exploitative and degrading, some form of financial incentive to encourage the donation of organs may be ethically permissible. A number of non-financial strategies to encourage donation have been pursued aggressively for many years, with only limited success (e.g. Public Service Announcements, and on-going yet sporadic educational programs). A carefully designed and regulated program of future contracts in cadaver organs could significantly increase the supply of organs and for some organs save many more lives, while avoiding the ethical pitfalls associated with other forms of financial incentives.

The actual effectiveness of future contracts in increasing the supply of organs is, like all untried policies, difficult to predict. A great deal would depend on public reaction to the issue. Recent polling evidence suggests that some large sectors of the public and physicians still feel uncomfortable with the idea of financial incentives for donation. For instance, in a recent Gallup Poll, only 12% of respondents said they would be more likely to donate their own or a family member's organs if financial incentives were offered, 81% said financial incentives would have no effect, and 5% said financial incentives would make them less likely to donate.¹²

It is clear that a system of future contracts, though ethically acceptable, raises a number of practical issues regarding its feasibility. Since the empirical effectiveness of incentives cannot be settled in advance, some limited experimentation with future contracts or other incentive may be appropriate. Of course, toward this end, the existing

legal prohibition against the use of financial incentives would have to be lifted, at least temporarily, to allow for such experimentation/pilot programs to take place.

An Ethical Compromise

Opponents of financial incentives point out that there would be potentially decreased emotional gain for the donor family, decreased respect for life and the sanctity of the human body and a loss of the personal link that currently exists in the donation process. Great concern has been expressed theoretically regarding a potential rich vs. poor phenomenon and the fact that financial need should not be linked in a coercive way to giving consent for organ procurement. Ironically, such incentives directed primarily at the Black community would undoubtedly recall for many the past experience of “commerce and bodies” that is unfortunately a part of our country’s history.

Beyond theoretical concerns, those opposed to financial incentives predict a tremendous increase in administrative requirements and therefore cost. Such money would be better spent on more education for the public and medical communities regarding the need for organ donation via the current altruistic system and the benefit to society as a whole through this process.

Beyond the fact that proposed financial incentives may actually prove to be *disincentives* to potential donors, it has been argued that financial gain by the donor family does not address the problem that many potential donor families are simply never asked. This failure by the medical community to participate in the donation process should not be addressed by incentives directed at the potential donor alone.

The current organ donor procurement policies, essentially in effect during the entire span of transplantation technology, has resulted in an ever-widening gap between demand and supply. Indeed, demand far outstrips supply. Yet persons who never would have considered being donors, bitterly complain when in need and no organ is available for them or their loved ones. In 1999 we have arrived at this untenable position by divorcing responsibility and obligation from rights. But can we grant such rights without also ascribing the correlating obligation and responsibility? If you feel that you have a right to an organ, should you need one, do you not have a duty to be prepared to donate yours should you no longer be in need of it while another is?

The concept outlined above, would function with relatively equivalent probabilities like an inexpensive insurance policy. For a potential donor, expressing a willingness to donate in the present would yield the potential payoff of a preferred status should the potential donor ever need an organ him or herself in the future. Should some unfortunate set of circumstances arise causing a end-stage organ failure, the enrolled preferred status donor would receive the equivalent of an insurance payoff by moving to the top of any waiting list for a particular organ that was necessary for his or her survival. Should the willing donor never suffer from end-stage organ disease, he would die knowing that altruistically he had affirmatively registered his desire to become a donor. This particular method would remove the ideal of family veto from the equation. All involved would know beforehand of the expressed wishes of the decedent. Again, the benefit is analogous to an inexpensive insurance contract. By agreeing to be a donor any time that death occurred, he would receive an incentive in the form of a preferred status should he at some point in the future require an organ himself.

At least two ethical issues are important in considering preferred status. If preferred status were initiated, what would be the balance between the ethical good and bad? And, as an independent utilitarian ethical issue, what would be the impact on the system? In other words, is it necessary to consider both whether the process is intrinsically justified ethically and whether it would actually help or harm organ donation?

The impact on the system would depend strongly on the perception of society and the transplant community as to the ethical worth of preferred status and this would involve mainly the degree to which the process was deemed to be fair. A net ethical good from this point of view would accrue from an increased perception that organ donation is important to all, transplants are successful, and the system works without barriers to the disadvantaged segments of society.

The net ethical worth of preferred status is partly an issue of justice. Is it fair for an individual who is willing to participate in the system of transplantation to not receive an organ while another medically similar individual who was unwilling to participate receives a transplant? On the other hand, it may be framed in terms of autonomy. Intrinsic to the altruistic approach to organ donation is the autonomy of each person to decide.

Because the life-giving organ represents a benefit that transcends money, its value is the same to a very poor disadvantaged person as to a wealthy one, unlike a monetary consideration. It would be hoped that the disadvantaged, now particularly likely to view organ donation and transplantation with suspicion, might realize a sense of democracy in their rightful access to the same option as any other citizen. This could be particularly

important in the case of minorities – and especially for Blacks, who have a particular need in view of their higher incidence of kidney failure. It would encourage donation by this segment of the population that is particularly likely to also need the availability of a transplant.

Some possibilities by which preferred status might produce harm are derived from negative speculations on its potential for good. A primary objection is that there are two sides to the issue of fairness. Consider the scenario of two medically similar patients, for whom preferred status would be the tiebreaker. The other patient has lived an exemplary life, has contributed financially and personally to medical causes including transplantation, and therefore has directly benefited many other people but has not felt comfortable agreeing to organ donation. Is there justice in the former person receiving the organ, allowing that one arbitrary fact of opting in to the system to override all the other comparative points, which would tilt the choice toward the latter? In fact, opting in is not considered a determinant of moral worth, but rather a social contract, again, as mentioned above, a sort of insurance that everyone has a right to, if they wish to make the commitment. However, it would be pointless to argue that there's not a measure of worth connected to the concept of preferred status. If only one factor, preferred status, were to be instituted, might that start the altruistic system down a slippery slope of increasing calculations of worth that have so far been avoided?

Advantages of preferred status over other approaches toward incentivizing organ donation include intrinsic fairness with regard to "opting in," the fact that special priceless organ does not represent financial payment, and that it would be equitable across all strata of society.

In Chapter Five, which follows, I'll examine the current policies, which regulate transplantation in the United States. The only existing law on the statutes is the 1984 NOTA, which contained a "sunset" clause calling for its expiration every three years. NOTA was re-authorized in 1987 and in 1990. Congress, however, has not re-authorized NOTA since 1990. Throughout the decade of the 1990's, there have been many significant advances in the fields of medicine, surgery, technology, and pharmacological therapies – in general, and quite specifically in the field of transplantation. Nevertheless, Congress has abdicated its responsibility, and as a result finds itself behind the curve in areas such as research and development, medical science, and especially ethical interpretations of the various innovations and improvements to the field. In early 1998, the U. S. Department of Health and Human Services, attempting to fill the vacuum created by Congress, issued new sets of regulations affecting the transplantation universe. The preceding nine years, law and regulations have fallen very far behind the current state of the art. Most of the recommendations and the new regulations proposed by HHS, were targeted at clarifying/remedying issues that everyone within the transplant community agreed needed to be addressed. However, several major issues relating to the donation, recipient selection, national allocation, and equity created something of a firestorm during the summer of 1998 when both houses of the U. S. Congress held hearings. Nothing was resolved during the course of the House and Senate Hearings on the HHS proposed regulations, but, both Houses voted in committee, to table the issuance of the regulations for one year. In Chapter Five we will examine the proposed new policies that had the potential for dramatically changing the transplantation world as it is evolved at the end of the Twentieth Century.

Endnotes

- ¹ Fox, Renee & Swazey, Judith, Spare Parts: Organ Replacement in American Society, Oxford University Press, N. Y., 1992, p. 65, according to Fox and Swazey, Jacobs' plan was condemned by the National Kidney Foundation, The Transplantation Society, The American Society of Transplant Physicians, and The American Society of Transplant Surgeons, all of which resolved to expel any members involved with the plan.
- ² Childress, J. F., "Ethical Criteria for Procuring and Distributing Organs for Transplantation," in Blumstein, J. F., Sloan, F. A., editors, Organ Transplantation Policy: Issues and Prospects, Durham, N. C., Duke University Press, 1989, pp. 87-113.
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- ¹¹ Murray, T. H., "Gifts of the Body and the Needs of Strangers," *Hastings Center Report*, 1987, vol. 17, 30-38.

¹² The Gallup Organization, "Highlights of Public Attitudes Toward Organ Donation and Transplantation," Boston Mass., *Partnership For Organ Donation*, 1995, pp. 1-8.

NOTE TO USERS

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CHAPTER FIVE

CURRENT POLICIES

CONCLUSIONS AND RECOMMENDATIONS

In the preceding chapters I have established the environment in which the medical specialty and practice of organ transplantation has evolved and developed during the last thirty-plus years. Although contemplated by mankind and medicine for centuries, transplantation truly has only been successfully performed since the early 1960s. In the early days of experimentation, and indeed even as the first living donor transplants were being performed, there was a great outcry amongst nearly all segments of the population regarding the ethical parameters within which organs were being procured and distributed to end-stage organ failure patients. The hypothesis herein is that the legal and moral legitimacy established in the beginning for organ procurement has always been based on altruistic volunteerism. However, within the first chapter, I made the claim that altruism has failed. It has failed in any sense of pragmatic measurement of being an efficient or efficacious method of procuring organs for transplantation. As discussed in earlier chapters, annually, a relatively constant number of individuals have actually benefitted from receiving an organ from a donor. The number of successful transplants has hovered at approximately 20,000 successful procedures performed over a span of the preceding five years. Notwithstanding, the advancements in surgical techniques, new

technologies, and the development of new immuno-suppressive drug therapies, the list of those waiting is approximately 60,000 and growing at a rate of approximately 500 new patients a month. Clearly, the supply of medically suitable donor organs has not kept up with the ever-increasing demand for this life-saving or life-enhancing scarce resource.

In Chapter One, I made a brief historical reference as to the efficiency, ethicacy, and legitimacy of the two existing United States laws governing and regulating transplantation. The Uniform Anatomical Gift Act of 1968 (ratified by all fifty states by 1973), and the National Organ Transplant Act (NOTA, enacted in 1984), remain the only two national policies relating to organ transplantation. As we near the close of the Twentieth Century, a vacuum in terms of direction and policy clearly exists at the national, as well as the local policy level.

In Chapter Five, I will be examining in greater detail the impacts upon organ donation of UAGA and NOTA, as well as, analyzing new policies that were first proposed in April of 1998. Following the critical assessment of the proposed new regulations, I will summarize my conclusions drawn from the analysis of the first four chapters, and make specific policy recommendations that can achieve a balance between efficiency and legitimacy on the one hand, and ethics and morality on the other.

Historical Transplant Policy Perspective

In 1984, NOTA envisioned a national transplant system operated by medical and healthcare professionals that would ensure an equitable allocation system serving the public's interest with oversight by the United States Department of Health and Human Services (HHS). The act created the Organ Procurement and Transplantation Network

(OPTN), a nonprofit private sector network to be operated by a contractor approved by HHS.¹ (See Appendix A, Table 5). Originally, OPTN membership and policies were voluntary. But with enactment of the 1986 Budget Reconciliation Act, all hospitals that perform transplants and all organ procurement organizations (OPO's) were required to abide by the rules and requirements of the OPTN in order to receive Medicare and Medicaid reimbursements. In December 1989, HHS issued a Federal Register notice indicating that all OPTN rules and requirements remain voluntary until the Secretary issued regulations to define the rules and policy-making procedures of the OPTN and HHS. However, a Notice of Proposed Rule making was not published until September of 1994, a lapse of nearly five years.

After two extensive comments periods and three days of special hearings, HHS announced a Final Rule aimed at providing the framework for the operation of the OPTN, and assurance that the nation's organ procurement and transplantation system operates for the greatest benefit of transplant patients. The regulation builds on medical technology advancements which can be adapted to accommodate future enhancements, directs the medical community to provide leadership in transplant development, sets procedures for involvement by patients, donors, and their families, and sets goals for the fair and effective use of donated organs. The 1996 announcement carried a two-year "buffer period" prior to becoming effective.

On April 2, 1998, Secretary Shalala published HHS' notice in the Federal Register announcing the implementation of the "Final Rule" 90 days hence (including a last 60-day comment period). The Rule provides the framework within which the OPTN, its members and all other participants in organ procurement and transplantation will

operate. The Rule sets the requirements for the structure of and membership in the OPTN, the OPTN policy-making process – including the Secretary’s oversight; standardized criteria for placing candidates on a national waiting list; equitable organ procurement and allocation; evaluation of OPTN activities; and record maintenance and reporting by the OPTN, OPO’s and all transplant hospitals.

Unfortunately, the topic of altruism in organ donation is only discussed peripherally or tangentially within HHS’ 1998 proposed Final Rule. The issues described herein, relating to incentives to improve the organ donor rate, are not discussed directly at all within the proposed HHS regulation. Indeed, the majority of the subjects covered in the Final Rule relate to the equitable allocation and distribution of organs – however many come into the distribution system. The Final Rule does not specifically approach the complex issues of procurement, whether they are related to altruism or to an incentive-based encouragement system. In other words, the 1998 proposed regulation essentially sets forth regulations and parameters for the recipient’s side of the transplantation equation. Granted, there are numerous inefficiencies and inequities that infect the recipient/distribution side. However, many if not most of the recipients’ problems – administrative, medical, legal, ethical, and several other practical/pragmatic categories – would not even exist if Congress and/or HHS had first worked on the donation side of the equation. The resultant state of affairs is that, HHS, acting in the near total vacuum of Congress’ nine years of healthcare legislation inactivity, effectively put the cart in front of the horse. This is not totally surprising, however, in that recipient side issues mostly relating to allocation/distributional aspects are more heavily weighted in the day-to-day administration of actually performing transplants. No one denies that

there are a myriad of ethical issues relating to recipient selection; rather it is that if the supply problems were eliminated or at the minimum greatly reduced, many of the ethical problems affecting recipient selection would cease to exist.

Therefore, in a chapter that should be devoted to analysis of current policies and integration of same with the ethical and moral issues that are the elements of my hypotheses, I arrive at something of a cul de sac. There are policies that are contained within the 1984 NOTA, and although they exist, they are not efficient, current or legitimate. 1984 NOTA policies are several orders of magnitude behind the advancements in medical and surgical techniques and procedures, pharmacological drug therapies and their applications, that are today's scientific realities. Pragmatically, NOTA policies in many cases, are even further orders of magnitude behind actual day-to-day operational realities.

1998 HHS Final Rule Impacts on Organ Donation

There has been at least one potential organ donation impact resulting from the proposed Final Rule. That impact on donation is related to and bound together with several very complex variables affecting organ allocation and distribution. One of the key goals of the HHS Final Rule, indeed, the main goal, is to "improve the *equity* of the nation's transplant system."² *Equity*, in this context means that as far as medically feasible, there should be a "level playing field" in organ allocations. Organs should be allocated based on patients' medical need and sound medical judgment, with less emphasis on keeping organs in the local area where they are procured. Patients should have an equal chance to receive an organ based on their medical need, not the accident of

geography. Efforts should be made to equalize waiting time among different regions of the country. Those goals, as stated by HHS in April 1998, when spelled out in detail would have wide-ranging impacts on not only donors but also potential recipients. The idea behind this proposal is that HHS wants to move donated cadaver organs from where they are harvested and send them in an *equitable* fashion to the end-stage patient that has the greatest medical need (urgency). This could mean no more than keeping it in the same hospital, moving it across town or at the extreme moving it across the country (an extremely rare occurrence today, given perishability). Notwithstanding medical criteria affecting perishability, this has become a hot political issue in several states.

Each state has adopted a version of the Uniform Anatomical Gift Act (UAGA) that provides for human organs to be donated for transplantation as a “gift of life” given by a person to another person. In the United States, it is state law that guides organ donation. The UAGA and the state UAGA describe classes of persons who are legally capable of making such gifts and further, describes classes of persons who are legally capable of receiving such gifts. The current organ procurement system was essentially designed to honor state UAGA laws.

If the HHS Final Rule is implemented on October 1, 1999, as currently anticipated, many within the transplant community fear that smaller transplant centers will end up closing. This will occur because if organs are shipped around the country based on need, they are going to be moved towards the major metropolitan population centers. Again, that is the goal and the stated objective, notwithstanding the perishability issues. Fearing the closure of transplant centers within their state, a loss of jobs, and

potential backlash in the numbers of donated organs, several states have already taken steps to preserve local transplantation programs.

Indeed, on April 30, 1998 Representative Robert Livingston of Louisiana, while attaching an amendment to a spending bill, remarked that Louisiana had enacted an amendment to its state UAGA law restricting the export of donor organs out of Louisiana. Further, Senator Robert Torricelli of New Jersey, testifying on September 10, 1998 in opposition to the Final Rule stated “the current organ transplant program has been an extraordinary success.” The problem, he said, “is that there are simply not enough organs being donated locally.” He expressed support for those states (including New Jersey) that have passed legislation to restrict the exportation of organs outside the state in which they are donated.³ Subsequent to the release of the HHS proposal on April 2nd, 1998, at least a dozen states have passed similar restrictions on exporting organs donated within those same states.

In Louisiana, the first state to enact an amendment to its state UAGA, there was a large outcry when the Final Rule was first proposed. The State Legislature hurriedly passed the amendment to its UAGA. Interestingly, donations within Louisiana have picked up in the third and fourth quarters of 1998 since the adoption of this export restriction.⁴ It remains to be seen, how many states will take a state’s rights position in the face of a planned federalization of transplant policies. The states have a few factors working in their favor. First, organ procurement has always been a localized activity. Second, the reason for that has been and remains, the perishability factor of the donated organs. Harvested organs have a very short viable life span once removed from the host body. Third, donor families have been interviewed in Louisiana, New Jersey, Oklahoma,

South Carolina, Wisconsin, and several other states that have passed laws mandating organs be offered first to their own citizens. These families have made anecdotal statements relating to the fact that given a relatively common understanding of the perishability factor, that they would not have gone ahead with the donation if they believed that it might be wasted in the process of getting it to a remote location in another part of the United States.

Unfortunately, local, state, and donor family backlash could significantly impact donation as well as the future of the proposed regulation. This backlash has come about because of the highly publicized and negative nature of the debate amongst the various transplant industry participants – physicians, hospital transplant centers, organ procurement organizations (OPO's) – and as trumpeted in the national media ever since the public announcement of the HHS regulation. Overall, it is believed that patients are losing because the highly publicized nature of the debate has to be dampening the U.S. public's willingness to donate organs. People do not trust the system and according to several opinion polls, that is a major reason why people who should donate do not. When newspaper headlines, wire service stories, and TV news programs feature one organization's victory over another in organ allocation/donation, commonsense says it must be hurting donations. Like it or not, fiery claims and counter claims lead to perceptions of confusion and mistrust, perception is reality.

Given all the year-long negative debate and publicity, the federally sponsored Coalition on Donation has been finding it extremely difficult to wage a successful public education campaign about the importance of being an organ and tissue donor in light of the above-mentioned heated public debate. The Coalition has only a ten million-dollar

budget appropriation in which to carry out its mission of promoting education regarding organ and tissue donation. Given all the negativity circulating around the proposed regulations, it should come as no surprise if the final numbers for 1998 and the totals for 1999 fall below expectations. It appears that the negative policy debate is about power. Actually it is about a lot more than that. It is about the self-appointed mandate by HHS to improve equity in the organ allocation system (along with departmental/federal oversight), that has so stirred the debate among the medical, legal, hospital, insurance, and patients' rights groups. Indeed, there is a great deal of money, power, prestige, and authority at stake for the first four above listed interest groups, while perhaps only life or a quality of life better lived, that is the driver for the patient's issues.

Conclusions

Along the way toward the goal of deriving a set of final conclusions, the analysis to this point has illuminated several intermediate conclusions about how and why altruism has failed to address adequately the organ donors supply problem.

Chapter Two examined the (mostly empirical) costs vs. benefits viewpoint of the supply problem. Health economics in its larger sense deals with creating policy tools that can be used in establishing and making a case for the allocation of healthcare in a greater societal top-down view. In this context, society may often decide that healthcare resources and public financial support are as scarce as any other normal economic goods. Society may decide that at some point there are diminishing marginal benefits to employing resources and monetary funding towards the solution or cure of a particular health problem. That would certainly be the macroeconomic viewpoint. In a

microeconomic sense, however, individuals often find that there are ways to obtain and utilize healthcare resources, such as organs for transplant, when society as a whole has made an empirical decision to allocate resources elsewhere. Closing Chapter Two was a listing and brief description of several practical suggestions for alleviating the donor shortage. Most of these had little or nothing to do with altruism, focusing instead on the concept of either market solutions to the problem or taking a more utilitarian (greatest good for the greatest number) approach. Most of these alternatives would be discarded while a few others were more thoroughly examined in a succeeding chapter.

The intermediate conclusion drawn from analysis in Chapter Three is that regardless of the large number of ethical, moral, cultural, psychological, racial, and other practical issues facing individuals in society, we are not going to be able to address why society has tepidly allowed altruism to fail, until we begin to treat organ donation as a societal obligation, rather than an act of volunteerism. Chapter Three examines all of the above categories in some detail, in the determination of which factors impact on a population made up of individuals that combine to prevent any of us as individuals from expressing, at the end of our lives, a desire to save or help others in desperate need. The many moral, ethical, psychological, behavioral, cultural and racial issues intertwine and become the ingredients of an attitudinal “soup” that when consumed from childhood on forms the basis of our moral viewpoint. The intermediate conclusions of Chapter Three drawn from the analysis, point to the desperate need to improve the donor rate in U.S. minorities. Both Blacks and Hispanics as groups are simultaneously on both ends of the donor-need continuum. First, a great deal of analysis has shown that those racial groups represent the greatest need factors when considering allocations to receive a transplant

and yet, simultaneously, these groups historically are donating at less than five percent of their population. With more Blacks and Hispanics, proportionately, on the waiting list, the two group's reluctance to donate causes an imbalance *vis à vis* saving lives. A second intermediate conclusion drawn from the analysis of the minorities, relates to possible solutions to this problem. A stepped-up continuous barrage of educational media needs to be more focused and re-targeted on the minority populations. These two groups represent the greatest number of patients waiting on lists, the greatest number of patients subsisting on dialysis, and the greatest number of patients who die either while waiting on a list or from ignorance or an original lack of knowledge about the transplant process. A third intermediate conclusion rising from the analysis in Chapter Three, points to the obligation of society in organ donation. Where there is an endemic cultural reluctance to become involved, society, here in the guise of a race or culture, truly has an obligation to step forward and energize the resources to communicate the benefits; while alleviating the fears and misunderstandings regarding donation and transplantation. Only then can the minority populations, which are particularly susceptible to certain end-stage organ failures, fully partake in the miracle that organ transplantation, via the "gift of life," represents.

Chapter Four revisits some of the incentive and/or proactive actions that have been discussed as potential solutions to the donor supply problem. Some of the issues analyzed, such as future contracts for agreeing to become an organ donor upon death and non-financial programs such as required response and presumed consent, all offer some possibility or hope for alleviating the donor supply problem. As discussed in the analysis, some of the incentives are ethically questionable. Similarly, some of the

proposed policy changes, also pose an ethical dilemma. In analyzing the various proposals for financial incentives, I looked at both pro and con arguments to determine where the greatest moral dilemmas might exist. I used the same analytical technique in discussing the non-financial policy recommendations. While financial incentives may seem viable, to implement any of them would require a change in existing law. For that matter, implementing any of the non-financial policy solutions would also require changing existing law.

Of the non-financial solutions, the concepts of required response and presumed consent offer the most potential for improving the raw numbers and thus the donor rate. Both ideas have been described in the transplantation literature for a number of years. However, the numerous references have differed as to scope, ethical viability and implementation strategies. Presumed consent is currently enacted as statute in Belgium, The Netherlands, Luxembourg, The Scandinavian Countries, and is part of a pilot program in the United Kingdom. Results from those countries over the last five years show dramatic donation increases versus a like period of time historically. Notwithstanding my arguments in Chapter Three which spoke to the dominance of libertarian moralities in the U.S., wherein stronger feelings toward individualism and property rights are pre-eminent, a communitarian effect appears to have much more influence in parts of Europe. This should not be surprising, as the intellectual underpinnings of communitarianism are, of course, socialism and earlier the more egalitarian versions of communism. Europe has long traditions of community priority over the individual – personal property rights there are nowhere near as sacrosanct as in the U.S. Nevertheless, in Europe, presumed consent is working and their society is

benefiting as evidenced by the increased numbers of both donations and transplants. The citizenry has banded to provide greater benefits for the society as a whole, and after several years of trial, do not appear to be ethically the worse.

Required response means that when citizens desire to obtain or renew certain public documents, they will be asked the question as to their choice when it comes to organ donation. Without penalty, they may choose either yes or no. Required response should be able to improve the participation rate of those who have predetermined what their wishes are for their body parts after they die. The act of requiring either an affirmative or negative response will over time increase the aggregate number of people who have indicated what their desires are. In Europe, statistically, this impact is positive.

A third non-financial action that could improve the donor rate is the concept of preferred status. This concept, which is gaining support within an ever-widening circle in the transplantation community, simply states that if you are willing to register as a donor, if at some point later in life you need a transplant, you would move to the head of the list. Preferred status is much less ethically challenging than presumed consent or even required response. The issue is, of course, could it generate the numbers necessary to narrow the gap between donations and the required number of organs needed for transplant. Indeed, that is the key question, because otherwise, it successfully answers most of the ethical problems/questions relating to receiving a payment for volunteering to donate. Indicating a willingness to donate appears to be an appropriate quid pro quo for the slim possibility that at some point later in life being rewarded by moving to the head of the list to receive one's own transplant. Projections have shown that the adoption of this proposal could generate adequate supplies of donor organs. Indeed, in the aggregate,

the numbers of identified “potential” cadaveric donors would likely increase sharply, ultimately benefiting many. Therefore, while the percentage of useable organs (per capita) donated would remain the same, at below 5 percent, the projected raw increases in “potential” donors would ratchet up the aggregate supply. Further, for the individual, the odds of end-stage organ failure requiring a transplant, are also slightly less than 5 percent. Ethically, that works well – no segments of the population would be asked to donate (after death) at a greater rate than the probability of ever needing an organ personally. That further assumes that the minority populations that are more susceptible to certain organ-killing diseases receive, accept and act upon increased targeted educational, informational, and communications programs about their particular groups’ need factors. Once known and understood, it is hoped that the minorities will increase their proportional participation in their rational self interest.

On the other hand, the twin concepts of presumed consent and required response are probably not yet ethically suitable for the U. S. culture and citizenry. Belgium has found that for practical reasons, implementing required response first and getting the population used to the idea of “opting-in” or “opting-out” gets the potential donor over the psychological hurdle of considering his’ or her’s own mortality, while at the same time effectively eliminating family veto as a barrier to the decedent’s altruistic final wishes.

Policy Recommendations

After all of the discussion and analysis of all of the various factors affecting altruistic organ donation, it is my conclusion that none of the ethical or practical solutions

can solve the supply dilemma on its own. However, I do not view the organ supply dilemma as a permanently unsolvable problem. Therefore, I make the following policy recommendations which, if enacted, can in various combinations of at least two or more, have a positive impact on the donor rate among all demographic segments of the population.

1. Educational programs that communicate the benefits of organ donation, while countering rumor and misconceptions, should be produced and widely disseminated via all types of media. This should be tactically implemented in a national campaign that specifically targets minorities by emphasizing their groups' particular tissue-matching needs.
2. Implement educational campaigns that emphasize that organ donation is an obligation, rather than a supererogatory act of charity or altruism. This would be an innovative approach, and not without risks. To avoid potential conflicts with autonomy and self-determination embedded in U.S. culture as libertarian body parts-property rights precepts, pilot or test campaigns should be conceptualized and implemented first. I think this would yield significant improvements in the organ donor rate over time, yet I recognize that it also would require a paradigm shift.
3. Required request, which as discussed in the body of this thesis, mandates an answer to a request to become an organ donor. This would occur at points of civil contact where the population interacts with local government, e.g., DMV, courts, licensing bureaus of all types, voter registration etc. Additionally, I call for the establishment of a national database that records the answers and is accessible to

Emergency Room personnel, hospitals, physicians and transplant coordinators – all of whom have the ability to access at the time the decision to harvest needs to be made. Further, concurrent with the enactment of required request, rules should be in place that say that the database record of any individual's consent or refusal to donate organs will govern, rather than the family's desire at the time of death. If a person cannot be found in the database, the person's organs would not be harvested. This upholds the ethical concept of consent being explicit rather than presumed. Required request is likely to lead to a widespread changing of attitudes in the U.S. regarding organ donations. If such a change in attitudes occurs, (1) discussing organ donations with families of the deceased will be much easier and (2) it may become commonplace and expected that donation will occur when medically appropriate.

4. Preferred status is recommended for persons who volunteer to become organ donors while living. In exchange, they would be given a preferred status on waiting lists in obtaining an organ, should they come to need one. This is a form of an incentive-based solution to the supply problems discussed in this thesis, and although not originally conceived herein, this approach is substantially new to organ procurement and has not widespread attention.

Any or all of the above will have to show in principle, that they can be set up and run without any appearance of ethical misconduct or abuse. When the total number of persons waiting on transplant lists is correlated with the number of people who are dying each year on those lists and further correlated with estimates of the number of individuals who statistically/realistically do not get counted on either list, the time for establishing

policy-based pilot programs for a combination or version of the above solutions is drawing near. In personal interviews with several transplant surgeons and clinicians at U.C.L.A. Medical Center, it is estimated that if the waiting list approaches to one hundred thousand people and/or the number of people dying while waiting on the lists reaches close to twenty to twenty-five thousand people, there will be a great awakening of interest and a movement towards establishing full blown solution programs. As discussed earlier in this chapter, any or all require changing the morally embedded UAGA and/or NOTA laws. My recommendations assume those changes as necessary preconditions.

As a final comment, the answer to the question asked by this thesis: Can the donor rate be improved in organ transplantation? – is unequivocally, yes. That answer will come into its own reality when, as the central theme of Chapter Three states, society comes to the conclusion and realization that donating organs upon death is an obligation, and not merely volunteeristic Good Samaritanism. Therefore, our society, perhaps goaded by the spectre of unnecessarily lost lives, must shed some of our libertarian individualism and look to ourselves as a whole community being better able to provide solutions for those in need. The whole acting together can, in most cases, solve greater problems than individuals acting alone. It is synergistic, and when we as the society, reach that conclusion, we will have collectively arrived at a higher moral level of civilization.

Endnotes

¹ Functionally, OPTN is a policy-making executive board of directors. HHS has oversight for OPTN. The OPO's are the local/regional procurement/allocation agencies that actually do the work. UNOS (United Network of Organ Sharing) is the day-to-day operational contractor which sets criteria, manages data collection, and maintains waiting lists for all OPO's.

² Department of Health and Human Services, Health Resources and Services Administration, 42 CFR, Part 121, Docket #: 98-HRSA-01.

³ Health Resources and Services Administration, "HRSA Newsbrief", Senate Subcommittee Hears Testimony on Organ Transplantation Regulations, September 17, 1998.

⁴ National Kidney Foundation, "Transplant Chronicles," vol. 6, No. 4, Winter 1999.

APPENDIX A

TABLE 1

Number of Transplants Performed in 1997*

Type of Transplant	Number
kidney-pancreas transplants	853
kidney alone transplants (3,712 were living donors)	11,470
pancreas alone transplants	208
liver transplants	4,165
heart transplants	2,292
heart-lung transplants	62
lung transplants	928
intestine transplants	67
Total	20,045

*Based on UNOS Scientific Registry data as of January 4, 1999. Double kidney, double lung, and heart-lung transplants are counted as one transplant. NOTE: Data subject to change due to future data submission or correction.

TABLE 2

Number of Donors Recovered, 1997*

Type of Donation	Number
cadaveric	5,478
living	3,820
Total	9,298

*Based on UNOS Scientific Registry data as of January 4, 1999. Double kidney, double lung, and heart-lung transplants are counted as one transplant. NOTE: Data subject to change due to future data submission or correction

TABLE 3

On March 31, 1999 the UNOS National patient waiting list for organ transplant includes the following:

Type of Transplant	Registrations for Transplant	Patients Waiting for Transplant
kidney transplant	42,981	41,135
liver transplant	12,817	12,618
pancreas transplant	454	444
pancreas islet cell transplant	119	119
kidney-pancreas transplant	4,219	1,807
intestine transplant	114	114
heart transplant	4,219	4,203
heart-lung transplant	250	247
lung transplant	3,247	3,195
Totals	Total Registrations: 66,071	*Total Patients: 62,068

NOTE: UNOS policies allow patients to be listed with more than one transplant center (multiple-listing), thus the number of registrations is greater than the actual number of patients.

*Some patients are waiting for more than one organ, therefore the total number of patients is less than the sum of patients waiting for each organ.

TABLE 4
Number of Patients Removed from the OPTN Waiting List Due to Death
January 1, 1988 - December 31, 1998

Organ	Year										
	1988	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998
Heart-Lung	61	74	66	41	43	51	47	28	49	56	41
Heart	493	517	613	778	779	761	724	769	745	772	767
Intestine	0	0	0	0	0	3	15	19	21	41	45
Kidney	734	749	916	974	1047	1277	1365	1503	1802	1989	2295
Kidney-Pancreas	0	0	0	0	14	59	70	84	91	121	93
Liver	196	282	317	435	495	560	655	797	956	1130	1319
Lung	16	38	50	137	218	251	286	340	386	409	486
Pancreas	5	21	19	35	32	2	8	3	3	11	9
Overall	1494	1659	1958	2351	2573	2883	3053	3414	3896	4313	4855

* Totals for each column will not equal overall total because some patients are listed more than once. Based on UNOS OPTN/Scientific Registry Data as of February 24, 1999. Data subject to change due to future data submission or correction.

TABLE 5

Number and Type of UNOS Members

Type of UNOS Member	Number
Transplant Centers	272
Consortium Members	3
Independent Organ Procurement Organizations (OPOs)	53
Independent Tissue Typing Laboratories (TTLs)	56
Voluntary Health Organizations	12
General Public Members	9
Medical/Scientific Organizations	29
Total	434

NOTE: Of the 272 transplant centers, 12 have in-house OPO's and 103 have in-house histocompatibility labs.

Number and Type of Organ Transplant Programs

Currently, 272 medical institutions in the United States operate organ transplant programs. These transplant centers can be separated into organ specific programs that include the following:

Type of Program	Number
Kidney Transplant Programs	252
Liver Transplant Programs	125
Pancreas Transplant Programs	125
Pancreas Islet Cell Transplant Programs	21
Intestine Transplant Programs	32
Heart Transplant Programs	153
Heart-Lung Transplant Programs	94
Lung Transplant Programs	89
Total	891

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

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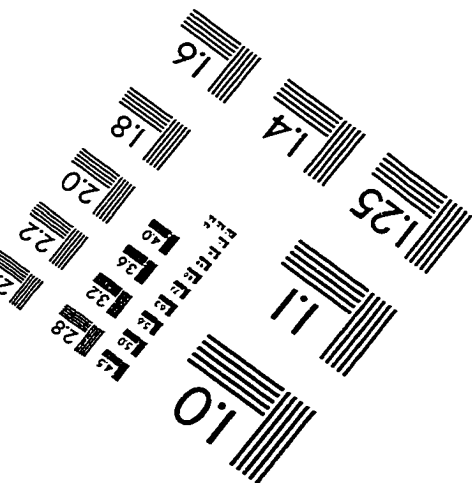
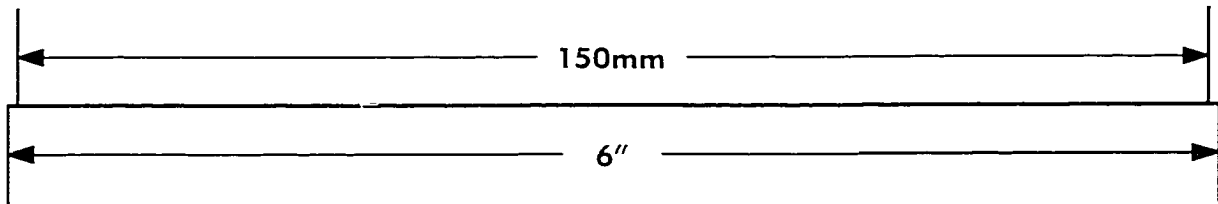
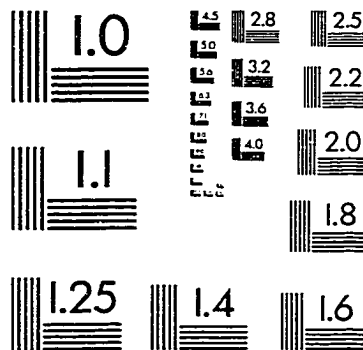
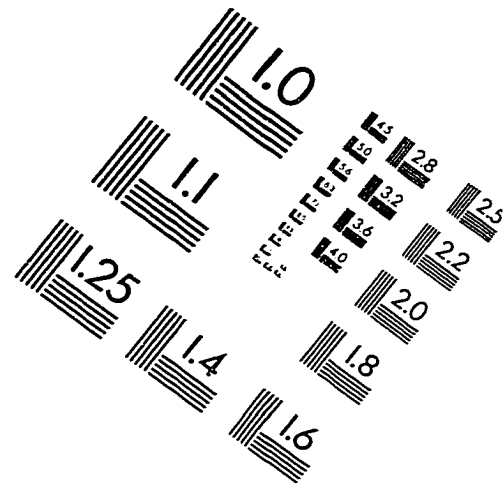
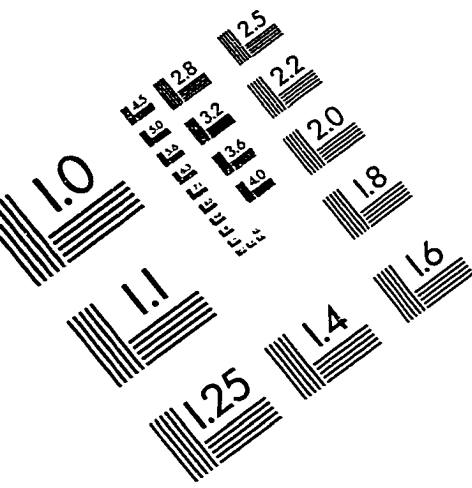
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