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"Reflections on the Unintended Consequences of Planning Local Justice; The Case of Organ Transplantation in the U.S."

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**Reflections on the Unintended Consequences
of Planning Local Justice: The Case of Organ
Transplantation in the U.S.***

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The study of human society would be bereft of subject matter if all attempts to change it were realized in the intended manner. The precise correspondence of intention and outcome would reflect a society whose lack of complexity does not require analytical sophistication or tedious empirical inquiry for its comprehension. Individuals in societies react to exogenous influences with sufficient unpredictability to frustrate not only the designers of interventions but also those who merely aim to understand their effects. Although the founders of sociology assumed that positivism would enable us to reduce human behavior into laws, we now in the main concede the futility of reining in the unintended consequences of human behavior and must settle for a mature appreciation that the best-laid plans often go wrong.

This paper examines the recent history of a particular kind of intervention, the regulation of organ transplantation in the U.S. The case study illuminates the trade-offs in institutionalizing a theory of local justice, as opposed to permitting local justice to remain a by-product of unregulated cooperation and competition. Human kidneys, livers, and hearts are distributed according to principles, whether considered fair or not, of local justice. The legislative attempt to thwart discrimination by transplant surgeons might have the unintended effect of both reducing organ supply and creating new and distasteful forms of discrimination. The paper is divided into sections on the concept of local justice, the then and now of organ procurement and distribution, the political history of regulation in organ transplantation, and a discussion of some of the intentions which have and have not been fulfilled. The purpose here is to demonstrate not the lack of foresight in the designers of the

regulations but that the enterprise itself was handicapped from the start. Though it is too early to say conclusively, there is evidence that organs are neither in greater supply nor more equitably allocated as a result of policy intervention.

Local justice

Local justice is conceived as one of several causes of the allocative behavior of individuals. Theories of local justice specify allocative principles by which particular kinds of scarce goods (and exemptions from burdens) are distributed. Administrators of institutions and others in discretionary control of the allocation of scarce goods are presumed to favor a theory of local justice which they would prefer to implement in practice. To the extent that they do, local justice contributes to the ways scarce goods are allocated. Theories of local justice are used in the allocation of scarce, in-kind goods (like admissions to universities, places in a day-care center, promotions in the workplace, and organs for transplantation) because theories of global justice have vague or non-existent implications for their distribution. J. Rawls's Theory of justice, for example, is silent on local allocative dilemmas. Instead, theories of global justice concern things which we all value and need, such as money or the right to free association.

Whether consciously or not, transplanters allocate organs to patients according to theories of local justice. For present purposes, however, the relevant variation is not which theories are accepted but their degree of enforced uniformity. (For a discussion of allocative principles such as need, equality, status, contribution, and productivity, see J. Elster's several papers on the topic.)¹ Allocative uniformity

implies political control. If the goal is to have every allocator distribute a given good in accordance with a particular vision of local justice (i.e., to maximize the number of life-years saved per treatment), a necessary feature is the vigilant administration of the allocators in order to assure their accountability. Mechanical decision rules are instrumental in making allocators accountable. Decision mechanisms like queues, point systems, allocation by age or status, and absolute equality employ comparatively coarse and easily derived data of patients and in this way lends themselves to monitoring.

Allocative mechanisms have their drawbacks. One potential drawback should attract our immediate concern: What are the effects on organ supply of the political attempt to make transplanters accountable for implementing a specified theory of local justice? A second question is, Does the resulting distribution of organs square with our received notions of local justice? Since the wished-for and obtained results of planning local justice are not necessarily coterminous, scarcity and inequities in allocation might be aggravated by enforcing uniform allocative practices.

In different terminology, the issue is whether policies enforced by first-order actors, motivated by a concern for local justice, compromise second-order autonomy such that the policies are consequently counterproductive. Following Calabresi and Bobbitt,² first-order actors (such as the federal government and health insurance companies) determine the total supply of a given scarce good by their macro-allocations of resources. Second-order actors, such as transplanters, make micro-allocative decisions, namely who is to receive a scarce good and who is not. Patients and their families affected by

local distributions are third-order actors.³ Second-order actors are rarely empowered to implement their favored theory of local justice since they must juggle first- and third-order interests.

There is considerable potential for conflict between first- and third-order actors on one side and second-order actors on the other. When transplanters, for instance, have allocative autonomy, the opacity of the decision process by which some are chosen and others are not invites the scrutiny of politicians, regulators, and patients unsatisfied with levels of organ supply and observed patterns of organ distribution. The temptation to bound second-order autonomy is great in such circumstances. As will be argued, contradicted by more sophisticated arguments and unsupported by the available evidence, the policy finding that second-order autonomy hurts transplantation is founded on a prejudice that planning local justice is better.

The old and new in the organization of transplantation

Transplantation took off in the early 1980s, passing from the stage of "experiment" to "mastery,"⁴ after clinical trials showed that new immunosuppressive drugs, especially cyclosporine, have a remarkable ability to forestall graft rejection. The surgical mechanics of transplantation had not been the bottleneck, despite an early pronouncement from a leading heart transplanter, Dr. Denton Cooley, that the prescription for success is to "cut well, tie well, get well."⁵ The number of kidney transplant procedures per year increased from 6 112 to 9 123 between 1983 and 1988; for hearts and livers, the numbers were 172 to 1 655 and 164 to 1 690, respectively. (See Appendix for more data on transplantation.) Transplant centers proliferated at a

maddening pace, especially for heart transplantation (done now at about 140 hospitals). The proliferation of transplant centers is akin to the spread of intensive care units in the 1960s, as having one became a prerequisite for respectability.

What follows below is a brief overview of both pre-regulation and current organ procurement and distribution practices. Describing the numerous contrasts between the two systems' structural characteristics is a necessary preamble to a discussion of the justifications argued on their behalf.

Until the federally-mandated Organ Procurement and Transplantation Network (OPTN) was executed in October 1987, transplant surgeons controlled the procurement of donated organs and their allocation to patients. That is to say, transplanters were more or less free to implement their own theories of local justice. Transplant centers carved out catchment areas or "fiefdoms." They were fiefdoms in two senses. A social norm among transplanters proscribed the "raiding" of patients in "foreign" catchment areas. Second, organs procured within a transplant center's catchment area were to be channeled to the same transplant center. Responsible for recruiting donor hospitals and making organ requests to the deceased's next-of-kin, procurement coordinators worked directly under the transplant surgeon in a hospital-based organ procurement agency (HOPA), the forerunner of organ procurement organizations (OPOs). In their zeal to receive more donor referrals from hospitals, procurement coordinators at times trespassed in the catchment areas of other HOPAs. Once receiving a donor referral and consent for donation, the local transplant team would

harvest or procure the organs and transplant them into their own patients.

In the early 1980s, a second kind of OPO, independent organ procurement agencies (IOPAs), began to supplant HOPAs. By 1984, the IOPAs and HOPAs reached parity in the size of their respective (potential) donor population pools. IOPAs, sometimes called organ banks, serve two or more transplant centers and are not directly affiliated with any one center. Transplant surgeons voluntarily established IOPAs without federal assistance in order to systematize procurement in their locales, prevent organ wastage, and coordinate the laboratory work involved in donor-recipient matching.

Transplant surgeons worked out a number of ways in which to "share" organs. When an organ is "shared," the procuring surgeon has handed over the organ to another HOPA or IOPA for distribution to an individual patient. Before the OPTN was established, organ sharing was limited to the local level.⁶ In transplantation short-hand, the three types of local sharing of kidneys are known as "keep two, share none," "keep one, share one," and "keep none, share two." That is, in "keep one, share one," the procuring surgeon keeps the first kidney for one of his patients under the "surgeon's option" rule and "shares" the second kidney with another local center. In areas of the country I have researched (mostly in Illinois, Minnesota, California, Texas, New England, and Virginia), the "keep one, share one" rule has been followed the most frequently, followed by "keep two" and then (rarely) "keep none." That is to say, the procuring surgeon had been given the right to transplant at least one of the two procured kidneys into one of his own patients.

The style of organ sharing is connected to how local transplant centers integrate their waiting lists of patients. OPOs manipulate waiting lists in four ways (as outlined in the table below.) In

Types of Organ Procurement Organizations By Local Waiting Lists, Kidneys

1. Common-list OPOs
Common list is used to allocate both procured kidneys.
Example: Regional Organ Bank of Illinois (ROBI), Organ Procurement Agency of Michigan
2. Multiple-list OPOs
A donor network or organ bank which allocates center-specific allocations, not patient-specific allocations of kidneys.
Examples: Northern California Donor Network, South Texas Organ Bank since 1987
3. Common/multiple-list OPOs
Common list is used to allocate "first" kidney, list of the procuring transplant center is used to allocate the "second" kidney.
 - A. Authority to procure a donor is granted by the OPO.
Example: New England Organ Bank
 - i. The OPO permits transplant center to have "first dibs" on donor referrals in hospitals adjacent to it.
 - ii. The OPO makes no distinction between adjacent and non-adjacent hospitals when allocating procurement authority.
 - B. Procuring authority is self-assigned. Transplant center operates its own hospital-based organ procurement agency (HOPA). Example: Illinois Transplant Society (replaced by ROBI)
4. HOPAs
 - A. Affiliated with donor network or organ bank as in 3B.
 - B. Unaffiliated. Example: University of Wisconsin-Madison

the pre-OPTN era, common-list OPOs which provided for the "surgeon's option" (number 3) and HOPAs without local organ-sharing agreements (number 4) were the norm. The first two are found in large numbers today.

Common waiting list OPOs are organ procurement organizations which maintain a single list (per organ) including all the patients listed at local transplant centers. The common list serves as the basis for kidney distributions in the OPO. Since the OPO does not know which center(s) will receive the kidneys until after they have been retrieved and tissue typed at the OPO laboratory, the OPO uses a rotation system to determine which transplant center will be responsible for surgically removing the donor kidneys. Donor and recipient information are run against an allocative point system. A computer printout ranks the potential recipients without regard to which local center they are listed. The two top-ranked patients are accordingly given priority for transplantation. From the vantage point of the procuring surgeon, this arrangement is perceived as "expect to keep none, probably share two."

Multiple waiting list OPOs are purely organ-retrieval agencies. This second type of procurement organization is not charged with the allocation of organs to individual patients. Instead, multiple-list OPOs coordinate the placement of organs to transplant centers, not patients. For each type of organ, transplant specialists agree on a "rotating-share" arrangement. For example, suppose there are three centers in an OPO, one of which (center A) has about half of the total number of patients waiting for a kidney and the other two (centers B and C) have about one-quarter each. The transplanters devise a twenty-place rotation in which every other place on the rotation is labeled A, while the remaining places

alternate between B and C. (This is the system used in San Antonio.) When a donor becomes available, the two kidneys are procured and transplanted by a surgical team representing the center whose name is at the top of the rotation. A similar arrangement is used in San Francisco. As will be shown later, multiple-list OPOs were established by surgeons in reaction to the formation of OPOs designated by the Department of Health and Human Services (DHHS) in 1987.

Third, a hybrid of the common-list and multiple-list OPOs is found in considerable numbers today. Common/multiple-OPOs permit the procuring surgeon to match the first kidney with a patient on his center's waiting list and require that the second kidney be allocated against the shared, OPO-level waiting list. There are two types of common/multiple-list OPOs. First, the selection of the procurement team can be made by the OPO. The OPO may recognize that a transplant center should have priority access to donors in hospitals adjacent to the center or alternatively allocate procurement authority on the basis of rotating share (without regard to historical claims made by a particular center to a given hospital's donors). Second, procurement authority can be self-assigned. Here the procurement is on a "finders, keepers" basis. Transplant centers are affiliated to a local organ bank yet maintain their own HOPA. The organ bank in this case is charged with allocating the second of the two kidneys, preventing organ wastage, and engaging in professional education of ICU staff in donor hospitals.

Fourth, HOPAs are affiliated with an organ bank, as just noted, or remain independent. Independent HOPAs are a source of controversy since their distribution practices are not actively overseen by local competing transplant centers. When HOPAs happen to have large

catchment areas and no other transplant centers in the OPO, their patients tend to get transplanted faster than the norm. Such HOPAs have a market advantage which frustrates transplant centers which must compete for organs within their OPOs.

Until 1982 affiliated and unaffiliated HOPAs dominated the scene. Since then HOPAs have either been replaced by federally-designated OPOs or have become designated OPOs. In larger cities, the norm was that competing HOPAs were consolidated into OPOs. Congress charged OPOs with the responsibility to "allocate donated organs among transplant centers and patients according to established medical criteria" and granted monopoly rights to procurement.⁷ The reorganization of procurement erased common/multiple-list OPOs composed of affiliated HOPAs (3B above), as procurement coordinators became employees of OPOs rather than individual surgeons at HOPAs.

Interviews of transplanters and recent initiatives by the DHHS and the federally-designated manager of the OPTN, the United Network for Organ Sharing (UNOS), indicate that the future belongs to common-list OPOs. Multiple-list OPOs and common/multiple-list OPOs (i.e, 3A(i) above) are considered by federal regulators to be insufficiently "patient-centered" since the allocation of a given organ passes through the intermediary step of allocation to a transplant center. The product of bargaining between local transplant centers, rotating-share agreements are never a precise reflection of the actual distribution of patients across centers. Patients savvy enough to analyze the rotation deduce which center has the most favorable patients-waiting-to-organs-received ratio. Local justice, according to DHHS regulators and agreed to by Congress, requires a precise correlation between patient prospects for

transplantation and patient characteristics (e.g., length of time on waiting list, blood type, etc.) in an OPO.⁸

A second argument from local justice favors common-list OPOs since they are consistent with the value of medical efficiency. Allocations from common lists are thought to improve medical outcomes. The chances of finding a well-matched recipient (determined by tissue typing) increase in proportion to the size of the recipient pool. Medical ethicists and specialists in tissue typing share an interest in legislating common-list OPOs and ultimately a single national list from which all kidneys would be allocated. Much to the displeasure of transplanters, the argument by the tissue typers that matching makes for better medicine undercuts the legitimacy of multiple-list OPOs and local organ allocation.

If they are not able to run their own HOPAs, transplanters favor multiple-list and common/multiple-list OPOs because they make organ flows to individual centers predictable. These two systems assure transplanters that there will be a constant stream of organs to their respective centers. The issue here is whether the claims of "patient-centered" formulas are more valid than those from inter-center equity. In Northern California in 1987, the OPO included one very large kidney program, a second large program, and three smaller programs (now just two). If the programs were to share a common waiting list, the smaller programs argued, the supply of organs to the small programs would be intolerably irregular. The smaller programs lobbied and obtained an organ-sharing agreement by which each small center would receive the authority to procure the kidneys of every ninth cadaveric donor in the OPO. Since "O" blood type kidneys are particularly scarce relative to

demand, a second rotation was established so that each small center received every ninth pair of "O" kidneys. Once a center procures the organs, the transplanters distribute them within the center according to a point or priority system set up by the OPO and approved by UNOS.

A point which cannot be settled here is whether organ allocation by rotating share facilitates organ procurement. In a common-list OPO, as noted above, procuring surgeons retrieve kidneys without expectation of keeping them for in-center distribution. In a multiple-list OPO, with some exceptions for technical reasons (concerning retrieval of hearts and livers), procuring renal surgeons do subsequently transplant the kidneys into their own patients. Does the knowledge that it is a transplant team's "turn" to procure organs, ceteris paribus, raise the likelihood that a given donor referral will end in successful procurement?

One anachronism from the pre-OPTN era lingers on: the continuation of HOPAs which have been reorganized into OPOs and remain attached to a particular transplant center. These are exceptions now, as symbolized by the recent history of one of the most active HOPAs. The Pittsburgh Transplant Foundation and Dr. Starzl's transplant program at the University of Pittsburgh are nearly synonymous. Recently they have become distinct organizational entities, the reorganization being a response to an upstart hospital's decision to begin its own transplant program in Pittsburgh. It will be instructive to compare the procurement effectiveness of independent HOPAs, where all the retrieved kidneys (except for perfectly-matched ones) go to a single transplant center, and common-list OPOs, where a wall between procurement and distribution has been erected.

NOTA and dissatisfaction with decentralization

The reorganization of organ procurement and distribution followed from the "Gore for President Bill" (as it was called by some) or the National Organ Transplant Act of 1984. NOTA was conceived initially to legislate federal coverage for immunosuppressive drugs and provide federal money for fledgling OPOs. For the first time, transplanters were drawn away from the business of saving lives and experimentation and into the political realm. The transplanters got into politics in order to secure federal coverage for the drugs which revolutionized transplantation and which are too expensive for many transplant patients to buy independently. Chairing the first set of hearings, then-Representative A. Gore devoted much of the subcommittee's time to testimony from desperate children needing liver transplants, the relieved parents whose children had received them, and the pioneering liver transplant, Dr. T. Starzl, who lobbied before a sympathetic chairman that liver transplantation should be covered by the federal government.

The bill evolved into more of a regulatory device than a reimbursement mechanism. The elements in it which would have provided coverage for drugs and extra-renal transplantation at selected centers dropped out in lieu of the prohibition of organ purchases, the establishment of a procurement and transplantation network, and the creation of a federal task force on transplantation. The transplanters, with some exceptions, were lukewarm to the proposal for an OPTN, which (transplanters feared) would increase regional and national organ sharing. Federal coverage for extra-renal transplants was bogged down in disagreements over the propriety and legality of the mechanism by

which transplant centers would be selected for federal reimbursement. Coverage for cyclosporine likewise fell victim to an application of the ESRD metaphor, namely that disease-specific entitlement programs are budget-busters. The transplanters initially envisaged an exchange of federal coverage for federal regulation and were disillusioned when all they received was regulation. The transplanters received the reassurance that the created task force would examine whether immunosuppressive drugs should be covered.⁹

The National Organ Transplant Act of 1984 ushered in a new era of political transplantation. It resulted in the regulation of patient selection through the OPTN and the bureaucratization of organ procurement. DHHS assigned monopoly control to OPOs in designated services areas. That is, for a given area, such as the state of Arkansas, a single OPO monopolizes organ procurement, legally excluding the independent efforts of local transplanters in HOPAs, and regulates organ distribution. In addition, the organizational characteristics of OPOs were overhauled. Unless in a HOPA-run OPO, procurement coordinators work for a committee of transplanters and other health officials, not a single chief of transplantation. Lastly, the newly-beefed up OPOs compose a transplant network or OPTN which enforces the uniform and equitable allocation¹⁰ of organs to patients according to formulas approved by the UNOS Board of Directors.¹¹

Intervention for the better?

The intention of NOTA and the subsequent by-laws of UNOS was to increase organ supply and ensure the equitable allocation of organs. Since the national task force claims that "donated organs

[should] be considered a national resource to be used for the public good, the public must participate in the decisions of how this resource can be used to best serve the public interest,"¹² one might expect that rational deliberation informed the federal intervention. Study of the task force report and Congressional hearings, however, reveals that unargued and/or unsubstantiated premises prop up the justifications for the intervention.¹³ An appreciation that no one could predict the effects of the intervention is not in evidence. Scientific hubris takes many forms. In this instance it was assisted by the petitio principii that criminalizing competition in organ procurement, centralizing the administration of organ procurement, and placing allocative authority in remote computer hardware would benefit transplant patients. NOTA is an easily-won ideational victory of system over spontaneous ordering.

The task force appealed to three justifications in support of the establishment of rational organization, the OPTN. First, organ sharing between transplant centers and OPOs should be increased so that donors and recipients can be better matched. Organ sharing requires combined waiting lists--hence a national network or OPTN--and thus the separation of organ distribution from procurement. As also evident in the third justification, the task force betrayed a narrow understanding of the effects of allocation policy. It had ample sensitivity to the effects of allocation policy on the public's willingness to donate, yet did not analyze their effects on the willingness of transplanters to procure organs.¹⁴

Second, the consolidation of HOPAs into OPOs, the constitutive units of the OPTN, would increase organ supply. Noted above, IOPAs (or organ banks), had been proliferating spontaneously between 1980 (22 IOPAs) and 1985 (54). Transplant surgeons, then, had been forming

organ banks without federal intervention. Rather than allowing this process to work itself out, the task force reiterated NOTA's intent to certify one OPO with the characteristics of IOPAs per donor referral area (one state or area able to generate 50 donors a year). The suggestion was shored up and endorsed by a capable study which concluded that IOPAs are more effective than HOPAs. The data, though, drew on organ procurement in 1982--ancient history for transplantation, since the major growth years were 1984 and 1985. On top of sampling limitations, the task force found impressive that the kidneys procured per million population were 20.3 and 22.5 for HOPAs and organ banks, respectively. The study did not control for the size of the OPA fiscal budgets--that is, the very kind of deficiency which the federal government can correct.¹⁵ Armed with unconvincing data and some testimony that HOPAs in some large cities were at each others' throats, the task force recommended a restructuring of organ procurement.

Third, the ethicists on the task force argued that there are "moral connections between procurement and distribution."¹⁶ If organs are distributed inequitably, the argument went, then public willingness to donate organs would decrease. Similarly, if access to the lists of transplant centers is a function of personal wealth, the poor will be unwilling to consent to organ donation. The latter argument aside, sensitivity to organ allocation is, it turned out, of very little concern to the general public, as shown in a UNOS-commissioned survey of opinion¹⁷ and should have been evident to anyone who reads the testimonies given during the Congressional hearings (where concern for micro-allocation issues was almost non-existent). The task force overreacted to a scathing and near-demagogic series of articles in the Pittsburgh Press¹⁸ which

purported to show that Dr. Starzl's center favors rich non-immigrant foreigners over U.S. citizens on its waiting list.¹⁹

Privately, transplant surgeons offer justifications for leaving organ allocation and procurement decentralized. These justifications differ in kind from those offered by the task force. The surgeons focus on the dynamic, long-term, and systemic effects of transplant policy, while the task force report accents static, short-term, and particular effects.²⁰ Basing policy on an analysis of the latter set of effects gives the argumentative advantage to those who argue for formally rational policy prescriptions. For example, the task force noted that some, perhaps a minority, of hospital-based organ procurement agencies operated sub-optimally due to a lack of organization. The inferential leap was made that the organizational cure for this sub-set of procurement agencies would increase organ supply when extended to the entire organ procurement system. Once clearly stated it appears illogical to hold that the best procurement agencies should be remedied by a cure designed to improve the malfunctioning procurement agencies. A more sophisticated analysis would, first, have speculated on the long-term consequences of permitting the best procurement agencies to serve as a model for the inefficient ones and second, have inquired into the system-wide effects of rationalizing the entire system rather than some of its parts.

The example can be extended to illustrate one of the arguments based on dynamic effects which some transplanters offer. The point here is not so much that the argument is correct but that it has a degree of analytical sophistication not found in the task force report.

Some transplanters argue that hospital-based procurement agencies (or organ banks established by transplanters themselves) are

better adapted to the realities of organ procurement. The reality is that organ procurement is hard work involving an awesome amount of training and education of ICU and emergency room staff in a transplant center's locale. Due to high labor turnover and forgetfulness of the priority of procurement in donor hospitals, procurement coordinators must visit local hospitals frequently if they are to receive a steady stream of donor referrals. Organ procurement also requires untimely as well as time-consuming donor runs, often in the middle of the night and out of state. Transplanters argue that motivating procurement coordinators to do their job demands ample incentives.

The key difference between HOPAs and non-HOPA OPOs is that only in the former are the transplanters directly involved in the procurement process. Here is where the relationship between procurement and organ distribution is vital. Transplanters contend that the combination of having procurement coordinators under their direct control and an organ allocation system which permits the surgeon to keep at least one of the two kidneys provides a maximum of incentives for aggressive organ procurement. At a minimum, they contend, the dynamic interaction between procurement and distribution should be respected by institutionalizing the expectation that the procuring surgeon keeps one of two kidneys and has priority access to donors in adjacent hospitals. Whether by having them run HOPAs or by institutionalizing the "surgeon's option," the intended and beneficial result, transplanters argue, is that they have an interest in improving organ donation and referral rates in their locales.

In theory the pre-OPTN system supplied these incentives in two forms. On the negative side, slacking was noticed and censured by

the procurement coordinator's employer, the transplanter. The transplanter himself was motivated to monitor the coordinators because of the expectation that he would be allowed to transplant procured organs into his patients. Transplanters run cottage industries dependent on their reputed capacity to obtain organs, as well as their ability to achieve good medical outcomes. On the positive side, procurement coordinators do receive personal satisfaction in helping transplant patients in their own centers. It is an undeniable fact that an affective relation develops between the procurement coordinator and the patients in a given center. Knowing that procured organs are for in-center distribution, a transplant patient prompts the procurement coordinator not to miss a donor opportunity.

The transplanters acknowledge that their favored system of procurement will inevitably produce a non-trivial proportion of inefficient procurement efforts. A normal distribution of productive and unproductive procurement agencies is expected. Some transplanters and procurement coordinators will be less committed to their work. Ethicists contend that individual patients listed at such centers should not pay the cost of inefficient procurement. Again, since the argument looks at particular inequities, it fails to note that a greater inequity would be the implementation of a system which, though standardizing procurement practices, procures fewer organs as a whole. The argument also overlooks the fact that the federal government has demanded from UNOS that patients be unrestricted in their choice of transplant centers. Rational patients seek to find centers where the patients-to-available organs ratio is lowest. Accordingly, there is the promise of a general equilibrium between overpopulated centers with efficient procurement

agencies and underpopulated centers with inefficient procurement efforts.

Transplanters also concede that permitting them to allocate the organs according to their discretion entails some risks. Some transplanters might abuse the privilege and transplant wealthy foreigners over Americans or white, middle-class males will get transplanted at a higher than average rate. Dr. Starzl himself observed that once he had implemented his "multifactorial system" for organ distribution, a backlog of high-risk patients who had been waiting for years for a transplant was reduced substantially. This is not to say that Dr. Starzl's center had been transplanting the "wrong" patients but simply had been cautious in patient selection.

I propose that we consider the hypothesis that the architects of NOTA, the national task force on transplantation, and current reformists underestimate the negative influence of implementing "equitable" schemes of organ allocation on organ supply. It is wishful thinking to assume that fairness and supply go together. Organ procurement was centralized not only to increase organ supply but also, just as importantly, to rationalize the distribution of organs. Each OPO is to administer a queue of all local patients for each organ type, selecting patients for organ receipt without regard to which transplant center a given patient has been admitted. Organ procurement could have been modernized while leaving in place a system of organ allocation which provides incentives for transplant professionals to engage in the professional education of ICU staffs. One such system is to respect the "surgeon's option" in circumstances where the donor resides in a hospital affiliated with a transplant center. In this way transplanters would have

a direct interest in increasing organ donation in particular hospitals, as they would expect to receive one out of every two kidneys retrieved from them. In exchange for stimulating more professional education and a larger organ supply, the "patient-centeredness" of organ allocation would be sacrificed. The intellectual error was in supposing that the same method--formal rationalization--could improve both the equitability of organ distribution and the organization of procurement.

So far the argument has stressed the counterproductive effects of federal intervention on organ supply. With regard to its effects on equitable organ allocation, there are four additional kinds of effects to be discussed. First, graft and patient survival rates might be negatively affected because (a) they do not consider all relevant patient information and (b) consider the wrong information. Second, a rigid allocation process produces patterns of allocations which we might consider unfair. Third, it undermines medical innovation. And, fourth, it politicizes organ allocation. These will be elaborated in turn.

1. In the pre-OPTN period, transplanters and clinical coordinators would informally meet to decide on whom should be transplanted when an organ(s) becomes available. The amount of information considered in an informal decision process is vastly larger than could be used by a standard allocative formula. Who is feeling well today? Is one of the patients dangerously depressed on account of waiting for so long for a transplant? UNOS policy permits the surgeon the discretion to "pass" on an offer to receive an organ. Yet since offers are patient-specific, the transplanter is not empowered to give that organ to another patient simply because he has a "gut" feeling or medically-informed intuition that this patient should be transplanted next. The

incentive is to accept an organ offer, regardless of the patient's relative ability to benefit from the procedure.

Allocative formulas can hurt graft and patient survival rates not only by failing to take into account all relevant patient data but by singling out particular kinds of data. For example, it is well known that "sensitized" ESRD patients (i.e., those with a build-up of anti-bodies) have lower graft and patient survival rates than non-sensitized patients. Nonetheless Dr. Starzl's allocation formula and the present UNOS formula give this class of patients allocative priority.²¹ The goal is to increase their otherwise poor prospects for receipt of organs. If we agree that organs are a precious "national resource" (as the task force report claims) and that the national interest requires that each organ produce a maximum of life-years saved, then entrusting allocation to a formula which systematically gives kidneys to compromised patients would be inconsistent with proper "stewardship."

2. Patient-specific allocations have had an especially hurtful influence on black transplant patients. Allocation by formula has the capacity to overlook as well as take into account the special needs of patients. When it overlooks special needs, it ties the hands of transplanters who are predisposed to give priority to these patients. The UNOS formula includes a criterion (to over-simplify) which allocates points to patients whose strong antigens (genetic markers on T- and B-lymphocytes) match those of the donor. Three factors make this allocative criterion problematic for black patients. Whites and blacks have different antigen profiles on average; blacks have a higher incidence of ESRD; and blacks donate organs (both cadaveric and living-related donation) at a lower rate than whites. Inner-city transplant

surgeons complain that they would like to transplant their black patients in greater numbers and then cite the UNOS formula which hamstring their desire to do so. The complaint is most often heard in common-list OPOs, where centers with predominantly white patients can expect to receive more organs than centers with mostly black patients.

3. Transplanters also argue that allocation by formula inhibits innovation. Transplantation has not reached a steady-state in its development. Transplanters are continually testing the limits of their knowledge. In one common scenario, procured kidneys of dubious quality (i.e., damaged due to prolonged ischemia, mishandling, etc.) would be used for experimental purposes, such as the transplantation of a very aged patient. Another example is a Houston renal transplant who wants to attract patients who will undergo radiation therapy. He favors giving allocative priority to patients who are willing to undergo the therapy and as a result is under the scrutiny of UNOS officials. Allocation by formula when regulated narrowly, however, is intolerant of physician discrimination between good and less-than-good kidneys, experimental and non-experimental therapies.

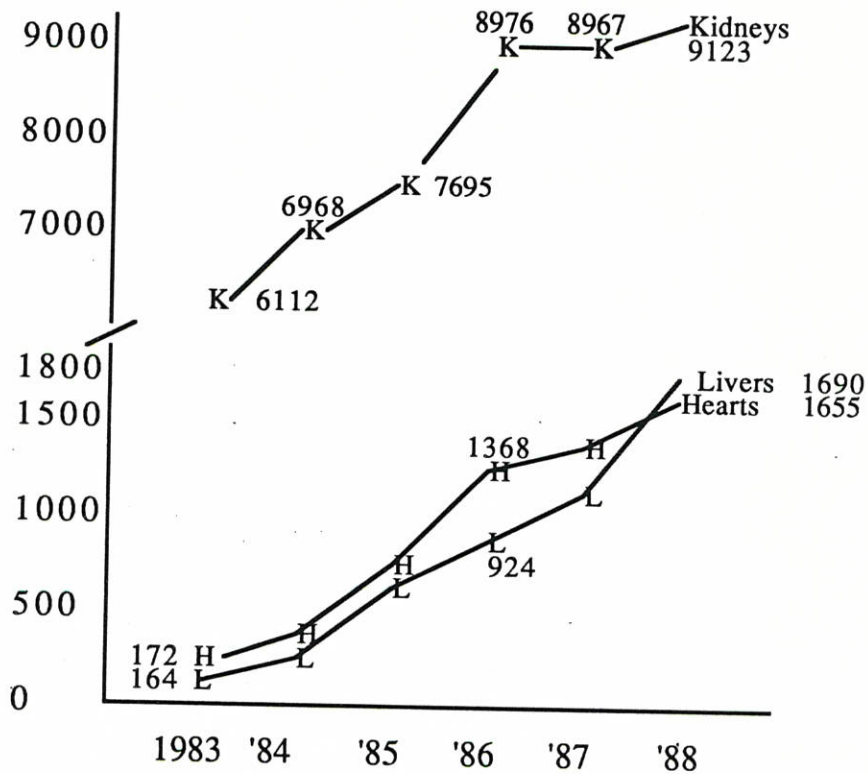
4. Allocative decentralization dispersed power across a large transplant community. Studies of allocative outcomes, such as by Kjellstrand, observe that white, middle-aged males were transplanted at a higher rate than other subpopulations. Tellingly, the studies could not assign responsibility of this fact to any particular interest.²² The application of cold medical logic by hundreds of surgeons appeared to be behind patterns of organ allocation. In the present period by contrast allocative outcomes are the direct descendant of formal allocative mechanisms of UNOS-approved design. For good or bad, a vital

difference between the pre-OPTN period and now is that in the former the charge of "inequitable allocation" lacked a suitably powerful target, whereas now the finger-pointing is in the direction of the UNOS Board of Directors.²³ Claims that the OPTN works against the interests of black patients now have force.²⁴

The rationalization of procurement and distribution has only since early 1989 become fully operational. It is not too soon to ask whether organ supply has been impaired by the OPTN. We already know that the OPTN has reduced the prospects for blacks seeking kidneys by imposing allocative formulas friendly to tissue-typing interests, lowered graft survival rates by favoring sensitized patients, and by assumption we can argue that medical innovation has been retarded.

Measured by the number of organs transplanted, supply has not increased during the OPTN period. Rather there is evidence that the expected rate of increase in organ supply was nullified by the intervention. The figure below charts organ supply from 1983-1988.

Number of Transplants in U.S., Per Year



Sources: UNOS, Quality Assurance Department, (1989), "Information Report," and P. Rettig (1989)

The figure suggests that the number of kidney transplants increased marginally in 1988, the first year the OPTN was in operation. Dr. W.K. Vaughn, the UNOS director of technical services, remarks that 1988 was the first year for which complete data on transplant procedures are available. Thus it is very likely that the pre-1988 statistics undercount the number of procedures. Massive gains in organ supply were achieved during the pre-OPTN period. The increase in the number of extra-renal transplants in 1987-1988 reflects the diffusion of heart and liver transplant centers during the same period.

Preliminary UNOS data suggest that 1989 was a bad year for organ procurement. During the first eight months of 1988 and 1989, there were 2 756 and 2 546 donors procured, respectively.²⁵ Cadaveric donation decreased by almost 8 percent. Since the decrease is coincident with the operationalization of the OPTN, there is reason to hypothesize a causal connection between the OPTN and UNOS allocative policy on the one hand and declining organ procurement on the other. Congressmen in 1984 had been persuaded that there were 20 000 donors available for procurement each year. The ability to procure these, however, appears to have been arrested once their measures to centralize allocation and procurement were executed. A caveat, however, is in order. It would be premature to pronounce with finality that the OPTN is a hurtful influence. We are unable at this point to isolate the effects of the transition to the OPTN from the steady-state effects which we can expect once the OPTN is stabilized and the transplant community has adjusted their expectations and behaviors accordingly.²⁶

Within the transplant community it is well known that a small minority of acute-care hospitals are the source for a plurality if not majority of donor referrals. Certain hospitals in Indianapolis and Peoria, for example, are active in referring donors. Hospitals having transplant centers are also active, on average. Persuading (and reminding persuaded) emergency room and ICU staff that organ donation should be a high priority is a task requiring a costly effort on the part of transplant surgeons and procurement coordinators. The suggestion is that once the organization of procurement was transferred to professionals removed from the transplant center and once allocative policy detached distribution from procurement, transplanters and their coordinators lost

the incentive to persuade ICU and emergency room staff that they should be committed to organ retrieval.

Conclusion

Congress and UNOS have attempted to reform organ procurement and allocation through implementing formally rational and uniform policies. The attempt was motivated by the belief that everything that can be done to increase organ supply should be done. In this sense, the goal was to transform a subject of local justice--where some patients must be chosen over others--into a collective good where the organ donation rate is equal to patient demand. However, planning local justice by denying the intractability of scarcity can actually make the scarcity worse.

Advocates of regulation also aspired to make access to organs equitable. Local justice requires that strictly medical considerations should determine who is and is not to receive an organ. When held to a high standard, local justice insists that second-order actors be accountable for implementing the principle of local medical justice. Since a prerequisite for accountability is the existence of rules to which to conform, uniform allocation policies were designed by identifiable persons. Consequently, politicization supplanted professional autonomy. Do we really want an institutionalized understanding of how our society ranks the relative needs of patients? Will not such understandings always exclude the legitimate claims of some? Also, uniformity in allocation has reduced medical innovation and negated the surgeon's discretion to give an organ to the patient he feels is in greatest need. Graft and patient survival rates are expected to be lowered significantly,

as high-risk patients are favored over others and patient selection is based on circumscribed information.

Perhaps most importantly, intentionalizing equitability through impersonal allocative formulas divorces the transplantor's role as surgeon from his role as advocate for transplantation. At present the transplantor labors to boost donor awareness without the expectation that his efforts will benefit his own patients. In so doing he is contributing to a collective good from which other surgeons benefit in equal proportion. We might agree that moral universalism is an ideal toward which we should all strive. Yet in the process we are gambling that the pursuit of this ideal will not be at the expense of critically-ill patients needing an organ transplant.

APPENDIX

Characteristics of National Transplant Waiting Lists, 1988

<u>Characteristics</u>	<u>Kidney</u>	<u>Liver</u>	<u>Heart</u>
Number Waiting January 1, 1988	12 009	454	699
Number added on list in 1988	12 030	2 052	3 742
Failed transplants % of total	18.5	23.9	5.7
Projected no. of additions due to failed transplant	3 609	N.A.	N.A.
No. of transplants Living related	1 845		
Cadaveric	7 278	1 690	1 655
Died Waiting No.	786	226	516
% of total waiting	3.7	9.6	11.8
No. waiting at year end	13 947	617	1 032
% change	16	36	48
No. waiting, 10/1989 % change from 1/1988	15 824 32	761 68	1 277 83
Listings/Organs Transplanted in 1988	2.6	1.5	2.7

ENDNOTES

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- * The Local Justice Project is funded by Russell Sage Foundation. Professor Jon Elster, Department of Political Science, University of Chicago, is the principal investigator. The concept of "local justice" is derived from his papers on the subject, "Local justice," "Local justice and interpersonal comparisons," and "Local justice and incentive effects" of the Working Paper Series on Local Justice. For a longer treatment, see M. Dennis "Local justice and the allocation of organs for transplantation" of same series. The paper was made possible by the contributions of numerous transplant surgeons and transplant coordinators, the Regional Organ Bank of Illinois, members of the Organ Procurement and Distribution Committee of the United Network for Organ Sharing, UNOS members D. Ferree and Dr. W. Vaughn, and Medicaid officials in several states, especially K. Staiano in Oregon. I would like to credit L. Rockley, L. Hopkins, Dr. S. Fellner, S. Ketchum, Dr. F. Stuart, Dr. J. Wolf. Finally to Patti Conley, many thanks.
- ¹Most relevant is J. Elster (1989), "Local justice and interpersonal comparisons," Number 2 of Working Paper Series on Local Justice, Department of Political Science, University of Chicago.
- ²The distinction between first- and second-order actors is derived from G. Calabresi and P. Bobbitt (1978), Tragic choices, New York: Norton, found in Chapter 1.
- ³J. Elster distinguishes third-order actors in his "Incentives and local justice," Number 7 of the Working Paper Series on Local Justice.
- ⁴A.L. Caplan makes the distinction, which he uses to explain the timing of public demands for federal funding of organ transplant procedures. See (1981), "Kidneys, ethics, and politics," Journal of Health Politics, Policy and Law 6(3):488-503.
- ⁵Quoted by N. Shumway in L. Gutkind (1988), Many sleepless nights, at p. 34.
- ⁶There were two exceptions. Budding national organ-sharing networks developed in the early 1980s. The United Network for Organ Sharing (SEOPF before 1984) provided a network of renal transplant centers for the placement of unwanted and well-matched kidneys and the Pittsburgh Transplant Foundation provided a less advanced service for extra-renal organs. Membership in both programs was strictly on a voluntary basis.
- ⁷National Organ Transplant Act of 1984, P.L. 98-507, 98 STAT. 2344.
- ⁸UNOS's current reevaluation of multiple-list OPOs is in response to Congressional action. National Organ Transplant Act Amendments of 1988 call for the OPTN to administer a system of organ allocation to "patients" striking out the earlier phrase "patients and transplant centers." See P.L. 100-607 (November 4, 1988), 102 STAT. 3115. UNOS President, Dr. R. Corry, wrote letters to certain OPO directors in October 1989 asking them to ascertain whether their organ allocation formulas are "patient centered."
- ⁹The task force later did recommend such coverage and subsequently the Immunosuppressive Drug Therapy Act of 1986 was signed into law.
- ¹⁰There are still some anomalous practices. They are being weeded out by UNOS.
- ¹¹In addition to NOTA, a second variety of federal intervention concerns the HCFA directive that all Medicare-participating hospitals (essentially all non-VA and military hospitals) must implement a protocol for the systematic identification of potential organ donors and asking of consent from the donor family. This intervention and its unintended effects on organ supply should be the topic of a

second paper and can only be hinted at in the next section. For the directive see DHHS, HCFA (March 1, 1988), Federal Register 53(40):6528-6551.

¹²Report of the Task Force on Transplantation, April 1986, Organ transplantation: Issues and recommendations, DHHS at p. 86.

¹³R.A. Rettig observes similarly in relation to the decision to grant OPO monopolies that "this policy is directed at several large cities...that have multiple transplant centers and have had multiple OPOs. The policy rests on practically no analysis, by either the task force or anyone else" at p. 209. See his Spring 1989, "Politics of organ transplantation," Journal of Health Politics, Policy and Law 14(1):191-228.

¹⁴See for instance Report of the Task Force on Transplantation, at p. 69, where a sensitivity to the motivations of transplanters should have been in evidence.

¹⁵The task force relied on J.M. Prottas (1985), "The structure and effectiveness of the U.S. organ procurement system," Inquiry 22:365-376. Prottas shows less that HOPAs are inferior to IOPAs than that small, presumably underfunded HOPAs are less effective than medium-sized HOPAs or IOPAs. Since he did not compare the relative budgets of HOPAs and IOPAs, the task force could not know whether smaller HOPAs are less effective because of budget constraints or organizational factors. Prottas says that transplant centers in IOPAs do not have their own procurement programs. It would have been interesting to compare the procurement effectiveness of IOPAs, such as the New England Organ Bank, which permit transplant centers to have first "dibs" on donor referrals in hospitals adjacent to the hospital to other IOPAs which allocate procurement rights without regard to the proximity of the donor hospital to the transplant center.

¹⁶The argument was advanced by task force member James Childress. See his (1987), "Some moral connections between organ procurement and organ distribution," Journal of Contemporary Health Law and Policy 3:85-110.

¹⁷See R.W. Evans and D.L. Manninen, (1988), "U.S. public opinion concerning the procurement and distribution of donor organs," Transplantation Proceedings 20(5):781-785.

¹⁸The sensationalist pieces ran May 12 and November 3-8, 1985. Some of the article titles are instructive of the moral temper of the pieces: "Exploiting trust: Neglect and greed infect transplant system," "Hard sell taints transplant market," "Neglect riddles U.S. kidney program," "Favoritism shrouds Presby transplant."

¹⁹A more careful assessment of the dynamics of organ donation would have shown that family refusals for organ donation have more to do with the behavior of neurosurgeons and inherent inconsistencies in the expected roles for ICU and emergency room physicians. Physicians are asked to do everything they can to save a patient's life while in constant contact with the patient's family and then without emotion report failure to the family with the footnote: We are sorry about your loss, Can we have the boy's organs?

²⁰Distinctions between partial/whole, short-term/long-term, static/dynamic are discussed fully in J. Elster's exposition of Alexis de Tocqueville's methodology in his Explaining technical change.

²¹Incidentally, sensitized patients are the only subpopulation of transplant patients meriting NOTA's special attention.

²²See C.M. Kjellstrand, (1988), "Age, sex, and race inequality in renal transplantation," Archives of Internal Medicine 148:1305-1309.

²³Very briefly, now that federal policy requires that UNOS agree on a single allocative mechanism for each organ type, the task of forging a consensus within the transplant community has been complicated by incompatible assessments of the

medical utility of allocation by tissue match, as well as other issues. As hinted in the text, since tissue matching goes along with national organ sharing, and medical ethicists and federal regulators believe organ sharing is more equitable than local allocations, a formidable alliance between tissue typers and ethicists has the transplanters pedalling backwards at this point in time.

²⁴This matter might not be containable to the transplant community. It was discussed with great concern at the October, 1989 UNOS Board of Directors meeting. Robert M. Veatch is one of the ethicists responsible for bringing the topic to wider, public attention, doing so in his "Allocating organs by utilitarianism is seen as favoring whites over blacks" (July 1989), Kennedy Institute of Ethics Newsletter 3(3).

²⁵UNOS, Quality Assurance Department, (1990), "Information report."

²⁶Again, the methodological distinction (transition/steady-state effects) is found in Tocqueville, as noted in J. Elster's Explaining technical change.