

# 12.5

## Commentary

### Organ Donation and Social Amelioration: A Two-Pronged Approach to Organ Trafficking

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This paper explores a model for reciprocating the contribution of organ donors to a health-care system characterized by inadequate resources and faced with the challenge of trying innovative ways of providing much-needed health care. A conceptual framework is proposed that recognizes a soft altruism being manifested in the contributions made by people who donate in the context of a social amelioration scheme. In order to bring out some of the characteristic features, a comparison is made with a presumed consent regime, which, while focused on cadaver organs, would appear to take advantage of the vulnerabilities of the poor when implemented in economically disadvantaged countries.

The model makes it possible for people to make their organs available for transplant while receiving benefits under a social amelioration program. The aim is to enable poor organ donors to emerge from the transactions in better health than otherwise, without loss of dignity, and having taken part in a collective undertaking that promotes the interests of organ donors and recipients alike.

An alternative model is offered that could be compared to better known methods for encouraging more people to donate organs for transplantation. Its merits can be seen in the following: (1) compared to other proposals based on the provision of incentives, it is less likely to be seen to regard human organs as mere commodities or to legitimize market transactions; (2) it involves a system for monitoring behavior of organ donors after transplant, ensuring post-transplant health care; (3) it offers a set of benefits that are already part of a social amelioration program in countries around the world; (4) rather than merely providing incentives, it seeks to ameliorate the conditions of the donors on a sustained basis; and most importantly, (5) it seeks to remove the donors from the exploitative conditions that have encouraged the poor to participate in human organ trade as vendors.

## The socio-economic context

The context assumed in this paper is one where there are many gaps in the public health care system as well as in the socio-economic support system so that many basic services are not readily available. In developing countries where kidney trade has been a problem, the public health insurance system is not comprehensive in scope. A similar situation is presumed to prevail in the discussion here. Health care is either too expensive or inadequate for many poor people. Private health insurance is beyond the reach of the poor. In a country like the Philippines, emergency health care for the poor is available only through public hospitals, which are already operating beyond capacity. In many instances, hospital clerks, interns, and residents have to provide medicine and medical supplies out of their own pocket so that necessary procedures can be carried out on patients assigned to them.

Although it costs less than protracted renal dialysis, organ transplantation is unaffordable for patients in developing countries who belong to the economic classes that many organ vendors are coming from. Thus we have a terribly asymmetrical situation where the sources of organs for transplant are always the poor and the beneficiaries of the transplants are always the rich.

Another area of disparity can be found in the foreigner–local citizens divide. A medical tourism program that caters more to foreign than local transplant patients has supported the activities of transplant centers. Despite current bans on organ selling, foreigners are attracted not only to relatively cheap organs but also to the relative ease of procurement through a network of organ brokers. Medical tourism has become a flagship program not only of private hospitals but also of governments as it provides them an opportunity to boost income and to promote other related services.

The system of governance is likely to be relatively weak and inefficient. As a result, a centralized waiting list is difficult to maintain. Transplant centers are left to devise their own procedures for matching ESRD patients with available kidney donors or cadaveric organs.

## Will presumed consent work?

Against this backdrop, it is difficult to see that presumed consent can serve as a viable and just option to improve transplantation rates. The establishment of a presumed consent or opt-in system for organ donation has been tried in many countries as a means of increasing the number of available organs for transplant. While its implementation may have resulted in an increase in donations, it is not certain that the success could be attributed directly to the removal of the need to opt in since other intervening factors come into play (Mossialos 2008; Gil-Diaz 2009: 260). Moreover, it would be risky to implement a presumed consent or opt-in system in developing countries where relevant governing institutions are not run efficiently and where the dissemination of information is not fully reliable. Many developing countries are also plagued by rampant corruption. Many countries where we would probably want a presumed consent system to succeed are also countries where the above-mentioned barriers to effective governance exist. We can accept that presumed consent has had a positive impact on donation rates, but

that that impact has not been due directly to the legalization of taking organs without the consent of families because in practice such consent has been sought, as in the case of Spain. Probably more important is the development of greater awareness among the public as a result of the intensive campaign among the relatives of the recently dead. But this intensive campaign does not necessarily have to take place in the context of presumed consent. It is also dangerous to implement presumed consent systems in developing and not efficiently managed countries where information dissemination cannot be fully relied upon and the poor and ignorant could be taken advantage of, even after death.

### Persistent organ trade

While organ selling has been prohibited, ESRD patients have continued to explore the resources available in an underground market, which has apparently flourished. Administrators of a leading hospital in the Philippines say that vendors have been roaming their premises, playing hide and seek with hospital guards who have had to chase them away. Out of 311 respondents to a survey of organ vendors conducted in the Philippines in 2007, 43 (13.8 percent) indicated the National Kidney and Transplant Institute as the site center where their nephrectomy was done. This represents a very significant number of cases that should not have taken place had authorities been more effective in their implementation of pertinent regulations. The situation reflects the economic desperation that has gripped organ sellers. The situation partly explains why the practice of organ selling has proven to be difficult to contain and control. It also illustrates a context where there has hardly been an opportunity for organ sellers to be altruistic in attitude. Obviously, organ sellers are being lured into the practice by the material incentives. An organ “donation” is often cast primarily as a straightforwardly monetary transaction. Given their tight economic situation, prospective organ vendors are ready to jump at any opportunity to make money in order to provide for their family’s needs. The focus is on the material gain and in what purportedly is beneficial in the transaction for them. The transaction is not situated in a context where an opportunity for altruistic contribution could be offered or where an altruistic attitude could be cultivated. This is evident in the particular reasons given by people for selling their kidneys—“feed one’s family,” “cancel a debt,” “buy land,” “improve the family shack,” “buy a pedicab,” having no better money-earning options, being tricked, being forcefully trafficked, and to purchase consumer items (Zargooshi 2001: 1790–9; Awaya, et al. 2009: 140; Mendoza 2010: 259). These studies also confirm some of the characteristics often attached to organ vendors—poverty, ignorance, and desperation.

### Altruism

In the context described above, one would think that there is no room for altruistic organ donation. Since material compensation is a primary consideration, any talk of altruism would seem to be incompatible. However, the view is offered here that it makes sense to speak of altruism in a “soft” sense of the organ donor having the willingness

to accept something of lesser value in exchange for the organ to be transplanted. In contrast, a “hard” form of altruism involves a willingness to give up an organ as part of a system of exchange where compensation is not expected (or is even forbidden) and is not regarded as a necessary condition for the donation of an organ.

In the soft sense, then, it is possible for an organ donor to receive compensation and still be regarded as altruistic. Because the organ that is being offered ordinarily has much greater value than the payment exchanged for it, the vendor can be regarded as altruistic, at least in the soft sense. There is a level of exchange value that the organ donor is sacrificing. A kidney has “incalculable” worth, at least to the extent that it has the potential to extend the life of a person indefinitely. Money or material concessions paid to an organ provider or donor cannot match the value of that life.

Closely related to this point is the view that those who accept compensation for their transplanted organs cannot truly be regarded as donors. One cannot be a donor and at the same time accept compensation for one’s donation. When certain people speak of “organ donation” in this context, it is merely as a euphemism for “organ trading.” For them, “organ donor” is a mere euphemism for “organ trader” or organ vendor.

This view is rejected here for failing to give due recognition to the contribution a person makes by making an organ available for transplant, regardless of whether that contribution is rewarded with monetary compensation or not. Moreover, the value of having a functioning kidney for an ESRD patient is so much higher than the money or materials usually paid to an organ seller. To refuse to recognize the organ seller as a donor is grossly to underestimate the value of the contribution being made to the organ recipient. (It is actually difficult to say that the amount given under the circumstances should be regarded as a payment for the kidney itself. Perhaps more acceptable is the interpretation that it is an incentive for the donor to part with a kidney.)

Moreover, the view that the organ seller cannot be a donor is inconsistent with the ordinary understanding of donors. Many donations are subjected to self-serving conditions. To take an example one encounters with academic research projects, a donor country might insist that only equipment sold by companies based in that country may be bought with the use of money it has donated.

The soft conception of altruism does not make a reference to an attitude toward another person. What it does involve is a readiness to accept an exchange in which one ends up with something of less value than that which is transferred. The organ donor is being altruistic by accepting compensation that is not at least equal in value to the kidney itself. One can see that this phenomenon is also related to the exploitation that often takes place in these settings. The kidney seller is exploited by not being given compensation proportionate to the value of the organ.

Giving recognition to soft altruism is significant in that it does not make altruistic giving an exclusive option for those who have the economic means to live a life that is comfortable enough. By accepting that even the poor and underprivileged can be altruistic, society signals its appreciation of what this group can contribute to society and of their productivity in terms of such a valuable input to the health-care pie.

Indeed, the contribution is so valuable that it would be exploitative to allow contributors to continue suffering because they themselves do not have adequate access to basic portions of that pie. The situation is patently unjust when people who contribute

so significantly to the health-care pie (or to any other service pie) are systematically prevented from getting a fair share when they are the ones in need. Instead of being systematically prevented, they should be helped to access certain services as they themselves require as citizens of the same state. So this is not saying that they should necessarily be paid for the benefits that they bring into the pie. The idea is to assist them to get what they are entitled to as citizens because they are being good citizens by playing their role as contributors to the system.

## Avoiding exploitation through a social amelioration program

The experience in developing countries shows that legislation or public pressure to prevent people from accepting compensation for organs has not worked. In countries like the Philippines and India, regulations prohibiting the sale of organs for transplant have not stopped the practice. The regulations have merely served to drive the practice underground. The practice has resulted in greater exploitation of organ donors since many are not given adequate information about the procedures and concomitant risks, proper preoperative and postoperative care, psychological guidance and counseling, or other information and services that are essential for their safety and well-being.

Prohibitions have also tended to leave the vulnerable poor disempowered and exposed to medical risks when they sell their organs anyway. In developing countries like the Philippines and India, bans on organ trade not only lack force but also tend to punish sellers and cause them more shame. Brokers and recipients have the means to run away. Poor donors hardly receive postoperative care and counseling, whether they received compensation or not. The health risks generally associated with organ trade might even be worse on the donors, as they stay away from “legal” health services for fear of being caught having done an illegal trade.

A successful compensation package must be able to explain how it can deal with the ways in which exploitation could arise. For example, the ignorance of organ donors tends to undermine their capability to make a well balanced decision on the basis of all relevant information—the risks and their likelihood, the proportion of risks to benefits, the anticipated benefits for the donor and the recipient, the impact of particular benefits on the life of the donor, the appropriateness of the specific benefits to the donor’s life goals, etc.

The poverty of organ donors constitutes a multidimensional barrier to their ability to make a balanced decision. Hence, it is also necessary to show how the poverty can be dealt with. Poverty puts individuals in a relative position of dependence or captivity associated with material or non-material indebtedness. A compensation scheme must be able to minimize (at least) the inhibiting effects of such indebtedness.

## A social amelioration package for organ donors

A social amelioration package for organ donors must be proportionate to the contribution they make to the exchange system. The level of compensation one receives may be

considered proportionate to the contribution one makes when it matches the benefits that one ought to expect from a hypothetical health-care and social security system to which it contributes. That system must be fair and responsive to the needs of the population. In the same way that the organ recipient is able to gain benefits from the transaction that are not provided in the existing health-care system, the organ donor must be able to expect benefits that ought to be part of, but are not yet provided by, that system.

One example of a compensation package could consist mainly of the elements of the Conditional Cash Transfer Program (CCTP) being implemented in the Philippines following models that had been tried in a number of countries earlier on. The program is aimed at bootstrapping people from vicious cycles of poverty by dangling incentives for people to achieve certain desirable outcomes in health, education, and nutrition. In what is known as the “Pantawid Pamilyang Pilipino Program” (Dizon 2010; Philippine Information Agency 2011), the poor are methodically enrolled to keep their children in school, meet nutritional goals, and, as parents, receive training to engage in livelihood projects. Similar programs in many parts of the world have achieved desired health and educational outcomes (Gertler 2004; Son 2008). The program could provide an organizing structure for multi-stakeholder “buy-in” for concrete, measurable outcomes in health, education, and economic productivity and could well take in energies from business, non-government organizations, and other civil society groups.

In addition to the elements of the CCTP, the package should perhaps include the following items that are crucial for non-exploitative organ donation: life and medical insurance, psychological counseling, and livelihood assistance and/or job placement.

Medical insurance is an obviously necessary component of a social amelioration package. Since organ donors are providing something that contributes to the health status of the transplant recipients, it makes good sense to help ensure that they can be given reasonable health care. They will then be contributing to a health insurance system that they also derive benefits from. It will be ironic if, after having contributed to overall health within their community, they were to be excluded from receiving benefits similar, or comparable to those that they will have contributed.

Life insurance ought to be a part of the package because the donor’s family also assumes certain risks arising from the donor’s involvement. The wife or husband and the children are part of the exercise and should not be left out of the calculations.

Psychological counseling is another need of organ donors that is not usually available in the black market. Studies have shown that organ sellers report various symptoms that are not usually expected of well informed donors. While some of them may actually have a reason to complain because of the consequences of their not being adequately followed up medically, it is likely that there are also many cases of psychosomatic conditions arising more from the donors’ being misguided or misinformed.

Livelihood assistance and/or job placement are also important components of the compensation package. Without a job or means of livelihood, a person cannot be expected to have reasonable access to things that are necessary for promoting a reasonable health status. Many organ donors are jobless and have a very undependable means, if any, of livelihood.

Educational assistance is another appropriate component, considering that many organ sellers have a very low educational attainment. Like all the other components

mentioned above, educational assistance ought to be seen as part of the proposal's response to the organ donor's vulnerability to exploitation.

What emerges from this compensation package is a framework where the organ donor is regarded as a highly valuable contributor to a health and social security system that should be competent to provide certain basic and important goods and services to its members. Being such a contributor, the organ donor is regarded as entitled to a reasonable level of benefits that can be provided by that system. Unfortunately, such a broad and comprehensive system is not yet in place in many countries where organ selling is taking place. This proposal to provide a social amelioration package is also a proposal to set in motion a process toward the establishment of a broad and comprehensive system that is responsive to the needs of the population. That system should be able to provide a reasonable level of medical services and a social security system that effectively caters to employment, educational, and other emergency needs of its members.

Even when that broad and comprehensive system is not yet in place, it is useful (even essential) to view organ donation within that system's framework. This approach to developing a culture of altruism is supported by our continuing experiences with the uncontrolled and unregulated organ market.

The establishment of a broad and comprehensive health-care and social security system requires a financing program that has yet to be developed. In the meantime, a moderately sized program can be initiated on a manageable scale—depending on the amount of available resources—so that an example could be put forward and monitoring and evaluation could be undertaken.

## Conclusion

This paper proposes a model for the social amelioration of organ donors that makes it possible for the health-care system to generate more human organs for transplantation and for people to make their organs available for transplant while receiving compensation that takes various forms, to emerge out of the transactions in better health than otherwise, without loss of dignity, and having taken part in a collective undertaking that promotes the interests of organ donors and recipients alike. It recognizes that the implementation of presumed consent or opt-out systems has probably led to an increased supply in organs. However, it would be risky to implement such a system in developing countries where regulatory bodies and health services are not run efficiently and the dissemination of information is not fully reliable. Many developing countries are also plagued by rampant corruption. In those places where we would probably want a presumed consent system to succeed, the above-mentioned barriers to effective governance can be seen to prevail.

The willingness of those who are eager to be reciprocated for their organ donation can be regarded as "soft" altruism. This soft sense of altruism is a "middle ground" alternative to the "strong" altruism assumed in opt-out regimes and to money-only market that insults the poor's capacity to care despite the lack of genuine choices. Accepting this soft sense of altruism is important to this paper's proposal because it explains why the exchange cannot be understood in purely material terms.

Under the proposed system, the role of organ brokers is going to be taken over by the government's primary agency for providing social services, subject to strong accountability and transparency audits by the public and other stakeholders. The goal is holistic and goes beyond increasing the supply of organs. It is uplifting the conditions of otherwise exploitable organ donors. The program seeks to address broader needs not only of those desperately needing organs but also those of potential providers of organs and their families. Neither a superficial ban on organ markets nor an equally exploitable opt-out system could obviate the need for a broader institutional support mechanism in organ donation (cadaveric or otherwise) with material and financial benefits to the donors and their families who, in developing countries, are usually poor. Organ donation and social amelioration are inseparable solutions. Preventing such material support mechanism for the desired health outcomes is unjust, if not downright cruel.

Trust in the medical profession and the transplant community is not necessarily enhanced by the ban on organ markets. Coming from the ranks of the same profession and group are those who continue to exercise willful ignorance towards black markets for organs (Caplan 2014) that will persist so long as there is a much greater need than the altruism of organ donors could meet. What undermines trust in the context of organ transplantation is not the money that changes hands but the reduction of the whole process into a purely monetary matter. On the other hand, structures can be put in place to simultaneously value the donation and improve the well-being of donors and their families. Organ donation without an accompanying social amelioration package for donors is ethically "business as usual" for the transplant world maintained by either opt-out or opt-in regimes.

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