## The Ethics of Regulated Markets in Organs: Juggling with Interests and Shame

Miran Epstein MD, PhD (Hist. & Phil. Sc.), MA (Hist. & Phil. Sc)

The British Council and

Academic Unit for Human Science and Medical Ethics
Barts and The London School of Medicine and Dentistry
Queen Mary, University of London

#### The unregulated market

Commerce in organs is currently as much in the interests of those who deem it unethical as it is in the interests of those who deem it ethical.

## Regardless of whether it is ethical or not, it is in the interests of *all* stakeholders:

- Governments
- The tax payer
- Health insurers
- Health care providers
- Brokers and other middlemen
- Transplant surgeons, patients in need of organs
- The poor who have nothing to sell but their body parts.

## There is a stark *imbalance of power* between vendors and all other stakeholders.

- Vendors occupy the weakest bargaining position.
- They are poor and are likely to remain so even after the sale.
- In some places the majority are women, who often make their decisions under pressures of either brokers or husbands, or both.
- Unlike buyers, vendors receive little material support and sympathy from their local establishment and the general public.
- They are not organized and have no lobby; they are invisible.

When the stakeholders meet each other equipped with their immediate interests only, we get an *unregulated market*, better known as a 'free market'.

Such market is often deemed to be without ethics.

#### This is inaccurate, though.

The free market derives its moral justifications from the presumption that buyers and sellers are *in essence* autonomous, fully autonomous, and nothing but autonomous.

#### But this presumption is a fiction!

- The unregulated market involves a good deal of violence.
- Even without direct violence it fails to reflect freedom, certainly not of vendors.

Its ethics does nothing to protect them. On the contrary, by pretending that they are completely free, it actually validates and reaffirms their overwhelming vulnerability. But if the ethics of the unregulated market in organs is shaped by relations of pure power, then what shapes the ethics of the regulated market?

#### Compassion perhaps?

#### No!

The ethics of the regulated market reflects a conflict between our immediate interests in commerce in organs and the need to avoid the *shame* we feel for having such interests.

## Shame

#### (I) Inconsistency.

The shame is morally *inconsistent*.

After all, we have already moralized, legitimized, and, in some cases, legalized commerce in the many parts of the human body:

#### Commerce in labour power

Consider the case of a Filipino or Moldovan woman, whose only way of looking after her own children is either by leaving them to look after the children of a rich family in Europe or by selling her kidney to a rich buyer in Europe.

There is no essential difference between the options, but many of us still feel that the latter is shameful, while the former is not.

#### Sexual prostitution

One might be inclined to think that if kidney brokers disappeared from the picture, and if people could be made millionaires by selling their kidneys, a market in kidneys would surely become not just morally acceptable, but also socially respectable. No shame would be involved.

"Perhaps making the amount paid for organs substantial enough to make a significant difference in the life of a poor donor (e.g., \$100,000 for a kidney) would make organ sales more acceptable."

Rhodes R. Organ transplantation. In H. Kuhse and P. Singer eds. *A Companion to Bioethics*. 2001. Oxford: Blackwell. pp. 329-333, at 333.

#### Medical examples

- Paid participation in clinical trials
- Paid gestational and sexual surrogacy
- Paid donation of reproductive tissue

Indeed, we have conquered much of the shame in such instances, but still not in the case of kidneys.

Is there anything special about the kidney?

Perhaps the kidney is here just to remind us what shame is, before we lose it completely.

#### (II) Intensity

The shame is intense enough to deter most countries from openly legitimizing commerce in kidneys.

Too much shame is associated with being an importer of kidneys. But being an exporter of kidneys is not a great honour either.

In both cases, the heartless tendency of capitalism is exposed: everything, including the last *glomerulus*, must yield to the logic of the market.

#### (III) Genuineness

The interface between execution, robbery, theft, deception, inadequate disclosure and other forms of 'undue' pressure on the one hand and kidney vending on the other hand is well known.

Such phenomena interfere with the freedom of would-be vendors to choose between poverty and selling their organs. They are indeed shameful.

But none of them is an essential feature of such market; it could operate without them.

Does that mean that absence of such forms of coercion entails absence of <u>all</u> coercion?

Not at all. In fact, a market in body parts presupposes and implies some sort of coercion in any case.

Free people do not have to choose between poverty and selling their organs!

Rich countries, which have interests in the poor as depots of spare-parts, have a good reason to be ashamed:

They have often played, and are still playing, a significant historical role in creating their poverty in the first place, and thus in forcing them to choose between their poverty and selling their body parts.

#### The regulated market

What happens then when our interests in commerce in organs meet our need to avoid the shame for having such interests?

We get a compromise reflecting the relative power of these elements.

The ethics of the regulated market in organs is precisely about such compromise.

## (I) A fictitious prohibition of commerce

Laws, which on the one hand prohibit commerce, but on the other hand permit, and indeed encourage,

- (1) 'altruistic unrelated donations', and
- (2) compensation for 'expenses and inconveniencies'.

• Directive 2004/23/EC of the European Parliament and of the Council. 31 March 2004.

"As a matter of principle, tissue and cell application programmes should be founded on the philosophy of voluntary and unpaid donation, anonymity of both donor and recipient, altruism of the donor and solidarity between donor and recipient [Introduction, Pt. 18]."

"Member States shall endeavour to ensure voluntary and unpaid donations of tissues and cells. Donors may receive compensation, which is strictly limited to making good the expenses and inconveniences related to the donation. In that case, Member States define the conditions under which compensation may be granted [Chapter III Article 12.1]."

#### Nothing to do with commerce?

'Altruistic unrelated donation' and 'compensation' are classical examples of legal fictions—presumptions made by the law that something is true irrespective of whether it is true or not, and even though it might be false.

These fictions have the capacity to conceal commerce, and shame.

But how could we make sure that the unrelated donor's declaration of altruism is genuine and not fake?

## A process of 'reverse means testing', for example.

# But we don't impose such a requirement.

If asked 'Why not?' our ethicists would probably respond,

'Because we ought not to discriminate against the poor; they, too, and not just the rich, ought to have the right to express altruism'.

'Everyone is free to sleep under a bridge,

...but poor people are more likely to make use of the opportunity.'

# So, how do we actually make sure that the unrelated donor's declaration of altruism is genuine?

We don't. We simply presume that it is.

# And how could we make sure that 'compensation' does not become the primary motive for the donation?

Moreover, how could we preclude the possibility of additional payments, concealed from the eyes of the law?

Again, a system of 'reverse means testing' could prevent such risks.

#### But we reject such system.

Instead, we make a presumption that the sum of money defined as compensation is so small that it cannot become the primary motive for the donation.

This is, again, a fictitious presumption.

At any rate, 'compensation' does not preclude additional financial arrangements, provided that they remain concealed from the eyes of the law.

#### CAVEAT

- Truly altruistic unrelated donations can exist and they still exist.
- Compensation does not have to become the primary motive for the donation.

But - for a society, which has interests in commerce but also needs to avoid the shame of having them, the fictions of altruism and compensation are excellent solutions:

- They allow us to legalize commerce in organs de facto without legalizing it de jure.
- They allow us to pretend that we are a compassionate society when we are not always so.
- They allow us to conceal the shameful behind an ethical smokescreen.

A lifeguard expels a young boy from the swimming pool.

The boy cries, "but what have I done?" The lifeguard replies, "You peed in the water!"

"But everybody pees in the water", says the boy.

"That's true," says the lifeguard, "But not from the diving-board!"

There is really no need to make commerce in kidneys *officially* legal.

It has already been made legal, just not from the diving-board.

### II) Quasi non-commercial inducements

Some proposals conceal the commercial element of payment to vendors behind the veil of 'compensation'.

Unlike the abstract notion of compensation endorsed by the law, such proposals are *specific*. They include

- Tax exemption
- Life insurance
- Future entitlement to kidney
- Pension schemes
- Free medical care for the vendors and their families'.

#### A particularly ironic proposal designed to tempt people to enrol in clinical trials, while ensuring altruism and precluding commerce

The payment should have 3 different components:

- (a) Reimbursement of expenses and compensation for lost earnings
- (b) A little 'thank you' payment +
- (c) A potential future payment made depending on whether the drug ever becomes commercially successful and reflecting the increase in the share price of the company concerned.

The same logic could apply to kidney vending as well... Kidney donors would be paid after, say 10 years, provided that their kidney has not been rejected....

# III) A monopsonistic (single buyer) market.

Suggested by Erin and Harris, the scheme is largely designed to protect the interests of patients on the waiting list, but it also promises to "have built into it safeguards against wrongful exploitation and show concern for vulnerable people".

#### The scheme

- offers vendors a degree of bargaining power.
- offers vendors and their families greater priority in the allocation of organs if they become patients in need of organs than non-vendors.
- gets rid of brokers and ensures that rich people cannot prey on poor people.
- prevents rich nations preying on poor ones by confining the marketplace to a particular state or a regional bloc of states.
- exempts the profits from organs from tax and benefit reduction.

But the scheme fails to address the basic coercion that drives people to consider organ vending as a viable option.

Vendors will continue to come from amongst the poor and the poor only.

#### IV) Atonement

Some proposals are simply concerned with helping the victims by putting pressure on governments to ensure adequate health care and secure jobs for the vendors.

They suffer from severe shortcomings as well.

1. Jobs are worth money.

They are likely to become part of the commercial rationale.

2. Some governments might be tempted to abuse the proposal by offering jobs only to vendors.

Organ vending could run the risk of becoming a condition of eligibility for employment.

3. If commerce in organs and commerce in labour power are morally identical, then offering people jobs in exchange for their kidneys would double the exploitation.

It would send a sad massage to the poor: if you want to sell yourselves in the labor market and be compensated 'adequately' for your labor power, sell yourselves in the organ market first for some 'inadequate' compensation.

4. If there is a moral difference between commerce in organs and commerce in labor power, then why not put pressure on governments to secure employment for the poor *before* they have to consider the option of organ vending?

#### The alternative solution

The problems of the regulated market—
especially the fact that it validates the vulnerability of vendors in stark opposition to its explicit intentions—should lead us to consider other options.

#### Prohibition of commerce?

#### Not without problems either.

• <u>Unfeasible</u>. As long as poverty exists and organs are scarce, there will be a black market.

 Ethically problematic. Those who oppose legalization of commerce in organs should be reminded that a legal ban on 'sleeping under a bridge' would restrict the liberties of the poor rather than enhance them. "Trying to end exploitation by prohibition is rather like ending slum dwelling by bulldozing slums: it ends the evil in that form, but only by making things worse for the victims...

If we want to protect the exploited, we can do it only by removing the poverty that makes them vulnerable, or, failing that, by controlling the trade..."

Radcliffe-Richards et al. The case for allowing kidney sales. *The Lancet* 1998; 351:1950-2.

#### Conclusion

- Neither 'controlling the trade' nor 'prohibiting the trade' can prevent coercion and exploitation.
- Individual doctors should do whatever they can do to ensure that vendors receive the adequate medical and social support they deserve.

# Time to go beyond the pro and con debate and tackle the more fundamental social issues:

- How to prevent kidney disease and thus decrease the demand for kidneys.
- How to enhance solidarity in our societies and thus increase the number of *genuinely* altruistic donations, and, above all,
- How to eradicate poverty.

## As far as the latter point is concerned

Moratorium on the foreign debts of poor countries, the eradication of western colonialism and neo-colonialism, and putting an end to undue interference in the affairs of developing countries, **could be a good start**.