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The debate in Chile on organ donation revisited

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Abstract

The worldwide scarcity of cadaveric organs for transplants is on the rise, due in part to extended medical indications and longevity of chronic patients with organic insufficiencies. Chile has an extremely low donor rate of 6.7 per million. Although consent is presumed by law, and recently amended to include a "reciprocity principle", nearly four million persons have expressed in writing their unwillingness to donate and, of those remaining, 53% of families have rejected donating the organs of their deceased. New proposals are urgently needed, even if some of them have previously been rejected: nonmaterial incentives, partial donations and unveiling anonymity to enhance personal ties between donors and recipients. Transparency, information and assistance are to be reinforced in order to regain trust in transplant procedures.

Introduction

Contemporary biomedicine has been actively defending corporate interests involved in medical care systems and insurances, operating in for profit institutions and agents engaged in both clinical and research activities. In spite of this marked utilitarianism, bioethics has rigorously supported pristine altruism in cadaver organ donations. Medical indications for transplants are being extended as chronic patients live longer, increasing the scarcity of available organs. Reluctance to donate has unleashed a black and inequitable market, necessarily calling to reopen the bioethical debate on this issue.

Current situation in Chile

Transplantation of organs and tissues is regulated by Chilean law N° 19451 of 1996, mandating free and informed consent to the extraction of organs for transplant purposes after death has been duly certified. In 2010, law Nº 20413 was enacted, introducing presumed consent, indicating that every citizen over 18 years of age is a potential donor unless the person had signed a non-donor document.

The donor rate has never exceeded 10 per million (2006), currently having dropped to 6.7 per million. The number of transplants is stagnant, while waiting lists have increased to 2,000 patients, and the number of Chileans who have signed a non-donor declaration borders 4 million [1]. Of those who died in unrevoked presumed consent the retrieval of organs is being rejected by family members in 53% potential donors (2015); denial rates are increasing and exceeds international averages.

These empirical data show that altruism and solidarity are on the wane. The increase in number and waiting times of patients requiring organs, calls for a revision of bioethical arguments involved in search of new strategies aimed to satisfy pending receptor expectations and needs.

Ownership of the body

Roman right regulated ownership of objects, creating the exceptive juridical abstraction of the human body as person that cannot be owned nor transferred. The era of organ transplants has put to question the traditional distinction between person and human body. Persons can actually

dispose of body parts thus exercising a property right that in the judicial language remains explicitly unrecognized, replacing "selling" with "paid adjudication", employing "transfer rates" instead of "price" [2].

Debates about ownership include a diversity of body components that are extracted, disembodied, including blood, semen, amputated limbs, placenta, aborted embryos, biopsy samples and therapeutics excisions, all procedures done for therapeutic, scientific or ritual purposes. Rights of property over body parts separated from their corporeal origin, be it *in vivo* or *post-mortem*, has produced a plethora of judicial pronouncements, laws and theoretical discussions, deciding on a case by case basis either in favor or against the right of property and, consequently, the legitimacy of donation being gratuitous versus subject to compensation or retribution. Debate centers mainly on the sale of non-vital living organs [3], but it has been extrapolated to other situations including compensations or incentives for cadaveric donations [4].

The State represents social interests that mandate the regulation of such exchanges. By favoring presumed consent, the law proclaims by default the right to social ownership of the dead body and its transplantable organs, unless the deceased had formally disallowed this public appropriation. The claim to social property is argued as necessary to stimulate medical research and assure the fair distribution of organs [5]. Presumed consent is employed with due respect and caution, seeking the family's approval and deferring when donation is denied. In legislations with explicit consent, a clause is often included stating that willed donation cannot later be vetoed by the family [6].

Legal protection of ownership rights may need to be legally guaranteed in the face of scarcity, as occurs with transplant organs. Nevertheless, property rights may be supported or limited by inalienability or responsibility norms [7].

Donation

Laws and ethical norms categorically demand that donations be based on altruism and solidarity. Donation is an act of exchange that commits the receiver to eventually reciprocate with a gift. Donation is generous but not gratuitous, it is a social ritual that required a "counter-donation" [8]. Donations usually provide social credit and tax advantages, thus characterizing them as not quite disinterested goods exchange. A classical study showed that blood donations were equally prevalent whether paid for or freely donated [9], in both instances blood and derivatives becoming merchandise that is obtained, elaborated and treated as a clinical commodity. The high cost of transplant procedures, whether subsidized or not, is initiated by a free donation that sets in motion a train of expenses and profits, variable in different countries in dependence of fees involved, which may be free of regulated.

In spite of legally presumed consent, difficulties and obstacles in accessing organs are on the rise, putting to question the purported prevalence of altruism and solidarity in modern individualistic society, which remain totally insufficient to cover the needs of the severely ill.

Altruism

The idea of altruism has been overused with a lightness that is disavowed by reality. Authentic altruism is understood as assisting others without further motivations devoid of self-interest or the intention of benefitting specific persons, for it ought to be based on "objective values" so that the intended goal should be free from any personal tint. Altruism applies to "any situation in which there is reason for one person to promote some end … should the person be in a position to to so" [10]. It will be a conditioned altruism if organs are donated "on the understanding that they will be used for the purposes consented to (be it transplantation or research)" [11]. Somewhat less rigorous is the idea that altruistic conduct is focused on the satisfaction of it being 'good to be sympathetic, compassionate, concerned, and caring for other human beings' [12].

Altruism as required by law presupposes trust in the correct disposition of the retrieved organs and yet, distrusting that this will happen is a major factor in family members' denial. Empirical data that support this statement stem from a series of denunciations against German physicians that manipulated waiting lists for the benefit of their own patients [13]. Public disclosure of these transgressions lead to a drastic 40% reduction in the willingness to donate under the German system of expressed consent [14]. Surveys and anecdotal evidence confirmed mistrust in the system's fairness in assigning organs, the bias of benefitting undesirable individuals –terrorists-, the suspicion of discriminating against ethnic minorities, or redirecting organs towards goals other than transplantation. The symbolic value of some organs –heart, eyes- also appear as cause for rejecting donations.

Attitudes and beliefs

Familial disposition to donate helps ease the pain of loss, and may give some sort of meaning to the death of a loved one; in other words, donation has a moral value that unfortunately is frequently overlooked when rejecting a presumed donation. Occidental religious doctrines support donation as an act of love, even as a duty, and yet groups and individuals rely on religious motives to deny their participation [15]. Nonetheless, religious motivation is part of a cluster of sociological patterns that include age, education, communal integration, previous experiences, the complexity of which confirm that initiatives to reach cultural changes in favor of donation faces a difficult and slow task [16],[17]. Media campaigns concerning severely ill patients promoting "first national priority" cases are of short-lived influence, doubtfully effective in energizing the disposition to donate, and institutional campaigns do not achieve desired results. Much research and anecdotal narratives point to the convenience of shedding anonymity in cases where involved families prefer to meet.

Incentives

The previously mentioned Chilean law was amended in 2013, introducing the so-called "principle of reciprocity". Without modifying the requirement that donations be based on altruism and solidarity, it offers "a double incentive for donating: avoid the costs of documenting the unwillingness to be donor, and receive priority on the waiting list" [18]. The first incentive is ineffective considering that four million Chileans have actively rejected being donors in spite of the "costs" such documentation purportedly involves. The second incentive implies the mandate *do ut des* –I give so I may receive-, which is clearly distinct from an altruistic donation. Nonetheless, it suggests bending the law –free donation versus incentives-, and opens a cleft that allows a revision of the ingrown idea of the impeccable gratuity of purely altruistic donation, allowing ongoing debate and furthering material incentives and reciprocity to stimulate the donation of cadaver organs [7].

A more drastic proposal suggests that only donors should eventually be recipients of organs [19]. Rearranging priorities based on moral merits or demerits shows undesirable traits of discrimination. No less repugnant is allowing any kind of direct monetary contribution, incentive or payment in relation to human organs meant for transplants [20].

Conclusion

The disposition to donate organs is decreasing in spite of presumed consent legislation expected to boost availability. The vague and unpredictable hope of a cultural change is a slap in the face to the urgency of vitally compromised patients.

This urgency calls for a recognition that public policies and transplant legislation have been defective, that institutional efforts and campaigns to stimulate donation, although praiseworthy, are mostly inefficient. Debate needs to be reopened and will have to evaluate perspectives hitherto discarded for respectable moral reasons, but the rigidity of which is costing human lives.

A more flexible attitude towards incentives is desirable, not by increasing their magnitude, but rather being imaginative about a number of services that could be offered: funerary arrangement, legal assistance, promoting contact to self-help groups or institutions that welcome donor families; all these and other options are known as ethical incentives [21]. Another unattended issue is to suggest partial donation, where donors can limit their donation to certain organs or exclude others for their symbolic value. Thirdly, too strictly prevailing anonymity should be given more thought, putting to question whether it supports donating or dissuades from it. Most importantly, transplant procedures ought to proceed with transparency, information and assistance, in order to gain in the short run the trust that donated organs will be properly managed.

Notes

From the editor

The author originally submitted this article in Spanish and subsequently translated it into English. The *Journal* has not copyedited the English version.

Conflicts of interest

The author completed the ICMJE conflict of interest declaration form, translated to Spanish by *Medwave*, and declares not having received funding for the preparation of this report, not having any financial relationships with organizations that could have interests in the published article in the last three years, and not having other relations or activities that might influence the article´s content. Forms can be requested to the author or the editorial direction of the *Journal*.

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