COMMENT

Organ transplant and presumed consent: towards an "opting out" system

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Abstract

This paper examines the "opt out" system of organ donation wherein the State permits removal of tissue and organs posthumously unless an express objection is made by the person prior to the death. This paper examines the need for "presumed consent" and the jurisprudential arguments in support of it. The social contract theory and the sociological approach based on the principle of "common good" support this system. However, the ethical concerns raised while implementing such a system are debatable. It is for societies to evaluate the situation and make a choice between "ethics" and "common good". The answer may not be obvious in a country like India where religion may supersede the question of life and death. The paper critically assesses both the issues, and concludes that presumed consent may be a viable method of addressing the organ shortage in India. However, we need public discourse and public awareness to change people's attitude to this concept.

Introduction

The viability of organ transplantation as a means of saving lives cannot be denied. Organ transplantation has become indispensable for ensuring the survival of many and thousands of people all over the world lose their lives due to severe shortage of organs (1). The official policy underpinning almost all transplant regimes is that of organ donation. Consent assumes a central place in legal and ethical analysis of transplantation practices, notably with regard to living donors but also vis-à-vis cadaveric donors (2). In the latter connection there is an ongoing debate as to whether express or presumed consent regimes are the preferred legal response, the premise being that the latter will result in a greater volume of organs for transplant.

The availability and use of cadaveric organs and tissue is inevitably closely connected to the ability and willingness of the deceased (prior to death) or surviving relatives to veto removal (3). There are essentially three ideal-typical systems: opt in, opt out and conscription. An "opt in" or "contracting in" system is one permitting tissue and organs to be posthumously removed for transplantation only with appropriate consent.

An "opt out" or "contracting out" system is one permitting tissue and organs to be posthumously removed for transplantation unless an appropriate objection is made. It is argued that the term "presumed consent" is misleading because consent is fictionalised in the absence of any positive indication that permission for posthumous removal for transplantation has actually been given (2). A distinction can be made between systems that recognise objections only from the deceased prior to his death (narrow opt out systems) and those that recognise the objections of the relatives after his death (wide opt out systems). Opt out systems can also differ according to the level of formality required for registering or recording an objection and according the grounds for a valid objection (eg religious conscientious objection only). Most supporters of this system envisage a narrow opt out system in which the objection need only be recorded on a formal register without any reason being required.

A "conscription system" is one where tissue and organs can be removed posthumously for transplantation, irrespective of any consent or refusal. Under such a system, dead bodies and their parts would be treated as public property either indefinitely or for a limited period before what remains is released for burial.

Need for presumed consent

There is dissatisfaction with the current regime of informed consent which has led to progressively deepening of the imbalance between the need for and supply of solid organs for transplantation. The reasons often given for the failure of the above regime are: failure of potential donors to sign written directives; inability to locate existing donor cards; failure of medical personnel to recover organs based solely on written directives; failure of hospital personnel to approach families to request donation when the decedent does not have a donor card, and the family withholding consent.

In addition to the obvious cost represented by the deaths of patients on the waiting list, there are other significant economic and non-economic costs associated with the shortage of human organs for transplantation (3). For instance, research has indicated that, compared to dialysis, a successful kidney transplant saves as much as $60,000 per patient over a five-year period (4). The non-economic costs include reduction in the quality of life with restriction of mobility and inability to work. The enormous hardship suffered by the living donor, the patient on the waiting list, as well as the family of the patient, cannot be discounted.

Conscription is a stronger form of presumed consent and the property rights to the organs of all deceased individuals are transferred to the pool of potential transplant recipients (5).

Though this system may increase the availability of organs, the political feasibility of such a regime is doubtful as it is likely to meet with overwhelming objections by the general public (6).

Many countries such as France, Greece, Portugal, Spain, Luxemburg, Austria, Belgium, Denmark, Great Britain, Italy, Norway, Sweden, Turkey, Singapore, Israel, Japan, Switzerland etc have tried to increase organ donation rates by implementing a presumed consent or opt out approach to organ donation. Organ donation rates in Belgium, Spain and Austria suggest that the presumed consent approach may have a positive effect on rates of organ donation. For instance, the number of organ donors in Spain has risen continuously from 14.3 per million population in 1989 to 25 per million in 1994 (7). The most celebrated success of these experiences is the case of Belgium, where organ recovery more than doubled following implementation of its policy of presumed consent (8).

The laws in these countries may vary (9). For instance, the French and the Belgian systems of presumed consent permit the removal of organs from the cadavers of persons who have not, during their lifetime, indicated their refusal to permit such a procedure, with exceptions for the cadavers of minors and the incompetent. Both these countries allow due regard to the wishes of the next of kin. The Austrian model differs in that it is not hindered by deference to the wishes of the next of kin. As a result, Austria has had much more success in procuring organs, supplying kidneys twice as effectively as the United States and most European countries (10). Brazil's experiment with presumed consent illustrates the drawbacks of the presumed consent model. The Brazilian law moved from a voluntary donation system to a wide opt out system which had to be abandoned due to lack of awareness among people, hesitation of doctors in removing organs without the consent of the family, and certain administrative difficulties (11).

An opt out system requires that the deceased and his surviving loved ones have little moral claim to control what happens to the cadaveric material, or that any such moral claims are attenuated by positive duties owed to those in need of cadaveric material (3). A presumed consent system is not only effective for procurement of organs for medical purposes, but it can also be an effective way of controlling the black market by addressing the acute shortage of organs. In addition, presumed consent leads to improvements in tissue matching between donor organs and recipients, and it allows surgeons to be more particular about which organs are selected.

Jurisprudential justifications

The social contract theory actually justifies non-consensual body part appropriation by the State (12). Rousseau, Rawls, Hobbes and Locke carved out early thinking on social obligations, duties and responsibilities for the nation state. According to Rousseau, "Through our relationships with the State are born obligations that are entered into involuntarily for the good of the common or the whole." (13) He refers to these as general wills, in which the best interest of the group is common or the whole. Presumed consent, as with other organ procurement schemes, poses ethical and legal challenges. Fentiman, Dukeminier and Nelson argue that these moral challenges are largely overcome by the tremendous social good that is done (13). Proponents suggest that presumed consent could ease the collective suffering and death of people awaiting organ transplants. Accordingly, they also argue that the policy maximises a community good for the benefit of all people, with a relatively small collective burden (13). It has been held by the American courts that "the State has to rely on social contract to address public health concerns and a fundamental principle of the social contract requires that citizens are governed according to common good, and therefore must sacrifice, comply and otherwise acquiesce to that 'common good'." (14)

Rawls's conception of the "original position" and his theory of distributive justice include the equitable distribution of primary goods in a manner that is for the greatest benefit of the least advantaged (13). Though it assumes a definite limit on the strength of social and altruistic motivations, it relies on the theory that the decisions taken will be for promoting common good. Thus, adopting the system of presumed consent can effectively combat organ shortage in the interests of the general public.

Roscoe Pound postulates that "law as a form of social control needs to be adequately employed for enabling just claims and desires to be satisfied, must be developed in relation to existing social needs." (13) An organ donation law based on a system of presumed consent which leads to an increase in the availability of organs then may also be justified as being in the social interest.

Criticisms

However, this system had been criticised on various grounds. It has been argued that presumed consent disregards autonomy, privacy and the right to choose how one's body will be used after one's death. Contrary to this it is argued that presumed consent respects the principle of individual choice by giving objectors to organ donation an opportunity to empower their anti-donation preference and thus does not infringe the right to choose. It is argued that an individual's interest in preserving bodily integrity while alive is not equivalent to bodily integrity after death and the former gains precedence over the latter (15).

Another criticism that is levelled is that a social contract, along with any legal transaction, should be granted legitimacy only according to its potential for equitable implementation and results (3). Presumed consent has been criticised on the grounds that it may lead to exploitation of the vulnerable sections of society and there may not be an equitable allocation of organs (16). Also, certain cultural expectations and religious doctrines emphasise human dignity, the sacredness of the body, and preservation of life, even when medically the body is considered to be "dead". However, the main reason why the "opt out" system is preferred to the "conscription" system is that it gives the individual the autonomy to withdraw her

consent based on the above or any other considerations.

Presumed consent laws have also been criticised for assuming that organs and tissues belong to the State or to society rather than to individuals or families. However, such criticism does not necessarily hold, for such laws could be held to be presuming donation rather than assuming communal ownership of the bodies. Also, the question may arise whether it vests the property interest in the body to the State. Answering the above criticism it was held in the case of Brotherton v. Cleveland that "Under the Anglo-American Common Law there is no property right in the cadaver, instead the next of kin in the United States have a quasi property interest in the body which is limited to custody of body for burial or lawful disposition." (17) In his discourse on property, Locke defends the right to physical subsistence even when it undermines property rights (18). Presumed consent cases do not address whether a property interest was at stake or not. They focus instead on the value provided to the greater society balanced by an abrogation of the rights of the deceased or her kin. It is argued by the proponents of this system that if a property right is abrogated by the State's interest in preserving the health of the living, then this would be properly within the scope of the State's authority, pointing to a social contract between the State and its citizens (12).

Public awareness

The "tacit consent" appealed to by John Locke is a consent that is expressed silently or passively by omissions or by failures to express or signify dissent (12). The system of presumed consent envisions a similar tacit consent but also stresses providing all the relevant information to the potential consentors. The potential consentors must be aware of what is going on and must know that consent or refusal is appropriate and must have a reasonable period of time for objection. They must understand the expected means of performing dissent and these means must be reasonably easy to perform. Finally, the effect of dissent must not be extremely detrimental to the potential consentor (19).

Fuller stresses that the publication of law is the most important duty to fulfil the inner morality of law (13). In the case of presumed consent laws this becomes all the more important since there may be a large body of people against it. Also, in order to ensure that people always have a choice to "opt out" if they so please, it is critical that there is widespread dissemination on the means by which they may express their objection. It has been observed that public attitudes tend to be an impediment to organ procurement. Media publicity, highly visible public and parliamentary debates, public education and hearings are necessary for the promotion of such laws (13). Habermas's theory of "social construction of reality" emphasises the need for "use of the public sphere" and discourse as an essential ingredient of law (20).

According to Hart's conception of obligations, the regulation of self and society requires not just legal instruments; it also requires that individuals and groups internalise the public moral norms as part of their own internal value systems. These norms inform the choices that they make for themselves and their society to ensure that all people have the capability to be healthy (13). Such internalisation in turn leads to the greater efficacy of, and greater compliance with, domestic policy and legal instruments. It is submitted that promoting laws through the above mentioned means may actually help change the attitude of people to organ donation, and the introduction of a presumed consent law may help people internalise the values associated with it.

Conclusion

As the above discussions show, criticisms leveled against presumed consent may be circumvented for the benefit of society. Though presumed consent laws may alleviate organ shortages, it is important to understand how societies may perceive and respond to legislative changes of this nature. It is also necessary to have an effective organ procurement system with adequate safeguards to protect the interests of individual citizens from potential abuses inherent in gaining presumed consent for organ donation.

Currently there are two types of presumed consent removal statutes in the United States: quasi, which require a search for the next of kin to obtain consent, if the search is successful; and pure, which requires no search or consent of the family (21). Both types of presumed consent statutes are typically limited to the removal of corneas and pituitary glands. The courts in these states have upheld these presumed consent legislations (22).

Considering that the system results in higher rates of organ procurement it may also be beneficial to introduce presumed consent legislation in India. However, this will be possible only after creating widespread awareness about organ transplantation and addressing the religious and cultural overtones that are associated with it. It can be effective only when there is good infrastructure, for instance an actively involved government agency that coordinates procedures for the removal, distribution, transportation and transplantation of organs.

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