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SPECIAL ARTICLE

ORGAN DONATION AND FAMILY REFUSAL. BIOETHICAL REASONS FOR A CHANGE

LA DONACIÓN DE ÓRGANOS Y EL VETO FAMILIAR. RAZONES BIOÉTICAS PARA UN CAMBIO

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ABSTRACT

Cases of next-of-kin veto, i.e., a family refusal to allow organs harvest contrary to donor wishes or when the law presumes consent, is a widespread practice that seriously harms thousands of people. This is a practice settled in many countries Family refusal to donate reduces an already shallow donor pool by approximately 43% in the Americas, 25% in Europe (37,3% in United Kingdom) and 54% in Asia.

Some countries, such Argentina, France, Colombia and Wales, current reversed its policy on organ donations to a system that prevents next of kin to dishonoring the donor's wishes restricting the confirm donor status only with the National Donor Registry and unless evidence of their objection is produced. In part I we review the latest amended transplant legislation of those countries that are trying to change this scenario. In part II we question the most frequently cited arguments to uphold the next-of-kin veto right and the countries that successfully changed their legislation banning this practice to encourage organ donation. We conclude that it is imperative to change this practice because the harm caused by promoting the family veto is greater and more serious than the potential harm of not allowing it.

KEYWORDS: health care system reform; organ donation; health laws; bioethica; family refusal

RESUMEN

Los casos de veto familiar a la donación de órganos son una práctica generalizada que perjudica seriamente a miles de personas. Esta es una práctica establecida en muchos países. La negativa de la familia a donar reduce en un 43% las donaciones bajas de los donantes en las Américas, un 25% en Europa (37,3% en el Reino Unido) y un 54% en Asia.

Algunos países como Argentina, Francia, Colombia y Gales han intentado revertir su política de donación de órganos de modo de impedir que los parientes revoquen los deseos del donante. En la primera parte, revisamos las más recientes reformas legislativas de aquellos países que están tratando de cambiar este escenario. En la segunda parte cuestionamos los argumentos más citados para defender el derecho de veto de la familia. Concluimos que es imperativo cambiar esta práctica porque el daño causado por el veto familiar es mayor y más grave que el daño potencial de no permitirlo.

PALABRAS CLAVE: reformas legales; sistema de salud; donación de órganos; legislación en salud; bioética; veto familiar

INTRODUCTION

Cases of next-of-kin veto, i.e., a family refusal to allow organs harvest contrary to donor wishes or when the law presumes consent, is a widespread practice that seriously harms thousands of people. Family refusal to donate reduces an already shallow donor pool by approximately 43% in the Americas, 25% in Europe (37,3% in UK) and 54% in Asia.[15] Family members often experience substantial grief when losing a loved one and cannot bear the thought of organ harvesting. Their objections are often strong enough to keep health care staff from persevering; even when both the regulations and the law require honored the donor wishes.

Some countries, like Argentina, France, Colombia and Wales, current reversed its policy on organ donations to a system that prevents next of kin to dishonoring the donor's wishes restricting the confirm donor status only with the National Donor Registry and unless evidence of their objection is produced.

We claim that next of kin chances of countermanding the wishes of the deceased should be minimized. In part I we review the latest amended transplant legislation of those countries that are trying to change this scenario. In part II we question the most frequently cited arguments to uphold the next-of-kin veto right and the countries that successfully changed their legislation banning this practice to encourage organ donation. We conclude that it is imperative to change this practice because the harm caused by promoting the family veto is greater and more serious than the potential harm of not allowing it.

1. Presumed Consent Restricted By Family Refusal: Legal Conundrums

Although many people are prepared to donate their organs after death and apprise family and friends of their decision to do so, few see their wishes realized - not just because only about 1% of deaths occur under circumstances that make organ donation feasible, but because of next-of-kin objection.

In Brazil, according to data from the Brazilian Registry of Transplant, in 2017 the absence of family member authorization accounted for 43.8% of organs not donated.[21] This is a practice settled in many countries. The United States has an opt-in system or First Person Authorization (USA, UK or Australia)[7] that work much like a living will or advance directive. The United States Revised Uniform Anatomical Gift Act states that no one can override the deceased's previously expressed wishes regarding organ donation.[6] Although studies suggest that between 69 and 75% of adults would be willing to become organ donors, half of the families that are asked to consider donation after a relative has died do not give their consent to the procedure.[5]

Recent law reforms are trying to change this scenario. France has reversed its policy on organ donations to a presume consent system (2016-41). The new rules, which came into effect on January 1, 2017, must be followed even if it goes against the wishes of the family.[2]

In Colombia, the new Organ Donation Act (Law 1805/2016) provides for presumed consent. In order to prevent next of kin or health care personnel from dishonoring the donor's wishes, the new law requires that, in cases of document concerns or inconsistencies, attending physicians confirm donor status with the National Donor Registry. This sole mandatory consultation under the law rules out a role for the next of kin.[3]

In Argentina, although the latest law specifies that donor wishes "will be honored regardless of manner of consent" the fact is that the next of kin are still called upon to testify to the donor's preference.[1] In 2014, this resulted in a 48.6% family overrule rate.[10] The parliament recently approved (July 4, 2018) a presumed consent law reform called "Justina Law" that seeks to modify the legislation to avoid the participation of the family. Then, it will no longer be necessary to check the family to approve or revoke the deceased decision.

Table 1. European Union Countries

Countries	Actual deceased organ donors (PMP)	Family refusals (%)
Belgium	31,6	12,9
Bulgaria	**6,3**	**47,2**
Croatia	40,2	16
Cyprus	**2,5**	**45,5**
Estonia	**16,2**	**33,3**
Ireland	17,2	13,0
Italy	**22,9**	**30,3**
Latvia	**18,5**	**31,0**
Lithuania	19,7	28,6
Poland	13,6	15,6
Romania	5,8	18,1
Slovakia	17,4	10,3
Spain	40,2	15,3
UK	**20,3**	**34,2**
Average	19,4	25,1

Table 2. Latin American Countries

Countries	Actual deceased organ donors (PMP)	Family refuals (%)
Brazil	**13,6**	**44,2**
Colombia	**8,4**	**39,7**
Cuba	13,9	6,5
Dominican Rep.	**0,7**	**72,2**
Ecuador	3,9	11,1
Panama	**6,4**	**51,0**
Paraguay	**1,5**	**68,8**
Peru	**2,6**	**67,1**
Venezuela	1,7	29.4
Average	**5,85**	**43,3**

Table 3. Asian Countries

Countries	Actual deceased organ donors (PMP)	Family refusals (%)
Israel	**9,5**	**40,3**
Malaysia	**1,0**	**67,8**
Average	**5,25**	**54,05**

A similar situation occurred in Chile where, despite a recent reform that instituted a system of presumed, conditioned and absolute consent, donor wishes continue to be frustrated upon death by family refusal. In 2016 this led to a 51% drop in an already shallow donor pool.[11] In 2015, Peru had 2.6 actual donors per million inhabitants and a striking family objection rate of 67.1%.[15] In order to improve this situation, Law 30.473, enacted in 2016, created an express, absolute consent system that can only be rescinded by the donor. The next of kin cannot contest donor wishes and health care personnel are not allowed to inquire about their views to this effect.

The United Kingdom had a donor rate of 20.3 per million inhabitants and a family refusal rate of 34.2%. In Wales the 2013 Human Transplantation Act states that adults dying in Wales (with certain exceptions) are "deemed" to consent to donation unless evidence of their objection is produced.[13] "Wales uses a soft opt-out, meaning that it's not intended to be legally enforced and that potential situations where doctors remove organs for transplant directly against the surviving family's wishes will not occur".[14]

Finally, there are countries that tried to change the family veto, not through legal reforms, but rather through important incentives. In *Singapore* despite doctors prefer to ask the families of the deceased for their consent and usually respect their wishes, the system does have a mechanism that provides an important "incentive" for families that authorize donation. Every time that an immediate family member permits an organ donation, he or she receives a 50% subsidy in medical expenses for the five years

following the donation.[9] *Israel,* regulated by the 2008 Organ Transplant Act, has developed a system of express consent, wherein people can register their wishes by signing a donor card. In practice, although family refusal is allowed, there are important incentives for donation in place, as there exists a points system that gives preference to direct family members of those who have donated organs to be, in turn, organ transplant recipients.[8]

2. Autonomy Or Family: Two Parallel Organ Allocation Schemes?

Current studies show that the principal reasons for families opposing donation are: denial and rejection of brain death,[21] social, cultural and religious beliefs,[22] the moment the request was made, little knowledge on organ donation (especially on the length of the procedure), feeling overwhelmed, preserving the deceased's body,[23] unknown donor wishes about donation,[24] medical mistrust, fear about the organ trade, and fear of objection on the part of other family members or family division over the decision.[25] Finally, there are also family members that do not consent to donation due to the express rejection of this possibility by the deceased.[26]

The discussion about the legitimacy of family consent appears to be unsuitable in "presumed consent systems" because organs could be harvested from those who were not able to express their opposition due to reasons such as illiteracy, disorganization, apathy, or a lack of awareness or understanding of the system. In the case of Spain, some has argued that if it were not for the fact that families have the final say and judges play a subsidiary role, the system would be one of organ conscription very much resembling the practice of autopsy.[27]

Contrarily, "express consent systems" are coherent with the idea that organ donor registries are, indeed, *a form of advanced directive,* because they allow living persons to make decisions about their future after death. In this sense, allowing family refusal is inconsistent with the rights we generally think people have over their property and body after they die or lose mental capacity. And many would feel that their autonomy has been violated if their wishes about the disposal of their body after death were not followed.[28] In this opt-in system or "First Person Authorization" adopted in USA, UK or Australia, we believe that it is not ethical to even allow procurement health professionals to approach families to overrule the donor's decision.

Advocates of allowing the next of kin to override donor wishes argue that it is often the only means to reduce anguish among family members and lessen stress for medical personnel. They also argue that, in the case that the deceased has changed his or her mind about donation, harvesting should not proceed without next-of-kin confirmation. They further argue that overruling the next of kin could undermine confidence in the transplant system.[11] This consequentialist line of thinking deems it unwise to override the next of kin because they are likely to share their experience with others. If these experiences are disheartening, they could turn public opinion against organ donation.

On the contrary, we stand with the views of the European Platform on Ethical, Legal and Psychosocial Aspects of Organ Transplantation (ELPAT) Deceased Donation Working Group, which suggests that even after taking all of the above arguments into consideration, next of kin chances of countermanding the wishes of the deceased should still be minimized.[25] The harm caused by promoting the practice of family veto is greater and more serious than the potential harm of not allowing it. As such, and unless their objection is shown to stand on solid ground (i.e., the deceased had changed his or her preference about organ donation, or was unaware that the law provided for the presumption of consent), family members should not stand in the way of donation.

Indeed, family members have been known to subsequently regret a decision to prevent organ harvesting. This comes as no surprise, as these are often decisions made under very trying circumstances. In addition, many family

members who allow organ donation to take place will, in time, find solace in the idea of having helped save a life or lives. A survey conducted in Brazil showed that over half of family members who had objected to organ donation would allow it if placed again in similar circumstances.

Finally, we also need to consider that family members should agree to organ harvesting in the same way people put up with other constraints put upon them by the authorities for good and valuable reasons, including protecting public health, criminal investigations, or disposition of bodies.[20]

CONCLUSIONS

It is true that organ donation requests are often mediated by decisions made by people who are facing intense upheaval: uncontrollable, unanticipated, unexpected and massive events whose impact can be incapacitating on a cognitive, emotional and motor level. This is also often accompanied by feelings of being unable to control the situation or respond effectively. But it is also true that it is unreasonable, highly inefficient and morally objectionable to allow family pain, however great, to result in deaths that could have been prevented.

Allowing legislation and health care practices to countenance next-of-kin veto in organ transplantation sends the entirely wrong message. Next of kin are led to believe that they hold actual subjective rights over the dead body and that they have the absolute right to decide on the matter, when, in reality, they should only have the right to receive information about the death and the removal of the deceased's organs.

We argued that relatives do not have the right to override the donor's stated. Their objections, while valid, clash with other strong consequentialist arguments in favor of proceeding with procurement. First, allowing family refusal is inconsistent with the rights we generally think people have over their property (and their wishes about the disposal of their body after death). Second, we can notably reduce the organ shortage and save the lives of waiting patients.

After taking all of the above arguments into consideration, next of kin chances of countermanding the wishes of the deceased should be minimized. In the opt-out systems, law reforms should prevent next of kin to dishonoring the donor's wishes, restricting the confirm donor status only with the National Donor Registry. In the opt-in system or First Person Authorization (like advance directives) we must consider that, with certain serious exceptions, the decision of the donor needs to be unbreakable.

Conflicto de intereses: Los autores declaran no poseer ningún interés comercial o asociativo que presente un conflicto de intereses con el trabajo presentado, y expresan su adhesión a la Declaration of Istanbul on Organ Trafficking and Transplant Tourism (2008).

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