

Family response to presume consent system on organ donation from a review of literature

Makmor Tumin¹, Khaled Tafran², NurulHuda Mohd Satar³

Background: Most countries around the world have experienced a shortage in organs needed for transplantation. Organ donation performance is widely attributed to two important factors: the legislation and the role of the family. Thus, this literature review aims to examine the willingness of people for organ donation while highlighting the importance of having a presumed consent system.

Methodology: In this study, we explored many papers of which 10 articles were studied to gain conclusive understanding of the two factors and their interactions.

Results: Our analysis of literature regarding the legislation and family response showed that the presumed consent system for organ donation accounted for 21 – 30% higher organ donation rates than the informed consent system. We also found a gap between the willingness of people to donate their own and their relatives' organs. The ratio of people willing to donate their organs after death was estimated to be 10 – 12% higher than the ratio of those willing to donate their relatives' organs. Furthermore, the study revealed the importance of a presumed consent system in raising the willingness of the people and their relatives for donation, but that did not eliminate the gap.

Conclusion: Countries seeking to overcome organ shortage and increase organ donation rates by moving towards the presumed consent system should consider the importance of providing families with proper information about this system. The fact that a gap between the willingness of the people to donate their own as well as their deceased relatives' organs exists, has to be conveyed to the governments, which will be helpful in optimising organ donation rates.

IeJSME 2015 9(3): 20-26

Keywords: Family, informed consent, organ donation, presumed consent, public view

Introduction

Most countries around the world have experienced a shortage in organs needed for transplantation. However, some countries have succeeded in overcoming this problem while others are still lagging behind in terms of organ donation rates. The first step to solving this problem was cited as the change in the legislation of organ donation. Further, the role of the family in getting the expected results for such changes has been widely argued to be imperative.

The family has been considered as one of the most important factors affecting organ donation. The role of the family is crucial due to its implications on shaping an individual's personality and major life decisions. After one's death, the family replaces the individual's position regarding the decision making of their will and after death responsibilities. The last argument also applies for organ donation since various studies have found that a family played a vital role in determining the organ donation rates in most of the countries worldwide (Fevrier & Gay, 2004; Siminoff *et. al.*, 2001).

Social activities of individuals and families are believed to be affected by the organ-donation legislation. In this context, many studies have discussed the implications of those legislations on organ donation rates (Abadie & Gay, 2006; Fevrier & Gay, 2004; Siminoff *et. al.*, 2001). Although there is no consensus regarding the best legislation for optimisation of organ donation rates, most studies concluded that the presumed consent system resulted in higher organ donation rates than the informed one. These two systems were compared after controlling the other factors, such as education, religion, age, etc., which are believed to affect the organ donation rates (Abadie & Gay, 2006).

Based on the expected advantages of presumed consent over informed consent system and the successful experience of countries, some countries such as Spain, have shifted from the latter to the former system and

¹Associate Professor, Department of Administrative Studies and Politics, Faculty of Economics and Administration, University of Malaya, MALAYSIA

²Graduate Research Assistant, Institute of Research Management and Monitoring, University of Malaya, MALAYSIA

³Senior Lecturer, Department of Economics, Faculty of Economics and Administration, University of Malaya, MALAYSIA

Address for Correspondence:

Associate Professor Dr. Makmor Tumin, Department of Administrative Studies and Politics, Faculty of Economics and Administration, University of Malaya, 50603 Kuala Lumpur, MALAYSIA
Email: makmor@um.edu.my

have recorded higher organ donation performance. However, the experience of some countries have not been in favour of the presumed consent system proponents.

Given the vital role of both family and legislation in organ donation, the association between the legislation and organ donation rates can be explained by the role of the family (Rosenblum *et. al.*, 2012) as a mediator between the two. It is thus imperative to explore the literature regarding the response of families towards organ donation decision-making, within the framework of both legislations. Based on the results of the previous studies, a conclusive understanding of the mechanism of family, legislation and organ donation performance has been provided. Additionally, the comprehension of such mechanisms requires exploration of any difference between the family members' decision regarding the organ donation cases of their own and their loved ones, after death.

Thus, in this study, we focussed on exploring the literature pertaining to the following questions: (i) Does the family affect the relationship between the legislation and the resulting donation rates of this system? and (ii) Does the family members' response to organ donation differ when it comes to their deceased relative's organs rather than their own?

Methods

A limited number of studies have dealt directly with this issue. Therefore, we needed to explore many scholarly articles that investigated the matter to be able to present this literature study. For fulfilling this study purpose, we ran our search in different databases using the keyword "organ donation" combined with one or more of the following keywords: "family", "legislation", "presumed consent / opt-out", "informed consent / opt-in", " ", and "family response". The search was mainly conducted in the following databases: Medline, Embase, PsycINFO, and ScienceDirect.

Our research found 1,335 articles pertaining to the subject matter of organ donations. After reviewing the titles and abstracts of these articles 1,250 papers were excluded as these papers were not directly relevant to the topic searched. The full text of the remaining 85 papers were analysed and only 10 papers were found relevant to the scope of this study. The 10 papers were selected as they were compatible with our inclusion criteria. We only chose (1) papers that discussed family responses towards organ donation, (2) papers that offer comparative analysis of countries, (3) and also those that are cited in the Publish or Perish software. Papers that chose to discuss apart from family response on organ donation or just focussed on the analysis of a particular country were excluded. Papers that were not cited in the Publish or Perish software were also excluded. The 1,335 papers were reduced to 85 on the basis that only papers that discussed about the presumed consent system were included. The papers were further reduced to just 10 by only including papers that discussed on family responses towards organ donation. This explains the reasons why a total of 1335 article was narrowed down to just 10 papers.

Before performing detailed analysis of family response and organ donation system, it was important to access and compare the findings of literature on the performance of organ donation systems in general. Hence, this study was structurally divided into three sections: (a) presumed consent versus informed consent systems; (b) legislation and family response; and (c) biasness in donation decision.

All human studies had been reviewed by the University of Malaya Research Ethics Committee (Reference Number: UM.TNC2/RC/H&E/UMREC-35) and have therefore been performed in accordance with the ethical standards laid down in an appropriate version of the 2013 Declaration of Helsinki as well as the Declaration of Istanbul 2008.

Results

(i) Presumed consent versus informed consent systems

Theoretically, the presumed consent system is believed to enhance organ donation rates. According to a recent survey (Rithalia, McDaid, Suekarran, Myers, & Sowden, 2009), the number of countries which adopted this system has rapidly increased; currently, 25 nations have applied this system officially. The proponents of the informed consent system are increasing in those countries who are unclear about the transition towards the presumed consent system. For instance, in the UK, the 2007 surveys revealed that around 60% of the respondents were in favour of replacing presumed consent with informed consent, compared to 20% in a survey done in 2000 (Mossialos, Costa-Font, & Rudisill, 2008).

In a review of 26 scholarly articles, five articles compared organ donation rates in different countries, before and after their shifting from an informed consent system to a presumed consent system (Rithalia *et. al.*, 2009). The authors concluded that countries that had shifted to the presumed consent system witnessed an increase in organ donation rates. Organ donation rates per million people (pmp) were recorded at an increased range between 21% and 30%. Eight of these studies were related to cross-country analysis, which revealed that the presumed consent system is responsible for increased organ donation rates compared to the informed consent system.

A cross national empirical analysis revealed that the legislation is one of the determinants of organ donation (Abadie & Gay, 2006). Their study showed that once the other determinants of organ donation were controlled, the presumed consent system appeared to record an average of 25 to 30% higher organ donation rates over the informed consent system.

The outcomes of studies within the European countries also supported the superiority of the presumed consent system over the informed consent system. A survey

of 16,230 respondents from 15 European countries concluded that people are more likely to donate in the case of presumed consent system (Mossialos *et. al.*, 2008). Similarly, Gimbel *et. al.* (2003) found that the presumed consent system is one important factor for getting higher organ donation performance, besides other factors such as the number of transplant centres, education and religion.

In contrast, some other studies showed that the shift towards presumed consent may lead to negative outcomes. For instance, when Chile shifted towards the presumed consent system in 2010, the percentage of non-donors increased. The donation pmp decreased from 8.31 (mean of donation rates between 2000 and 2009) to 5.95 pmp (mean of donation rates between 2010 and 2011). Previously, Chile and Brazil had the same negative experiences, which urged the officials to abolish the presumed consent system in 1997.

(ii) Legislation and family response

In a recent study of legislations of 54 countries worldwide (25 countries with presumed consent and 29 countries with informed consent), Rosenblum *et. al.* (2012) found that in most of these countries, the deceased's families are involved in the organ donation process regardless of the consent system adopted. The study also showed that the family played an important role regardless of whether the deceased expressed a wish to donate organs.

In another study, Fevrier and Gay (2004) explored the role of the family in determining the relationship between the legislations and organ donation rates using mathematical models. The models were built based on the assumptions taken from the theoretical literature of organ donation decision and the utility theory arguments of cost and benefit. Initially, they proved that the presumed consent system resulted in higher organ donation rates than the informed consent system, without considering the role of family. However, after they included the role of family in the

model, the results were surprisingly new and a first of its kind in the field. They found that the informed consent system became more efficient than the presumed consent system in terms of organ donation rates. Results of this study opened new dimensions for scholars to rethink on the importance of including family response when explaining the interaction between the legislation and organ donation. However, real world data analysis of some studies were not in accordance with that the above argument.

Mossialos *et. al.* (2008) argued that the legislation system played an important role not only in people's preferences on donating their own organs but also their relatives' organs. Their study added that people from those countries with presumed consent system were more willing to give consent to donate their deceased relatives' organs compared to those countries with an informed consent system.

In contrast, the studies on Chile and Brazil concluded that the reluctance of families to give consent for organ procurement from their deceased relatives had increased after the countries applied the presumed consent system. However, these results were widely attributed to other reasons rather than the legislation only. The distrust towards medical systems and the absence of proper knowledge among the families regarding organ donation were cited as the main reasons for their reluctance to donate their own and their relative's organs. This explanation agreed partially with Mossialos *et. al.* (2008)'s findings, regarding the interaction of families

with the legislation, where the interaction was found to affect organ donation significantly.

(iii) Biasness of the donation decision

Some of the reviewed studies investigated the differences between donation decisions of family members, regarding their own and deceased relatives' organs. The analysis of their findings showed that people are more willing to donate their organs rather than donating the organs of their deceased relatives.

In Belgium, where the presumed consent system has been applied since 1987, a study of three age groups was conducted: (i) young (18–29 years), (ii) parents (30–59 years) and (iii) grandparents (above 60 years) (Roels *et. al.*, 1997). The study revealed that 84.5, 83 and 60.2% of the three respective groups were willing to donate their organs. However, peoples' willingness to donate their relatives' organs was around 10% lower on an average; whereas only 72.3, 75.2, 54% were recorded for the three generations, respectively, stating their willingness to give consent regarding their deceased relatives' organs. The results from the Mossialos *et. al.* (2008)'s findings accorded with the notion. According to their outcomes, although 60.1% of people were willing to donate their organs, only 48.4% gave their consent for the procurement of organs of their deceived relatives. These findings implied that there is an approximate 10% gap of organs available for donation, which are lost due to the biasness in the preferences of people regarding their own and their relative's organs.

Table 1: Countries implementing presumed consent system for organ donation

Year	2010		2011		2012		2013	
Country	Deceased donor	Living donor	Deceased donor	Living donor	Deceased donor	Living donor	Deceased donor	Living donor
Austria	24.3	7.2	26.2	6.8	24.60	7.70	24.60	9
Belgium	25.2	6.9	29.3	7	32.9	8	29.9	9.6
Chile	5.4	0	6.61	0	9	0	6.43	0
Croatia	28.66	4.96	34.96	2.79	36.5	3	35	0.9
Hungary	15.80	4.19	13.08	4.69	14.32	5.30	15.61	4.03
Luxembourg	6.02	0	18	0	7.9	0	14.9	0
Singapore	5.10	7	0	6.11	0	5.4	0	0
Slovenia	20.5	0	15.5	0	23	0	24.30	0
Spain	32	5.53	35.30	7.20	34.80	8.20	35.12	8.59
Sweden	12.60	18.77	15.45	19.90	15.03	17.15	16	16.42

*Sourced from The International Registry in Organ Donation and Transplantation (IRODaT)

*Figures are presented in “PMP” form (per million of population)

Table 2: Countries implementing informed consent system for organ donation

Year	2010		2011		2012		2013	
Country	Deceased donor	Living donor	Deceased donor	Living donor	Deceased donor	Living donor	Deceased donor	Living donor
Australia	14	13.40	15.10	11.5	15.60	10.80	16.90	10.80
Brazil	9.60	9.10	10.70	9.17	12.60	8.40	13.2	7.90
Denmark	12.92	18.06	13.11	17.96	13.38	13.53	10.16	18.74
Germany	15.90	9.20	14.70	10.60	12.80	10.40	10.90	10.10
Ireland	9.70	0	20.67	6	17	7	18.81	8.31
Netherlands	13	28.80	13.23	27.10	15.08	29.32	15.26	31.24
Malaysia	0.7	1.30	NA	NA	0.64	1.84	0.5	1.87
Saudi Arabia	3.86	15.30	3.40	20.20	3.07	22.10	2.5	24.70
United Kingdom	16.40	16.90	17	17	18.34	16.86	20.77	17.80
United States	25.60	21.20	26	19.20	25.60	15.40	25.99	18.83

*Sourced from The International Registry in Organ Donation and Transplantation (IRODaT)

*Figures are presented in “PMP” form (per million of population)

The two tables indicate higher organ donation rates in many countries that have implemented the presumed consent system such as Belgium, Spain and Croatia, in contrast to the informed consent system. However, in Singapore and Chile, the organ donation rates have been dismal, even lower than some countries that implemented the informed consent system.

Discussion

While numerous campaigns and awareness programmes may have been carried out globally, organ donation rates remain dismal in most, if not all sovereign states. This is understandable because organ donation is more complex than one can imagine as it involves not only the consent of the possible donors, but also their immediate family members' approval. In the countries that have implemented the presumed consent system, the process of organ harvesting may become complicated if a deceased did not file any objection in his or her lifetime and the family members cite lack of information in filing such official objections in the past. The efforts taken through campaigns and awareness programmes may be dampened by disinterest or fear against organ donations caused by external factors. Such external factors may include the acts of corruption in handling the process of organ donation and transplantation or even unpleasant experiences of former organ donors. In the second half of 2012, Germany experienced a drastic plunge in organ donations from the deceased compared to the preceding year. This came about as corruption acts of doctors reporting their patients' health worse than it is in order to be placed as more urgent patients in the organ waiting list, were exposed. Apart from that, botched surgical procedures have also caused the donors not only health complications, but even death, although it has to be assured that such incidences remain very minor. Films, albeit aimed for entertainment, may also cause fear against organ donation. Examples such as "Recycled Parts" (2007) and "Kaaki Sattai" (2015 – Tamil film) portrayed "organ theft" from patients by doctors and unscrupulous syndicates, and may influence

the audiences to reject organ donations in the future. On the same note, it is worth to be noted that films such as the block-buster flick "Seven Pounds" (2008), have encouraged the act of organ donation in the quest of saving lives.

Although the theoretical argument of Fevrier and Gay (2004) indicated a negative implication of family on organ donation rates, most of our reviewed studies, which were based on actual world data, concluded that the consent of the family for organ donation of their relatives was higher under the presumed consent system rather than the informed consent system. However, a few exceptions of this argument, such as the cases of Chile and Brazil, did not refute this argument but rather highlighted the importance of public trust and family education regarding the organ donation systems.

Our review showed that:

- Willingness of people to donate their organs after death was approximately 10 – 12% higher than their willingness to donate their relatives' organs. Further, the willingness in both the cases was higher under the presumed consent than the informed consent system.
- Most of the literature found, with some exceptions, the significant effect of legislations on organ donation and proved the effectiveness of presumed consent system in bringing the organ donation rates to 21 – 30% higher than the informed consent system.

Based on the information summarised in Tables 1 and 2, further studies on this area are highly warranted and can be used to understand the willingness towards organ donation among the population.

Conclusion

The issues highlighted in this study are the backbone of our suggestion that countries seeking to overcome organ shortage and increase organ donation rates by moving towards the presumed consent system should

consider the importance of providing families with proper information about this system. Furthermore, the fact that a gap between the willingness of the people to donate their own as well as their deceased relatives' organs exists, has to be conveyed to the governments, which will be helpful in optimising organ donation rates. This should be done by dedicating more studies to understand the reasons behind this gap and to suggest the possible solutions.

Acknowledgements

The authors wish to thank the University of Malaya for funding the research under Research Grant Scheme 2013 (Project No.: RG511-13HTM) and also Mr Ganeshwaran Kana for his help in preparing the draft of this paper.

REFERENCES

- Abadie A, Gay S. The impact of presumed consent legislation on cadaveric organ donation: a cross-country study. *Journal of Health Economics* 2006; 25(4): 599-620.
- Fevrier P, Gay S. (2004). Informed Consent Versus Presumed Consent: The Role of the Family in Organ Donations. Available at SSRN 572241.
- Gimbel RW, Strosberg MA, Lehrman SE, Gefenas E, Taft F. Presumed consent and other predictors of cadaveric organ donation in Europe. *Progress in Transplantation* 2003; 13(1): 17-23.
- IRODaT. (n.d.). Retrieved August 21, 2015, from <http://www.irodat.org/?p=database>
- Mossialos E, Costa-Font J, Rudisill C. Does organ donation legislation affect individuals' willingness to donate their own or their relative's organs? Evidence from European Union survey data. *BMC Health Services Research* 2008; 8(1): 48.
- Rithalia A, McDaid C, Suekarran S, Myers L, Sowden A. Impact of presumed consent for organ donation on donation rates: a systematic review. *BMJ* 2009; 338.
- Roels L, Roelants, M, Timmermans, T, Hoppenbrouwers, K, Pillen, E, Bande-Knops, J. (1997). A survey on attitudes to organ donation among three generations in a country with 10 years of presumed consent legislation. Paper presented at the Transplantation Proceedings.
- Rosenblum, AM, Horvat, LD, Siminoff, LA, Prakash, V, Beitel, J, Garg, AX. The authority of next-of-kin in explicit and presumed consent systems for deceased organ donation: an analysis of 54 nations. *Nephrology Dialysis Transplantation* 2012; 27(6): 2533-46.
- Siminoff LA, Gordon N, Hewlett J, Arnold RM. Factors influencing families' consent for donation of solid organs for transplantation. *JAMA* 2001; 286(1), 71-7.