



The Role of the Family in Deceased Organ Procurement: A Guide for Clinicians and Policymakers

Janet Delgado, PhD, MA, RN,^{1,2,3,4} Alberto Molina-Pérez, PhD,^{3,5} David Shaw, MML, MA, MSc, PGCE,^{3,6,7} and David Rodríguez-Arias, PhD^{3,5}

Abstract: Families play an essential role in deceased organ procurement. As the person cannot directly communicate his or her wishes regarding donation, the family is often the only source of information regarding consent or refusal. We provide a systematic description and analysis of the different roles the family can play, and actions the family can take, in the organ procurement process across different jurisdictions and consent systems. First, families can inform or update healthcare professionals about a person's donation wishes. Second, families can authorize organ procurement in the absence of deceased's preferences and the default is not to remove organs, and oppose donation where there is no evidence of preference but the default is to presume consent; in both cases, the decision could be based on their own wishes or what they think the deceased would have wanted. Finally, families can overrule the known wishes of the deceased, which can mean preventing donation, or permitting donation when the deceased refused it. We propose a schema of 4 levels on which to map these possible family roles: no role, witness, surrogate, and full decisional authority. We conclude by mapping different jurisdictions onto this schema to provide a more comprehensive understanding of the consent system for organ donation and some important nuances about the role of families. This classificatory model aims to account for the majority of the world's consent systems. It provides conceptual and methodological guidance that can be useful to researchers, professionals, and policymakers involved in organ procurement.

(*Transplantation* 2019;103: e112–e118)

Received 7 October 2018. Revision received 27 November 2018.

Accepted 8 December 2018.

¹ University Institute of Women's Studies, University of La Laguna, Santa Cruz de Tenerife, Spain.

² Vulnerability and Human Condition Initiative, Emory University, Atlanta, GA, USA.

³ Ethical Legal and Psychosocial Aspects of Organ Transplantation (ELPAT), European Society for Organ Transplantation (ESOT), Padova, Italy.

⁴ University Hospital of Canary Islands, Tenerife, Spain.

⁵ FiloLab-UGR Scientific Unit of Excellence, Department of Philosophy I, Philosophy School, University of Granada, Granada, Spain.

⁶ Institute for Biomedical Ethics, University of Basel, Basel, Switzerland.

⁷ Department of Health, Ethics and Society, Care and Public Health Research Institute, Maastricht University, Maastricht, The Netherlands.

The authors declare no conflicts of interest.

The Project INEDYTO was supported by Ministry of Economy, Spain (grant FFI2017-88913-P).

All authors have contributed in the design of the research, participated in the writing of the paper, and contributed new analytic tools.

Supplemental digital content (SDC) is available for this article. Direct URL citations appear in the printed text, and links to the digital files are provided in the HTML text of this article on the journal's Web site (www.transplantjournal.com).

Correspondence: Janet Delgado, PhD, University Institute of Women's Studies, University of La Laguna. C/ Pedro Zerolo, s/n. Edificio Central. Apartado 456. Código postal 38200. San Cristóbal de La Laguna. S/C de Tenerife, Spain. (jdelgad@ull.edu.es)

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ISSN: 0041-1337/19/10305-0e112

DOI: 10.1097/TP.0000000000002622

INTRODUCTION

Families in different jurisdictions can play very different roles in organ procurement after death, and their views often determine whether the organs are eventually obtained for transplantation. In fact, their objection to organ procurement is a leading cause of organs not being procured in many countries.¹ Transplant coordinators and organ procurement teams have to decide whether, when, and the extent to which family members of deceased donors are involved in the decision-making process related to organ procurement. That decision depends on legal, medical, and organizational considerations, and has different ethical implications. In most countries, families are allowed and expected to make decisions, which may or may not accord with the wishes of the deceased,² whereas in other countries, they may be informed but are not involved in the decision. The former are often called “soft” systems, while the latter are known as “hard” systems.^{3,4} However, these labels do not capture the many roles relatives can play in diverse situations in each country, or account for the differences between countries. For instance, one soft system may rely on the family to decide only when the preferences of the deceased are unknown, but another soft system may also let the family decide against the expressed preferences of the deceased.

Two factors determine the role relatives actually play in organ procurement: the preferences of the deceased and the model of consent in place. On the one hand, depending on the existence or absence of expressed preferences by the

deceased—and the content of such preferences—relatives can authorize or refuse organ procurement either: (a) on behalf of the deceased, according to what they believe the patient would have wished, (b) because of their own values, regardless of what the deceased might have wished, had a wish been expressed, or even (c) against the explicit wishes of the deceased, whether in favor or against donation.

On the other hand, the family's role and decision-making capacity depend on the model of consent. Under an opt-in or "explicit consent" system, organs cannot be removed unless the person had expressly consented to such removal before death, while under an opt-out or "presumed consent" system, organs can be removed by default unless the person had expressed an opposition.⁵ Actually, both systems involve presumptions: opt-in systems presume that consent is not given, and their default policy is to do nothing, while opt-out systems presume that consent is given, and their default policy is to remove the organs.⁶ In theory, the application of these default policies is quite straightforward. In reality, however, relatives' involvement adds complexity to the implementation of both opt-in and opt-out. When the deceased had neither consented nor clearly expressed opposition to organ removal, which is common in both opt-in and opt-out jurisdictions, families' views become particularly decisive in clinical practice, even if it is not a legally enshrined right. In opt-in systems, relatives can override the default—not to procure the organs—by authorizing organ procurement, whereas in opt-out systems, relatives can override the default—to procure the organs—by opposing organ procurement. In some jurisdictions, their authority in the decision can even prevail over the deceased's explicit wish to donate.

Many articles have analyzed the role of the family in several countries,^{2,7-17} but these accounts are often incomplete or too imprecise to determine exactly what relatives are allowed to do in a given jurisdiction, in each of the situations described. For instance, Rosenblum et al² published in 2012 a detailed analysis on the authority of next of kin in deceased organ donation, which included 54 opt-in and opt-out nations. They found that relatives are almost always involved in the organ procurement process, even if the deceased's wishes to donate are documented. However, their classification does not distinguish what exact role families are allowed to play, within a given nation, under 3 possible scenarios: (1) when the deceased had expressed consent; (2) when the deceased had expressed refusal; and (3) when the deceased had not expressed any preference.

Within a given country, the role families are stipulated to play in the law may differ from the role they actually play in practice. However, most descriptive accounts on the role of families in organ procurement fail to make this distinction.

To cast more light on this topic, we interviewed 53 experts from 18 countries attending the 2016 annual meeting of the ESOT-ELPAT (European Society for Organ Transplantation—Ethical Legal and Psychosocial Aspects of Transplantation) with a series of questions about the role families play in their country (Table S1, Figure S1, SDC, <http://links.lww.com/TP/B681>). A salient outcome of that preliminary exploration was that the majority of these experts reported differences between the content of the law and the actual practice in their country regarding the role families play in organ procurement. Later, in 2017, we emailed government officials and legal experts all over

Europe with similar questions, obtaining 22 responses (Table S2, SDC, <http://links.lww.com/TP/B681>). On both occasions, the answers we received were strikingly inconsistent or ambiguous. Such ambiguity can be partially explained by discrepancies between local regulations and actual practices, but we also noticed that some common terms, such as "presumed consent," "family consent," and "family veto" are being used with different meanings. For more detail, the methodology and results of both exploratory surveys are explained in the Supplemental File (SDC, <http://links.lww.com/TP/B681>).

We take these exploratory findings as a symptom of the complexity of policy and as a sign that conceptual clarity is needed regarding the role families play in organ procurement. These reasons led us to propose a simplified systematic model of organ procurement policies.

In this article, we propose a theoretical framework of all possible roles that relatives can play in any given country, either according to the law or in clinical practice. This framework aims to be simple yet complete. It encompasses the 2 variables that determine the role relatives can play: the preferences of the deceased (nonexpressed preference, consent, refusal) and the model of consent (opt-in, opt-out). First, we propose a series of definitions to explain different actions in relation to the consent models. Next, we provide a reasoned list of actions that relatives can possibly take to intervene in the organ procurement decision-making process. Then, we propose a classification of the different roles families can play according to the 2 variables (Table 1). Finally, we present several examples of application of our classification.

Our classification does not take into account family decisions that have no impact on the process of organ procurement, for instance, cases where relatives can object to organ procurement, but without implying stopping the removal of organs. We only consider situations in which family's decisions have consequences in the organ procurement process.

The goal of this proposal is to gain a more comprehensive and granular understanding of the consent system for organ donation as a whole and the role families play. The scope of this model is broad, as it aims to account for the majority, if not all, of the world's consent systems.

DEFINITIONS

Opt-in (also known as explicit consent system). Under an opt-in system, organs may be removed from a deceased person if the person had expressly consented to such removal during his or her lifetime, either verbally or, depending on domestic law, such consent may also be recorded on a donor card, driver's license or identity card, medical record, or a donor registry.⁵

Opt-out (also known as presumed consent). Under an opt-out system, organs may be removed from a deceased person for transplantation unless the person had expressed his or her opposition before death.⁵

Mandatory choice (or mandated choice). Under a mandatory choice system, individuals are required by law to express their preferences regarding organ procurement. This procedure can be made while they execute a state-regulated task, such as registering for a driver's license, applying for a renewal of their identity card, or filing income tax forms. Since organs cannot be removed unless

TABLE 1.
Levels of involvement of the family

Deceased wishes	Model	Role of the family			
		No role (L0)	Witness (L1)	Surrogate (L2)	Full decisional authority (L3)
Unknown	Opt-out	–	Can inform about the deceased's wishes	Can oppose organ procurement	Can oppose organ procurement
	Opt-in	–	Can inform about the deceased's wishes	Can authorize organ procurement	Can authorize organ procurement
Consent	Opt-in, opt-out	–	Can update the deceased's wishes	Can update the deceased's wishes	Can overrule consent
Refusal	Opt-in, opt-out	–	Can update the deceased's wishes	Can update the deceased's wishes	Can overrule refusal ^a

Levels are ordered by columns in increasing order from no role at all (L0) to full decisional authority (L3). Each level specifies what relatives can do under 3 different situations ordered by rows: when the organ procurement team does not know the wishes of the deceased (Unknown), when they know that the deceased had expressed a wish to become a donor (Consent), and when they know that the deceased had objected to become a donor (Refusal). The table also takes into account the model of consent (opt-in or opt-out), although this variable has an effect on the role of the family only when the wishes of the deceased are unknown.

^aThis option is theoretically possible, but it is very unlikely that any consent system would allow the family to override a refusal, for it is contrary to current international laws and guidelines. However, families in, for example, the UK are permitted to provide evidence of consent that supersedes a recorded refusal, according to Human Tissue Authority guidelines. (Code of practice 10—Human Transplantation (Wales) Act). This would not technically be an overrule (but rather an update), although it might be regarded as one.

the person had expressly consented to such removal, this system works similar to an opt-in system.

Organ procurement refers to the operation of organ removal for transplantation regardless of whether it exists a consent given by the deceased person or an authorization by the next of kin.

Organ donation refers to the organ procurement expressly consented by the deceased. We suggest using the term “donation” when the person had granted permission to the removal of his or her organs, and “procurement” to both consented and not consented organ removal.

Consent refers to the explicit permission granted by the deceased to the removal of his or her own organs. We consider that the lack of an explicit refusal in opt-out countries is not equivalent to the deceased's consent. Hence, we suggest restricting the use of the term “consent” to the decision explicitly made by the deceased. Although some authors and regulations use the expression “family consent,” we suggest replacing it with “family authorization” to avoid confusion.

Refusal refers to an explicit objection expressed or recorded by the deceased person. We suggest to use the term “refusal” when the person had objected to the removal of his or her own organs, and “opposition” or “overrule” to refer to different types of family objection to organ procurement (see below).

Family refers to relatives, next of kin, and also friends of the deceased. We recognize that the family is not one monolithic unit and is made up of different people who may have different attitudes to and knowledge of both the patient's donation preferences and organ procurement in general.¹⁸ Furthermore, there can be internal disagreements within a family about what the deceased would have wanted, and whether to obey his or her wishes. In some countries, such as the United Kingdom and Chile, the decision-making person within the family is determined by law according to a hierarchy of relatives. For the sake of clarity we use the word “family” throughout to refer to whoever is involved in discussing organ procurement with healthcare professionals.

RELATIVES' POSSIBLE ACTIONS IN ORGAN PROCUREMENT PROCESS

There are 3 main ways in which the family can intervene in a given consent system, when they are allowed to. First,

by participating in obtaining, recording, and testifying to the deceased's preferences. Second, by reversing the system's default when the deceased did not express any preferences. Third, by overruling the deceased's explicit preferences.

Each of these intervention types can be further specified into different actions:

- The family can obtain and record the deceased's most recent expressions of consent or refusal, and communicate them to the medical team.
 - Relatives can inform about the deceased's preferences. When the medical team does not know if the deceased wished to become a donor, they may ask relatives to provide this information.
 - Relatives can update the deceased's preferences. When the medical team already knows the deceased's expressed preferences, through a register, a donor card, living wills, or by any other means, family members can update the record and communicate whether the person had more recently changed his or her mind.
- The family can be allowed to reverse the default course of action defined by the consent system when the deceased had expressed no preferences. The family can either ground their decision in their own views or in what they speculate the deceased may have wished.
 - Relatives can authorize procurement when the default is not to procure the organs in the absence of a consent expressed by the deceased person.
 - Relatives can oppose procurement when the default is to proceed with organ procurement in the absence of an objection expressed by the deceased person.
- The family can be allowed to decide whether organ procurement should take place, despite and against the decision taken by the deceased person while alive to consent or to refuse donation.
 - Relatives can overrule a consent. When the deceased had expressed the explicit wish to become an organ donor after death, the family can nevertheless impede the donation and prevent the removal of organs. This is also known as family veto to organ donation.
 - Relatives can overrule a refusal. When the deceased had expressed an explicit refusal to become an organ donor,

the family can nevertheless allow or authorize the medical team to proceed with organ removal.

These generic actions clarify how each consent system ought to be interpreted and/or how they are actually implemented.

- 1.a. Relatives can inform about the deceased's preferences under 2 circumstances: if there is no record whatsoever on the deceased's preferences, and if there is no valid record. It is the system of consent which defines which records are deemed valid (ie, official registries, living wills), as well as which types of information from the family may be taken into account: documents written by the deceased, a declaration signed by family members, a mere oral declaration, etc.
- 1.b. Relatives can update the deceased's preferences when there is a valid record known to the medical team. The family can confirm the already expressed preference by the deceased or indicate a change of opinion, if the case arises.
- 2.a. Relatives can authorize procurement. We suggest restricting the use of the term "authorization" to those situations where the deceased did not express any preference and where the default is not to procure the organs (opt-in system). In addition, when a person is not capable or not allowed to make a decision on organ donation (eg, children, mentally disabled), the family can act as surrogate decision-maker. Also, in some countries, people can express the wish that, after death, their family or a designated person makes the decision on their behalf. Under a prototypical opt-in system, organs cannot be procured without the deceased's expressed consent to donate. However, most opt-in countries allow relatives to nevertheless authorize the removal of organs (Table 2). In contrast, under a prototypical opt-out system, in the absence of the deceased's objection, organs can be automatically procured. In this case, since procurement is already the default course of action, no further action should theoretically be needed from the next of kin. We therefore consider that next-of-kin's authorization is only required in opt-in systems, that is, where the procurement would not proceed otherwise. However, it seems that most opt-out countries require nevertheless the next-of-kin's approval (Table 2).²
- 2.b. Relatives can oppose procurement. We suggest restricting the use of the term "opposition" to those situations where the deceased did not express any preference and where procurement is the default (opt-out system). As said previously, under prototypical opt-out and opt-in systems, in the absence of expressed preferences from the deceased regarding donation, the course of action is determined by the default, regardless of the family. We therefore consider that next-of-kin's authority to oppose the procurement process can only be granted in opt-out systems, that is, where the procurement would proceed otherwise.
- 3.a. Relatives can overrule consent. This action is also referred to as veto. We suggest using the expression "overruled consent" (or "veto") in situations where the family's opposition stops organ procurement, contrary to the wishes of the deceased.
- 3.b. Relatives can overrule refusal. This is the permission granted by relatives to proceed with organ procurement against the will of the deceased. These cases may either be very exceptional or underreported because of potential controversy.

FAMILY'S ROLE AND LEVEL OF INVOLVEMENT

We distinguish 4 levels of family involvement (Table 1). Each level includes several actions that relatives can be

allowed to do. Importantly, these levels are incremental, such that higher levels include all potential actions allowed under lower ones, except the Level 0.

L0: Family has no role

Level 0 (L0) describes situations where the family is not given the opportunity to be involved in the decision-making process. Relatives are not consulted and play no role at all, although they might be kept informed about what is going to be done with the organs.

L1: Family acts as mere witness

Level 1 (L1) describes situations where the family is just expected or allowed to communicate the witnessed wishes of the deceased, nothing more. Doctors may or may not know the preferences of the deceased. In the first case, the next of kin may still be approached to update the record to seek whether the person had changed his or her mind before death. In the second case, the family is asked to provide that information, if they have it. In either case, the family has no decisional capacity. It is the medical team who decides.

L2: Family acts as surrogate

Level 2 (L2) reflects greater implication of the family in the decision-making process. In addition to acting as witness of the deceased's wishes, if any, the family can reverse the default course of action defined by the consent system if no wishes have been expressed. In opt-out countries, they can oppose organ removal, whereas in opt-in countries, they can authorize it. The family can decide either according to what they believe the deceased can have wished or according to their own views. Whenever the deceased had expressed their preferences during their lifetime, either in favor or against donation, the family has not such decisional capacity.

L3: Family has full decisional authority

Level 3 (L3) describes the highest degree of decisional capacity relatives can have in the organ procurement decision-making process. As in L2, the family is consulted to make a decision if the preferences of the deceased are unknown to the medical team, and the family cannot provide any information. The distinction from L2 is that the family can also overrule the consent or refusal expressed by the deceased. However, it is very unlikely that any consent system would allow the family to override a refusal, for it is contrary to current international laws and guidelines.

EXAMPLES OF APPLICATION

Table 1 is intended to capture the role of relatives in any given country and to enable comparisons between several jurisdictions. If differences exist between law and practice, our table facilitates this distinction, as a national regulation may fulfill the description of one level but be applied more loosely or more rigidly and therefore qualify for a different level. Here are 3 examples: The Spanish opt-out law can be classified as L1 (witness),⁴⁶ because next of kin can solely inform or update doctors regarding the wishes of the deceased. However, in practice, a written authorization from the family is

TABLE 2.**Classification of countries according to the level of involvement of families, either in the law or in practice**

Level	0	1	2	3
Role of the family	No role	Witness	Surrogate	Full decisional authority
Law	Argentina ¹⁹ Austria ^{8,12,20} Uruguay ²¹	Chile ^{22,23} France ^{24,25} Singapore ²⁶ Spain ^{27–29}	Belgium ^{9,30} Canada ³¹ Germany ³² The Netherlands ^{33,34a} Sweden ^{9,11} United Kingdom ^{35,36b} United States ^{37,38}	India ^{39,40} Japan ^{41,42}
Practice			Belgium ³⁰ Germany ⁹ Singapore ²⁶ Sweden ⁹	Austria ¹¹ Canada ³¹ Chile ⁴³ India ⁴⁴ Japan ⁴⁵ The Netherlands ⁹ Norway ¹³ Portugal ¹³ Spain ^{9,11,46} United Kingdom ^{47–49} United States ^{50–52c}

^aWe refer to the Act of 24 May 1996, concerning rules concerning the provision of organs (Law on organ donation).⁵³

^bNot including Wales since December 2015 because the law changed to an opt-out system.⁵⁴

^cAccording to one study, only 20% of Organ Procurement Organizations in the United States may allow families to overrule the deceased's consent.⁵²

always required to proceed with organ procurement.⁴⁶ Some authors interpret this situation as Spanish families having a de facto power to overrule the consent of the deceased.⁵⁵ If this is the case, although Spain's legal system can be classified as L1 (witness), it might be operating in practice as L3 (full decisional authority). The law in Singapore—another opt-out system—can be classified as L1 (witness), but some accounts suggest that it actually operates as L2 (surrogate), because families can oppose organ procurement when the deceased's preferences are unknown.²⁶ All Canadian provinces have an opt-in legislation where families can act as surrogate (L2), but they seemingly operate as if families actually had full decisional authority (L3).³¹

The countries analyzed in Rosenblum et al² can be classified as follows under our taxonomy according to the information provided by the authors. However, we could not determine whether their classification refers to the legal or the de facto role families play in organ procurement. In addition, it must be noted that some of the following countries may have changed their legislation and/or practice since the publication of Rosenblum's article in 2012 (such as France, the Netherlands, and Wales).

- Surrogate: (opt-in) the Netherlands, Romania, United Kingdom, and most of the United States; (opt-out) Belgium, Finland, Singapore, and Sweden.
- Full decisional authority: (opt-in) Australia, Brazil, Canada, Cuba, Denmark, Estonia, Germany, Iceland, India, Ireland, Israel, Japan, Kuwait, Lithuania, Malaysia, Malta, Mexico, New Zealand, Philippines, Saudi Arabia, South Africa, South Korea, Switzerland, Thailand, Venezuela; (opt-out) Armenia, Austria, Belarus, Chile, Colombia, Costa Rica, Croatia, Czech Republic, Ecuador, France, Italy, Luxembourg, Norway, Paraguay, Poland, Russia, Slovak Republic, Slovenia, Spain, Tunisia, and Turkey.

In Table 2, we provide a classification of countries according to the level of involvement families have, both according to the local regulations and in practice, in organ procurement decision-making. Since Table 2 is used as an illustration of our framework's applicability and usefulness, we decided to include a country when there was at least one reliable source in the literature describing that country's practices, although no hard data were provided about their prevalence. Whenever described practices were different from the law, single cases or marginal accounts were not taken into consideration.

Overall, it appears that legislation tends to be stricter than actual clinical practice, perhaps because clinicians do not wish to alienate families.

LIMITATIONS

Our proposed theoretical framework comprehensively maps the different consent systems and potential family roles, but it has some limitations. For instance, it does not reflect the fact that in many hospitals (in both opt-in and opt-out countries), an authorization from the family is commonly required even if the patient had recorded his or her consent on the donor register. If the deceased's preferences prevail over the family's, then it may be considered an inconsistency of current organ donation systems. However, if the consent of the deceased and the authorization of the family are both required, then this may be a new "double consent" system not described in the literature.

Our framework does not reflect either some systems that are possible in theory but atypical or unusual in reality. For instance, Singapore's presumed consent law initially excluded Muslims, who were automatically considered objectors as a group, even though they could still opt-in as individuals—the law was eventually amended in 2007 to remove the exemption.⁵⁵ We cannot rule out that other

jurisdictions may currently or in the future include provisions to allow community consent or refusal (beside that from the individual and the family), similar to the situation of consent for research with indigenous communities.⁵⁶

Another area where our model cannot entirely reflect reality concerns the honesty of family members. Though data on this phenomenon are scarce, it is possible that families might claim to be updating regarding the deceased's preferences, when they are actually misrepresenting what they wanted to prevent (or, possibly, enable) organ procurement. For the purposes of our article, we assume that families are being honest—as clinicians must also do.

CONCLUSIONS

The systematic description, analysis, and taxonomy we have developed in this article offer a clarification of the role of the family in the organ procurement decision-making process. To have a clear classification of the different kinds of actions available to relatives when discussing and deciding about the deceased's organ procurement is critical in implementing new policies. National organ procurement organizations ought to clarify to the public what procedure they are following and the precise level of involvement of the family. This article provides a feasible and useful model to categorize the role of families in most scenarios. The aim of this taxonomy is informative: we seek to clarify what are the different levels of family's involvement. It contributes substantial content to the theoretical and practical spheres, and it can be helpful for policymakers, health professionals, scholars, and citizens. Our clarification provides conceptual and methodological guidance for further theoretical or empirical studies on the role of the family in organ procurement. The taxonomy does not offer recommendations about the optimal level of participation of the family in the decision-making process. We consider it as a necessary first step for the discussion of ethical and legal problems regarding family's involvement in organ procurement. Further studies addressing ethical and legal aspects may use this taxonomy to understand and critically assess different scenarios, and the ethical repercussions of each level of family involvement.

ACKNOWLEDGMENTS

The authors thank the following persons for their contribution to a discussion on the difference between family consent and family authorization: Marina Morla, Anne Dalle Ave, Íñigo de Miguel, Iván Ortega-Deballón, and Pablo de Lora.

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