2. Defining Consent

Autonomy and the Role of the Family

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1. Introduction

> "[O]rgans may be removed from the bodies of deceased persons for the purpose of transplantation if: (a) any consent required by law is obtained, and (b) there is no reason to believe that the deceased person objected to such removal." (World Health Organization)

Consent is usually considered the ethical cornerstone of organ procurement (OP). The World Health Organisation's Guiding Principle 1 on human organ transplantation stresses its ethical importance and emphasizes that a valid indication of the deceased's objection to the removal of his or her organs must prevent such removal. In addition, it indicates that procurement programs under explicit consent (opt-in) policies "typically seek permission from the family even when the deceased gave pre-mortem consent", while programs under presumed consent (opt-out) "may be reluctant to proceed if the relatives oppose the donation" (WHO 2010, 2).

A trend towards presumed consent (according to which every deceased person is a potential donor) can be observed in Europe, where several countries have changed their legislation in that direction in recent years (England, Greece, Iceland, The Netherlands, Scotland, Wales) or considered doing so (Denmark, Germany, Romania, Switzerland). Beyond Europe, Chile and Japan switched to presumed consent in 2010, and Uruguay did so in 2013. Australia and several US states have also considered this but eventually decided against it.

A tendency towards lessening the role families have in the decision about OP is also evident. In 2006, the USA amended the Uniform Anatomical Gift Act to restrict the family's authority to veto the deceased's first-person authorization. France amended its law in 2017 to "reinforce" presumed consent so that families can no longer oppose nor veto OP. Argentina updated its opt-out law in 2018 so that relatives are not even required to inform the medical team about the deceased's wishes, thus removing any family involvement. Uruguay enacted a similar law in 2013. Prior to this, only Austria was known to have such a 'hard' opt-out legislation.

While consent is considered a key element for acceptable OP, how it is understood varies widely. In the first section, we attempt to systematically classify all different models of consent in that field. We claim that these models can vary widely depending on whether decisional authority is given only to living prospective donors, to donors and their relatives, or exclusively to the family. In the second section, we examine the concepts of autonomy underlying these models: individual, relational, and family autonomy. In the third section, we discuss some ethical issues derived from presumed consent and family veto.

2. Consent Models for Organ Procurement

There are three main kinds of systems for deceased organ procurement (OP): altruistic, commercial, and compulsory. *Altruistic* systems are the most common worldwide, based on the idea that organ donation is a free gift that relies upon individual autonomy. *Commercial* or *market-based* systems are based on incentives (financial or not) and on the idea that organs are commodities subject to supply and demand. Finally, *compulsory* systems do not depend on the individual's autonomous decision to donate or to sell their organs but on national or local regulations. Compulsory systems can take two opposite forms: conscription (or confiscation), under which OP is mandatory; and prohibition, under which OP is illegal. In the following, we will only focus on altruistic and compulsory systems.

Altruistic models of consent for deceased OP can be classified according to the relative authority they grant to three main variables: (1) the preferences expressed by the deceased, if any; (2) the preferences expressed by the family, if any; and (3) the default policy when no preference has been expressed by either the deceased or the family (Delgado et al. 2019).[1]

2.1 Definition of Terms

2.1.1 Preferences of the Deceased

Individuals can either consent or refuse to donate their organs after death. 'Consent' is understood here as explicit permission granted by the deceased to the removal of his or her organs, while 'refusal' is an explicit objection by the deceased. We consider that the absence of an expressed refusal is not equivalent to the deceased's consent, and the absence of expressed consent is not equivalent to the deceased‘s refusal. In some countries, individuals also have the option to request a proxy or surrogate to make the decision on their behalf after they die.

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[1] Several other variables could have been taken into account, but they would have excessively complicated an already complex picture. For instance: the decisional capacity of the medical, legal or religious authorities; the role of community leaders; procedures to express preferences; incentives (e.g. prioritization in the waiting list of recipients, monetary rewards for survivors); directed post-mortem donation (e.g. family-oriented priority).

2.1.2 Role of the Family

The family[2] may be allowed to intervene in three incremental ways in the decision-making process:

1. *As a witness of the deceased's preferences*: The family can obtain and record the deceased's most recent expressions of consent or refusal and communicate them to the medical team.
2. *As a surrogate of the deceased*: The family can be allowed to decide on OP when the deceased has not. Depending on the default policy, they can *authorize* or *oppose* the removal, and their decision can be based either on their own views or on what they speculate the deceased may have wished.
3. *As the final decision-maker*: The family can be allowed to make the final decision on OP despite and against the wishes of the deceased. They can: a) *overrule* the deceased's *consent* by blocking (vetoing) the removal of organs, or b) *overrule* the deceased's *refusal* by allowing the doctors to proceed.

In some jurisdictions, the family may not be allowed to intervene at all in OP decision-making. Although they might be kept informed about what is going to be done with the organs, they are not consulted.

2.1.3 Default Policy

Organ procurement policies can be defined by the default option that applies when the deceased's wishes are unknown to the medical team. Opt-out policies allow organs to be automatically removed under such circumstances, while opt-in policies forbid it. A third option, known as 'mandatory choice', requires by law that all adults express their decision while executing state-regulated tasks, such as registering for a driver's license or applying for a renewal of their ID card.[3]

2.2 Clarifying the Complexity of Systems

The labels 'soft' and 'hard' are sometimes used in the literature to characterize opt-in and opt-out policies depending on whether or not families are involved in the decision-making process (cf. Rithalia et al. 2009a; Shepherd et al. 2013; Etheredge et al. 2018). However, these categories are unable to account for the complexity of a family's range of possible actions in different circumstances, and they may create more confusion.

For example, according to their laws Austria and Spain can both be called 'hard opt-out' countries, but their systems are actually quite dissimilar. In Spain, because there is no register of refusals, physicians are required by law to ask relatives about the

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[2] We use the word "family" throughout to refer to those involved in discussing OP with health care professionals: relatives, next-of-kin, and friends of the deceased, who may have different knowledge and opinions regarding both the patient's donation preferences and OP in general, and who may disagree about what the deceased would have wanted, and whether to obey his or her wishes. In some countries, such as the UK and Chile, the decision-making person within the family is determined by law according to a hierarchical list of relatives.

[3] To our knowledge, New Zealand is the only country worldwide to implement a true mandatory choice system.

deceased's preferences. In addition, physicians are required by practical guidelines to ask for an authorization from the family to proceed with organ removal. In Austria, by contrast, individuals can register their refusal to donate, and relatives have no legal role whatsoever. In practice, the situation is less clear, and physicians may or may not consider the wishes of the family.

Deceased's wishes	**Model of consent**	**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 OP*	Can oppose OP*
	Opt-in	–	Can *inform* about the deceased's wishes	Can authorize OP*	Can authorize OP*
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**

Table 1: Levels of involvement of the family by columns in increasing order. Each level specifies what relatives can do under three different situations ordered by rows: when the medical team does not know the wishes of the deceased ("Unknown"), when the deceased had explicitly consented to becoming a donor ("Consent"), and when the deceased had explicitly objected to becoming a donor ("Refusal"). The table also takes into account the model of consent (opt-in, opt-out), although this variable is relevant only when the deceased's wishes are unknown. Source: Delgado et al. (2019).
** The family can be asked to make a decision either on behalf of the deceased or according to their own views.*
*** This option is theoretically possible but unlikely in practice.*

For clarification and standardization purposes, we have proposed a simple but comprehensive framework that systematically categorizes the role of the family in relation to the deceased's preferences and the systems' default policy (Delgado et al. 2019).

Table 1 shows four possible incremental levels of family involvement. Each level includes actions families can do, depending on the deceased's wishes and the default system:

1. At the lowest level (L0, *no role*), the family has no involvement whatsoever. They may be informed about what will happen to their loved one's organs, but they are not consulted.
2. At the next level (L1, *witness*), relatives are considered as mere witnesses of the deceased's preferences. They may be asked for information about the deceased's last wishes, if any, but they are not allowed to make any decision on their own.

3. At the subsequent level (L2, *surrogate*), in addition to being witnesses, relatives may be allowed to make a decision *if the deceased has not*. This decision may be made on behalf of the deceased or according to their own views. At this level of involvement, the family can overrule the system's default, but not the deceased's wishes.
4. At the highest level (L3, *full decisional authority*), the family may be granted a full decisional capacity, even when the deceased had expressed a preference. They may be allowed to overrule the deceased‘s decision and, therefore, be given the last word regarding OP.

2.3 Taxonomy of Consent Models

Building on Table 1, we propose a comprehensive and fine-grained taxonomy of all justifiable models of consent, either actual or theoretical, that take into account the three variables: the deceased's preferences, family preferences, and the default policy. This taxonomy results in the following ten categories (Table 2, Fig. 1):

#	Model	Description	Default	
1	**Deceased's wishes only**	If the deceased expressed a preference, it is respected; otherwise, the default policy applies. The family may or may not be allowed to inform/update the medical team about the wishes of the deceased, but they cannot decide under any circumstance.	**a** (opt-out)	**b** (opt-in)
			1a. Organs procured, unless the deceased had refused OP.	**1b.** Organs *not* procured, unless the deceased had consented to OP.
2	**Deceased's wishes mostly**	If only the deceased expressed a preference, it is respected; if only the family expresses a preference (the deceased did not), it is also respected; if both have expressed a preference, the deceased's prevails; and if neither party has expressed a preference, the default policy applies.	**2a.** Organs procured, unless the deceased refused OP or, if the deceased's wishes are unknown, when the family opposes OP.	**2b.** Organs *not* procured, unless the deceased consented to OP, or if the deceased's wishes are unknown, when the family authorizes OP.
3	**Deceased's wishes or agreement**	If the deceased expressed a preference, it is respected, unless the family disagrees; in that case and all other cases, the default policy applies.	**3a.** Organs procured, unless the deceased refused OP AND the family either opposes OP or expresses no preference.	**3b.** Organs *not* procured, unless the deceased consented to OP AND the family either authorizes OP or expresses no preference.
4	**Agreement only**	If both the deceased and the family agree, their shared preference is respected. In all other cases, the default policy applies.	**4a.** Organs procured, unless the deceased refused OP AND the family opposes OP.	**4b.** Organs *not* procured, unless the deceased consented to OP AND the family authorizes OP.

#	Model	Description	Default	
5	**Family wishes or agreement**	If the family has expressed a preference, it is respected, unless it contradicts the deceased's expressed preferences; in that case and all other cases, the default policy applies.	**5a.** Organs procured, unless the family opposes OP AND the deceased had either also refused OP or had expressed no preference.	**5b.** Organs *not* procured, unless the family authorizes OP AND the deceased either had also consented to OP or had expressed no preference.
6	**Family wishes mostly**	If only the deceased expressed a preference, it is respected; if only the family has expressed a preference (the deceased did not), it is also respected; when both have expressed a preference, the family's prevails; and when neither party have expressed a preference, the default policy applies.	**6a.** Organs procured, unless the family opposes OP or, if the family wishes are unknown, when the deceased had refused OP	**6b.** Organs *not* procured, unless the family authorizes OP or, if family wishes are unknown, when the deceased had consented to OP
7	**Family wishes only**	If the family has expressed a preference, it is respected; otherwise, the default policy applies.	**7a.** Organs procured, unless the family opposes OP	**7b.** Organs *not* procured, unless the family authorizes OP
8	**Refusal prevails**	If only the deceased expressed a preference, it is respected; if only the family has expressed a preference (the deceased did not), it is also respected; and when the deceased and the family have conflicting preferences, refusal/opposition (whoever has expressed it) prevails.	**8a.** Organs procured, unless the deceased had refused OP and/or the family opposes OP	**8b.** Organs *not* procured, unless the deceased and the family both agreed with OP, or at least one has consented or authorized OP while the other party has expressed no preference.
9	**Consent prevails**	If only the deceased expressed a preference, it is respected; If only the family has expressed a preference (the deceased did not), it is also respected; if the deceased and the family have conflicting preferences, consent/authorization (whoever has expressed it) prevails.	**9a.** Organs procured, unless the deceased and the family both objected to OP, or at least one has refused or opposed OP while the other party has expressed no preference.	**9b.** Organs *not* procured, unless the deceased consented OP and/or the family authorizes OP.
10	**Default only**	The default policy always applies, irrespective of the deceased's and the family's preferences.	**10a.** Organs always procured	**10b.** Organs never procured

Table 2: Taxonomy of models of consent for organ procurement according to three variables: (1) deceased's wishes, if any; (2) family wishes, if any; and (3) default policies. Several of these models (3a, 4, 5, 7, 9, 10a) are theoretically possible but may not have been implemented so far.

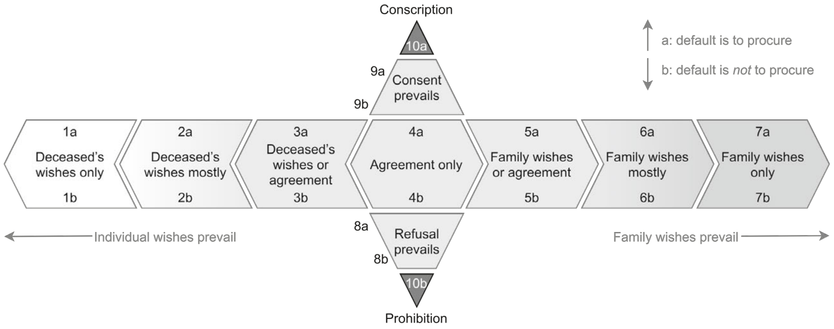

Fig. 1. Consent models for organ procurement organized in a cross diagram. On the horizontal scale, models that prioritize the wishes of the deceased on the left (#1 to #3) or those of the family on the right (#5 to #7). On the vertical scale, models that do not prioritize one party over the other but favor the objection to OP (#9a, #8b), whoever it comes from, over consent or authorization (#8a, #8b). On the edges of the vertical line are two models that do not take any preferences into account: organ conscription (#10a) and prohibition (#10b). At the center of the cross are the two models (#4a, #4b) that do not prioritize one party nor one decision over the other

2.4 Distribution of Consent Models around the World

Descriptive information regarding the existing policies for OP around the world is scarce, incomplete, and quickly outdated, because countries change their legislation from time to time. Additionally, there are differences between law and practice (Delgado et al. 2019). For instance, under Australian *law* (opt-in), prior consent by the deceased person is sufficient to authorize organ recovery. However, according to Government's Guidelines for Ethical Practice, the deceased's family needs also to be consulted and its agreement sought (National Health and Medical Research Council 2007).

Comparative international studies (Gimbel et al. 2003; Gevers et al. 2004; Bagheri 2005; Abadie/Gay 2006; Rithalia et al. 2009a; Horvat et al. 2010) often include incomplete information on the role of the family within a given nation, making it impossible to classify consent models according to the taxonomy above (Table 2). The most comprehensive data available to date regarding the level of involvement of the family in OP is summarized in Table 3.

Model of consent		**Role of the family**				**Source**[a]
		L0 No role	L1 Witness	L2 Surrogate	L3 Full decisional capacity	
Opt-out	law	AR, AT, PT, UY	BE, CL, ES, FR, SG, WA	SE, NO	JP	Delgado et al. 2019
	practice			BE, FR, SE, SG	AT, CL, ES, JP, NO, PT, WA	
	unspec.			BE, FI, SG, SE	AM, AT, BY, CL, CO, CR, CZ, EC, ES, FR, HR, IT, LU, NO, PL, PY, RU, SI, SK, TN, TR	Rosenblum et al. 2012
	unspec.	AT, CZ, LU		GR, PT, SK	BE, ES, FI, FR, HR, HU, IT, NO, PO, SE, SI	Bilgel et al. 2012
Opt-in	law			AU, CA, DE, NL[a], UK[a], USA	IN	Delgado et al. 2019
	practice			DE	AU, CA, IN, NL[a], UK[a], USA	
	unspec.			NL, RO, UK, USA	AU, BR, CA, CH, CU, DE, DK, EE, IE, IL, IN, IS, JP, KR, KW, LT, MT, MX, MY, NZ, PH, SA, TH, VE, ZA	Rosenblum et al. 2012
	unspec.	CA			AU, CH, DE, DK, IE, IL, NL, NZ, UK, USA	Bilgel et al. 2012

Table 3: Role of the family in several opt-out and opt-in countries according to three independent sources. Delgado et al. (2019) differentiates family's involvement according to the law and in clinical practice. The other two sources are not specific enough about this difference.

[a] *Data from Delgado et al. (2019) has been completed and updated for this chapter. Data from the two other sources may be outdated.*

[b] *The Netherlands, England and Scotland have implemented opt-out systems by 2020.*

Legend: AM: Armenia; AR: Argentina; AT: Austria; AU: Australia; BE: Belgium; BR: Brazil; BY: Belarus; CA: Canada; CH: Switzerland; CL: Chile; CO: Colombia; CR: Costa Rica; CU: Cuba; CZ: Czech Republic; DE: Germany; DK: Denmark; EC: Ecuador; EE: Estonia; ES: Spain; FI: Finland, FR: France; HR: Croatia; HU: Hungary; IE: Ireland; IL: Israel; IN: India; IS: Iceland; IT: Italy; JP: Japan; KR: South Korea; KW: Kuwait; LT: Lithuania; LU: Luxemburg; MT: Malta; MX: Mexico; MY: Malaysia; NL: The Netherlands; NO: Norway; NZ: New Zealand; PH: Philippines; PL: Poland; PT: Portugal; PY: Paraguay; RO: Romania; RU: Russia; SA: Saudi Arabia; SE: Sweden; SG: Singapore; SI: Slovenia; SK: Slovakia; TH: Thailand; TN: Tunisia; TR: Turkey; UK: United Kingdom (Wales excepted); USA: United States of America; UY: Uruguay; VE: Venezuela; WA: Wales; ZA: South Africa.

Each country's policy could be more accurately classified if enough information was available. Here are some examples: Germany's legal policy for OP corresponds to the consent model #2b ("Deceased's preferences mostly"); it is an opt-in model where the wishes of the deceased are always respected, and where the family can make a decision if the deceased did not. Wales' legal policy is similar to Germany's but operates under presumed consent, thus being classified as #2a. Spain's legal policy corresponds to model #1a ("Deceased's preferences only") because the family is legally granted a witness role. However, according to clinical guidelines, it operates in practice as model #8a ("Refusal prevails"), because refusals are always respected, whomever they come from – the deceased or the family – and they prevail over the other party's explicit consent or authorization (Caballero/Matesanz 2015).

Failing to understand these nuances not only leads to confusion but can also result in misconceptions on the part of transplant policymakers. For instance, in countries where the family has full decisional capacity, moving to opt-out might be ineffective. By focusing on changes from opt-in to opt-out, policymakers may be overestimating the limited effect of the consent system, and underestimating the importance of the family.

3. Concepts of Autonomy Underlying the Consent Models

Consent in medicine is both an ethical requirement and a legal concept. Individual consent is a key element of the Nuremberg Code (1947) and the Declaration of Helsinki (1964) that established ethical principles for protecting human subjects from clinical research malpractice. The term 'informed consent' in the context of medical care emerged in the USA in the 1950s through court decisions (Beauchamp 2011). As a legal tool present now in most jurisdictions, informed consent has the role of protecting a patient's rights, and also protecting medical practitioners from liability in case of harm to the patient.

In the context of deceased OP, the notion of consent should be used with some caveats, because deceased individuals are not patients, and the removal of their organs cannot cause them any sort of physical or psychological harm. Therefore, consent for organ procurement may be interpreted differently than informed consent for medical care or clinical research. This is the case in opt-out countries, where organs can be lawfully procured from a deceased individual without any evidence of informed and voluntary consent from that individual while alive.

In most countries, both opt-in and opt-out, individual consent for OP is neither necessary nor sufficient, and the family's decision may be more consequential than the deceased's preferences. To make sense of this, we propose to show how different models of consent may rely on different concepts of autonomy beyond the individual. Models #1 to #9 (Table 2, Fig. 1) may indeed be accounted for by a continuum of three forms of autonomy: individual autonomy, relational autonomy, and family autonomy. This proposal does not preclude other possible interpretations.

3.1 Individual Autonomy

The principle of autonomy in biomedical ethics (Beauchamp/Childress 1979) can be traced back to the moral philosophies of Immanuel Kant (1724–1804) and John Stuart Mill (1806–1873). For Kant, autonomy should not only be understood as the possibility of choosing between one option or the other, but also as the capacity and even the obligation to know for ourselves, as rational agents, what we should do. This means that our choices and actions must obey self-imposed norms dictated solely by our rationality, without influence from social and moral conventions, or from political, legal, and religious authority, or even from our own inclinations and desires (Kant 1785).

By contrast, Mill considers that individuals are autonomous when their choices and actions rely on their personal values, desires, and inclinations. For Mill, personal freedom is the absence of impositions and external interventions. Hence, paternalism should be limited to situations in which it is clearly justified: "the only purpose for which power can be rightfully exercised over any member of a civilised community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant […]. Over himself, over his own body and mind, the individual is sovereign" (Mill 1856: 13).

Individual autonomy in liberal bioethics reflects Mill's understanding of the individual's freedom to develop his or her own life according to personal choices, without any kind of undue interference from others (Charlesworth 1993). Nobody else's preferences, including those of health care professionals and relatives, should prevail over the preferences of a patient. Hence, any intervention by the family or others could be interpreted as a disruption of individual autonomy.

In the context of OP, the requirement of consent, either explicit (opt-in) or presumed (opt-out), would somehow imply that individual autonomy should be respected after the individual's death. The fact that the organ donor is dead raises doubts about the applicability of this interpretation of freedom to this context. A proper analysis would need to address the topic of the legal and moral existence of posthumous rights and interests (cf. Sperling 2008). This important topic is however quite speculative and falls beyond the scope of this chapter.

Assuming that an individual's interests and rights survive after death, individual autonomy would be respected, according to our classification, in consent models where the deceased person is the sole decision-maker. This corresponds to the first column (L0) in Table 1, and to models #1a and #1b ('Deceased's preferences only') described in Table 2.

3.2 Relational Autonomy

Individual autonomy is supported by the individualistic paradigm: the idea that people are independent, self-interested and rational decision-makers. In the context of Feminist Theory, the term of *relational autonomy* has emerged to better explain the fact that people's autonomy, needs, and interests are shaped by their relations to others (Dove et al. 2017; Delgado 2019). We contend that, in the context of organ procurement, relational autonomy can better account for the connection between individual choice and family decisions as guardians of the deceased´s beliefs and values.

Over the last decades, an increasing amount of literature in Bioethics advocates that human beings are socially embedded and that, consequently, personal decisions take place in a context of social relationships (Nedelsky 1989; Mackenzie/Stoljar 2000; Rogers et al. 2012; Mackenzie et al. 2014; Straehle 2017). Relationships, responsibility, care and interdependence are key attributes of relational autonomy, for "people develop their sense of self and form capacities and life plans through the relationships they forge on a daily and long-term basis" (Dove et al. 2017: 153).

Relational autonomy does not reject the notion of the self but reflects on how individuals develop the capacity to make autonomous decisions with the support of family and friends (Herrings 2014). The development of the capacity of autonomy requires an appropriate environment to make it possible. This requires a change in our understanding of rights, shifting the attention from the protection from the interference of others towards the construction of relations which nurture autonomous decisions (Nedelsky 1993, 2011). What really makes autonomy possible is not separation from others but relationships with others (Nedelsky 1989). Relational autonomy is not seen as a static attribute but as a capacity that is continuously developing throughout our lives. What makes it possible is the context of social relations that supports it (ibid.). In the clinical context, the development of this capacity requires the contribution of health care professionals (Delgado 2019).

Some critics of the concept of relational autonomy acknowledge that autonomy is socially constituted, but they argue that the influences of the social environment on the individual patient are too unpredictable to be considered by health care professionals. Furthermore, they raise the concern that prioritizing the decisions of other people over those of the patient, in the name of promoting the conditions that improve autonomy, can be a form of paternalism (Wardrope 2015).

In this chapter we assume that people need the support of others to make autonomous decisions and, ultimately, to fulfil their autonomy. As such, relational autonomy supports the claim that consensus between the patient and the family is a sign of autonomous decisions. In our classification, this understanding of autonomy underlies all models where relatives participate in the decision-making process – models #3 to #5, as well as #8 and #9 (see Table 2) – provided that they do not contradict the preferences of their loved ones. When they contradict each other, neither of them prevails over the other, and the decision to procure or not depends on the system's architecture (the default option established by opt-in or opt-out).

Model #3 ('Deceased's preferences or agreement') requires consensus, but the wishes of the deceased are respected and suffice when the family has not expressed any preference. To the extent that family preferences are taken into account, we cannot consider it as a purely individual autonomy system.

Model #4 ('Agreement only') requires consensus, which means that neither the deceased nor the family can decide alone. One of the aspects that underlies OP decision-making is the communication that has previously taken place between the deceased and the family about their preferences. In this regard, this is the model that best represents relational autonomy in the context of OP.

Model #5 ('Family preferences or agreement') requires consensus, although the wishes of the family are respected when the deceased failed to express his or her preferences.

Models #8 ('Refusal prevails') and #9 ('Consent prevails') require consensus too, but both deceased and family may decide alone when the other party has not.

3.3 Family Autonomy

Families come in different shapes and sizes. In the context of health care and OP, the family can be understood as a 'collective actor' with 'collective autonomy' (Beier et al. 2016). The expression *family autonomy*, developed in American Law, refers to the assumption that a family unit should be governed by the private decisions of some or all of its members (McMullen 1992). Ann Elliot (2001) argues that in the family-centred model of care it is the sole responsibility of the family to hear bad news about a patient's diagnosis and prognosis and to make decisions regarding care and treatment, and what or whether the patient should be told. This model is related to some cultural and health care aspects in which individual autonomy is viewed as a reflection of isolation and burdensome to patients who are too sick to make meaningful decisions.

The notion of family autonomy has also been developed by East Asian bioethics. According to Ruiping Fan (1997), the East Asian principle of autonomy requires family-determination, presupposes an objective conception of the good, and upholds the value of harmonious dependence of the individual upon his or her family. This means that the family itself is an autonomous social unit, and that, although both the patient and family members must reach an agreement before a clinical decision can be made, it is the family that has the final authority to make clinical decisions in accordance with this principle.

In our classification, this concept of autonomy corresponds to consent models where the family is the sole decision-maker. This corresponds to the fourth column (L3) in Table 1, and to models #7a and #7b ('Family preferences only') described in Table 2.

3.4 Mixed Types of Autonomy

Some models take into account the preferences of both the deceased and their family, but they eventually give priority to one party over the other in case of contradiction. Models #2 and #6 are transitional models that represent the pathway from individual autonomy (#1) to relational autonomy (#3, 4, 5, 8, 9), and from relational autonomy to family autonomy (#7).

Model #2 ('Deceased's preferences mostly') respects the deceased's preferences and allows the family to decide when the deceased has not. Both deceased and family may decide alone, but the deceased's preferences prevail in case of conflict. A system based on individual autonomy alone would not allow the family to decide. At the same time, it may be supposed that the decision of the family represents the wishes of the deceased.

Model #6 ('Family preferences mostly') is symmetrical to model #2. It allows both deceased and family to decide alone (when the other party has not), but relatives have the final say in case of conflict.

3.5 Models in Which Autonomy Plays No Role

Organ procurement policies may disregard autonomy entirely. In our classification, model #10a ('Default only') corresponds to theoretical policies in which deceased OP would be mandatory. For example, a system of *organ conscription* would require organs to be automatically procured from every person who dies under the circumstances enabling organ transplantation, regardless of people's (the deceased and family) objections. Some have argued that such system would save lives by increasing the number of transplants (Hershenov/Delaney 2009) without thereby violating the autonomy of the deceased or harming their interests, because a person's autonomy is lost after death and the concept of posthumous harm is a fallacy (Spital/Taylor 2007). This system would still violate family autonomy.

Model #10b ('Default only') corresponds to policies in which cadaveric OP is forbidden or not legally permitted for some reason, including the absence of organ transplantation programs in the country. This is the case of several Islamic countries of sub-Saharan Africa (Ghods 2015).

4. Ethical Issues

Transplantation policymaking seeks to govern competing interests in ways that foster the interests of patients on the waiting list while minimally compromising the interests of potential donors and their relatives. These trade-offs need to be made without upsetting the public, whose trust in the organ procurement and transplantation system is essential for achieving high organ donation rates (Rodríguez-Arias 2018). Yet, these trade-offs are ethically challenging and may be negatively perceived by one party or the other.

For example, allowing the family to overrule the deceased's wishes to donate may prevent litigation and bad publicity, and thus help preserve people's trust in the organ procurement system. However, this implies violating freedom of choice and respect for individual autonomy, which is a central value our modern societies cherish. Paradoxically, open violations of such a core value could easily undermine the very trust policymaking intends to protect.

This poses a strategic dilemma: should morally contentious policies be disclosed to, discussed with, and deliberated on by the public, or should they be kept in the relative concealment of political and academic debates? That is, do openness and transparency contribute to or threaten public trust? (Racine et al. 2015)

This could also be seen as a dilemma between short-term vs long-term benefits. On the one hand, full information about the model of consent and the role families play may result in fewer donors in the short term but increased donation rates in the long term due to the perception that the system is honest and trustworthy. Indeed, the public perception of transparency seems to be related to higher willingness to donate organs (Boulware et al. 2007). On the other hand, lack of communication about specific policy choices may result in more donors in the short term but can also be a breeding ground for scandals and decreased donation rates in the future. As Dan Brock (1987, 1999) brilliantly put it, bioethics scholarship and bioethics policymaking, especially in the field of organ transplantation, often rest on a choice between truth and consequences.

These notions seem to be particularly relevant for two ethically challenging policy choices: presumed consent and family veto. Any decision made on these issues may result in higher or lower donation rates, and be more or less respectful for individual or family autonomy. We will show in the next paragraphs that compelling moral arguments have been made in favour and against each option. Our own general position is that the ethical acceptability of any organ procurement policy should not be assessed in isolation from its efficacy, its social acceptability, and the transparency of the means they employ.

4.1 Presuming Consent

Policy changes towards presumed consent (opt-out) seek to increase donation rates by widening the pool of donors and by removing one of the main obstacles to OP, namely people's bias to choose the status quo – their tendency to stick with the current state of affairs or choose default options (Mackay/Robinson 2016; see also chapter 3 in this book). Opt-out policies are intended to act as a nudge: a way of designing the choice architecture that "alters people's behaviour in a predictable way without forbidding any options or significantly changing their economic incentives" (Thaler/Sunstein 2008: 6).

Even though nudges are a form of manipulation, opt-out advocates insist that they preserve people's autonomy, because individuals can still consent or refuse to donate their organs by expressing their wish. In addition, since most people, when asked, express a willingness to donate, the presumption in favour of donation is more likely to honour the autonomy of the deceased person than a presumption against (Cohen 1992; English/Sommerville 2003).

To be sure, the risk exists that surgeons could remove organs from the bodies of people who did not want their organs removed (Cantrell 2019). However, some would argue that it is morally no worse than *not* removing organs from people who wanted them removed (Gill 2004). On the contrary, mistaken presumptions of consent can save and improve the lives of many organ recipients, while mistaken presumptions of refusal cannot. Besides, opt-out systems may produce fewer mistakes than opt-in systems if objectors are more likely to register their opposition than supporters are to sign up as donors (Gill 2004).

Opt-out advocates also claim that it is morally permissible to use the organs of someone who did not opt out, because they have by their silence actually consented (Saunders 2011). However, proper consent requires that the consenting person is at least aware of the consequences of both expressing and not expressing a preference (Rodríguez-Arias/Morgan 2016). Consistently, opt-out advocates emphasize two essential conditions for its ethical acceptability: it must be clearly communicated to all involved that this is how their silence will be interpreted, and it must be possible for people to opt out without facing unreasonable costs for doing so (Saunders 2011). In other words, everybody must be aware of, and understand, the opt-out system, and they must be given a genuine opportunity to object (English/Sommerville 2003). Therefore, widespread public information campaigns should target sections of society that are hard to reach, and mechanisms must be in place to ensure all members of the public are informed of their choices and can register an objection quickly and easily (Hamm/Tizzard 2008; see also chapter 4 in this book).

Are these conditions fulfilled in practice? Empirical evidence suggests that they are usually not. On the one hand, people's awareness of the consent model in their own country, as well as people's knowledge of the procedures to express their preferences regarding OP is much lower in opt-out countries than in opt-in countries (Molina-Pérez et al. 2018). On the other hand, some opt-out countries, including Croatia, Norway and Spain, do not have refusal registries or a standard card enabling people to refuse to donate, making it more difficult for individuals to choose against the default status quo (Rodríguez-Arias/Morgan 2016).

Regarding effectiveness, the relative impact of consent policies on organ donation rates remains controversial. Some have argued that opt-out laws lead straight to larger pools of organs for transplantation (Mossialos et al. 2008; Bendorf et al. 2013; Shepherd et al. 2014; Ugur 2015), while others dispute this claim (Coppen et al. 2008; Bilgel 2012; Fabre et al. 2010; Boyarsky et al. 2012; Arshad 2019). Part of the difficulty resides in the fact that this model has rarely been implemented in isolation from other strategies aimed at fostering OP. One systematic review concluded that, while opt-out policies seem to be associated with increased organ donation rates,

> "it cannot be inferred from this that the introduction of presumed consent legislation per se will lead to an increase in organ donation rates. The availability of potential donors, the underpinning infrastructure for transplantation, wealth and investment in health care, and underlying public attitudes may all have a role" (Rithalia et al. 2009b: 7).

4.2 Family Veto

In most opt-in and opt-out countries, organs cannot be procured without family authorization, even when the deceased explicitly consented (Delgado et al. 2019; Rosenblum et al. 2012). We have suggested that a relational autonomy approach may justify honouring family preferences in the absence of any wish expressed by the deceased (but not when the family opposes the explicit preferences of the deceased). Individual autonomy does not suffice, but relational autonomy applies when there is no contradiction between family and the deceased´s preferences. Family veto to OP can only be justified by absolutely embracing the family autonomy model, at the cost of individual autonomy.

Arguments in support of family veto capacity include the following: (1) it reduces family distress (while the deceased cannot be harmed and holds no relevant interest anymore); (2) it reduces health professionals' stress; (3) it preserves family and public trust by reducing conflict and scandal; (4) it ensures long-term OP rates (as a consequence of 3); (5) families need to cooperate for donation to take place; and (6) families might have evidence regarding refusal (Wilkinson 2005; Shaw 2017).

Arguments against family veto include the following: (1) it violates the deceased's wishes; (2) it reduces organ supply and costs lives; (3) it discourages people from registering as donors, because they know their family may eventually overrule their wishes anyway; and (4) families will regret the decision, resulting in more complicated grief[4] (Cronin 2005; Shaw 2017).

Importantly, in cases of disagreement between the preferences of the deceased and those of their families, family *opposition* seems to be more stringent than family *acceptance* of OP. In other words, family autonomy, *when expressed via opposition*, prevails over the deceased's consent and the collective good represented by the interests of patients on the waiting list. However, *when expressed via a request for organs to be procured*, it does not. Similarly, while the deceased's *consent* does not guarantee compliance, their *refusal* is commonly considered sufficient to preclude OP.[5] Consequently, the deceased's refusal prevails over family preferences (to donate) and over recipients' interests.

An insight that follows from this analysis is that it is wrong to assume that, in cases where the individual and the family disagree among each other, respect for the autonomy of one party always prevails over respect for the autonomy of the other. In fact, this depends on the nature of such preferences. Martin Wilkinson accurately described the position of the UK and New Zealand on consent for OP as a 'double veto', in which each party has the power to withhold and override the other's desire to donate (Wilkinson 2005). However, in case of conflict, our taxonomy shows that models #3, #4, #5, #8 and #9 privilege one decision (to procure or not to procure) over the other, regardless of whether it is expressed by the deceased or by the family (Table 2 and Fig. 1). In other words, *objections* often prevail over *requests*, whoever they come from. This policy might find some theoretical grounding in a liberal bioethics tradition in which negative rights expressed through refusals are deemed more compelling than positive rights expressed via individual requests (Feinberg 1973; Gert et al. 1998).

This conclusion leads to an annoying question: If the deceased's consent to OP is virtually irrelevant (because it is commonly ignored when the family holds a different view), why is it required for deceased donation in the first place? Does the ethical acceptability of OP really require individual consent? Some might argue that the surgical removal of organs from the deceased actually does not require their consent (Emson 2003). At the end of the day, the deceased cannot be physically or psychologically harmed or wronged by organ removal because they no longer exist as persons. When compared with the common good and the public interest, any residual posthumous interest of the terminally ill or already-dead individuals who are candidates for OP fade (Harris 2003). Ultimately, this reasoning leads to a justification of organ conscription described by model #10a (Hershenov/Delaney 2009).

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[4] To the best of our knowledge, this last claim has never been empirically substantiated.

[5] In Spain, a study on the effectiveness of targeted communication strategies to reverse family refusals by transplant coordinators shows that more than 40% of all family oppositions were attributed to and categorized by the authors as a "presumed refusal by the deceased". Among those, 25% could be reversed." (Gómez et al. 2001: 63, table 2).

5. Conclusions

This systematic analysis of the different theoretical and practical models of consent points out the insufficiency of the distinction between opt-in and opt-out systems. We hope the taxonomy that we have provided constitutes a useful tool for researchers, policymakers and clinicians to understand current policy options and their clinical implications. Our analysis of the models of autonomy underlying each consent model may increase our understanding of the complex relationships between individual wishes, family preferences, and the interests of the recipients. Both clarifying the taxonomy of consent models and analysing the models of autonomy can underpin a proper discussion of the ethical problems that arise in the context of OP policymaking.

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