

Review article

Should the family have a role in deceased organ donation decision-making? A systematic review of public knowledge and attitudes towards organ procurement policies in Europe

Alberto Molina-Pérez^{a,b,*}, Janet Delgado^{b,c}, Mihaela Frunza^d, Myfanwy Morgan^e,
Gurch Randhawa^f, Jeantine Reiger-Van de Wijdeven^g, Silke Schicktanz^h, Eline Schiksⁱ,
Sabine Wöhlke^{j,1}, David Rodríguez-Arias^{c,1}

^a Institute for Advanced Social Studies, Spanish National Research Council, Cordoba, Spain

^b Public Issues working group, ELPAT-ESOT, Padova, Italy

^c Department of Philosophy 1, University of Granada, Granada, Spain

^d Department of Philosophy, Faculty of History and Philosophy, Babes-Bolyai University of Cluj, Cluj, Romania

^e Institute of Pharmaceutical Science, King's College London, United Kingdom

^f Institute for Health Research, University of Bedfordshire, Luton, England, United Kingdom

^g Department of Public Information & Education, Dutch Transplant Foundation, Leiden, the Netherlands

^h Department of Medical Ethics and History of Medicine, University Medical Center Göttingen, Göttingen, Germany

ⁱ Department of Policy, Dutch Transplant Foundation, Leiden, the Netherlands

^j Department of Health Sciences, HAW-Hamburg, Hamburg, Germany

ARTICLE INFO

Keywords:

Organ donation
Health policy
Public views
Family decision-making
Family overrule
Europe

ABSTRACT

Goal: To assess public knowledge and attitudes towards the family's role in deceased organ donation in Europe.
Methods: A systematic search was conducted in CINAHL, MEDLINE, PAIS Index, Scopus, PsycINFO, and Web of Science on December 15th, 2017. Eligibility criteria were socio-empirical studies conducted in Europe from 2008 to 2017 addressing either knowledge or attitudes by the public towards the consent system, including the involvement of the family in the decision-making process, for post-mortem organ retrieval. Screening and data collection were performed by two or more independent reviewers for each record.
Results: Of the 1482 results, 467 studies were assessed in full-text form, and 33 were included in this synthesis. When the deceased has not expressed any preference, a majority of the public support the family's role as a surrogate decision-maker. When the deceased expressly consented, the respondents' answers depend on whether they see themselves as potential donors or as a deceased's next-of-kin. Answers also depend on the relationship between the deceased and the decision-maker(s) within the family, and on their ethnic or cultural background.
Conclusions: Public views on the authority of the family in organ donation decision-making require further research. A common conceptual framework and validated well-designed questionnaires are needed for future studies. The findings should be considered in the development of Government policy and guidance regarding the role of families in deceased organ donation.

1. Introduction

Organ transplantation relies on people's willingness to donate. The two main models of consent for *post-mortem* organ retrieval are opt-in (explicit consent) and opt-out (presumed consent). While in opt-in systems only those individuals who expressed their willingness to donate

are considered as potential organ donors, in opt-out systems all adult individuals are deemed organ donors unless they expressly refused while alive. In addition, families play an important role in organ retrieval decision-making. In most countries, the family is asked to make a decision when the deceased had not, that is, when they failed to express any preference regarding donation, and, in some countries, relatives

* Corresponding author at: Instituto de Estudios Sociales Avanzados (IESA-CSIC), Plaza Campo Santo de los Mártires, 7, 14004 Cordoba, Spain.

E-mail address: amolina@iesa.csic.es (A. Molina-Pérez).

¹ Shared senior authorship.

may even be allowed to overrule (veto) the deceased's explicit consent [1–3].²

The role played by the family in organ procurement decision-making may be more consequential than the model of consent [5]. To help increase organ donation rates and respect individual autonomy, scholars have proposed to prevent families from overruling their loved one's intention to donate [6,7]. In 2006, the USA amended the Uniform Anatomical Gift Act to restrict the family's authority to veto the deceased's first-person authorization. Recently, several opt-out countries, including Argentina (Law 27.447, 2018), Colombia (Law 1805, 2016), France (Law 2016–41, 2017), and Uruguay (Law 18.968, 2013), went a step further by implementing policies to prevent the family from making any decision at all, even when the deceased failed to express their preference regarding organ donation. Previously, only Austria was known to have a similarly restrictive opt-out policy.

The governance quality of national organ procurement policies can be assessed by using indicators such as the levels of public knowledge and support towards these policies [8]. This approach is also applicable to policies regarding the role of the family. On the one hand, public awareness over what relatives can and can't do in the organ transplant system serves as an indicator of the system's transparency and publicity, which are necessary means for the citizens' understanding and meaningful engagement in socially controversial health policy debates [8]. Public awareness also affects potential donors and their relatives' autonomy, and it may influence attitudes such as trust and willingness to donate that are crucial for the success of any transplant system [9,10]. For example, an information deficit about the role of the family may create an inner tension in the system, hinder the autonomy of the decision to donate, and amplify moral ambivalence and reluctance towards organ donation [11].

On the other hand, public support for the policy serves as an indicator of the policy's embodiment of people's shared values and preferences. Organ procurement policies aim to increase the availability of transplantable organs. However, efficiency should not be pursued at the cost of hampering other ends that are valuable to society, such as respect towards individuals' autonomy and their posthumous interests, and the autonomy and interests of the family [12]. Given that individual autonomy, family preferences, and collective interests may conflict with each other, ideal governance in democracy should ponder and integrate as much as possible the competing values and goods of the pluralistic society it serves. Organ donation policy-making may pursue that objective by striving for policies that can be supported by a majority, while minimally hampering the values of opposing minorities [8].

Assessing the governance quality of consent policies for deceased organ procurement, including the role of the family in the decision-making process, requires measurements of the levels of public awareness and public support towards these policies. In 2009, a survey indicated that only 28% of individuals residing in Europe were aware of the laws governing donation and transplantation in their country, but this study was not specific enough to draw any conclusion regarding individual consent or the relatives' role in organ donation [13]. A systematic review (SR) on public awareness and attitudes towards consent for organ donation was conducted in 2008 which focused on opt-out but did not address the role of the family [14,15]. In 2012, the Welsh government conducted an update review [16] as well as a review of the role of families in organ donation [17]. Its former report focused on opt-out

² We use the terms family and relatives in a broad sense, meaning those individuals involved in discussing organ procurement with health care professionals and who may have conflicting knowledge and views on the deceased's preferences, if any. In some countries, such as the United Kingdom and Chile, the substitute decision-maker within the family is determined by law according to a hierarchical list of relatives. More generally, in the context of health care and organ donation, the family can be understood as a 'collective actor' with 'collective autonomy' [4].

only and the latter failed to address public awareness and attitudes.

To fill in this gap of knowledge, we conducted a comprehensive SR addressing all consent systems—including opt-in, opt-out, and mandatory choice,—and the role of the family. The main objective of this SR was to measure the levels of public knowledge and support towards these policies. A partial synthesis of results from this SR, focusing specifically on individual consent, has been published elsewhere [18]. In this article, we provide a partial synthesis of results that focuses on knowledge and attitudes towards the role of the family. This is the first systematic review conducted on this topic.

2. Methods

We followed a seven-step approach for SR of empirical studies in bioethics, including the MIP model (methodology, issues, participants) to define research questions and inclusion/exclusion criteria [19]. We also followed the PRISMA 2020 reporting guideline whenever applicable [20]. (PRISMA checklist available as supplementary material).

2.1. Eligibility criteria

Eligibility criteria were: quantitative and qualitative studies addressing knowledge and/or attitudes towards the systems of consent for post-mortem organ donation by lay people in continental Europe (box 1). Given that a previous SR explored the literature up to January 2008, we decided to start our own search at that date [15]. We searched peer-reviewed articles as well as grey literature to reduce publication bias, increase comprehensiveness and timeliness, and foster a balanced picture of available evidence [21].

2.2. Search strategy

A scoping search was initially run in the PROSPERO database, the Cochrane Library, MedLine, and Google Scholar for similar or related systematic reviews as well as relevant studies. Then, we developed a 136-steps algorithm in Medline that we adapted following the respective conventions and mesh terms of alternative databases (Box 1). We used a wide range of terms and combinations of terms to capture different expressions of the same ideas, including 74 combinations of terms for "consent", 57 for "deceased organ donation", and 69 for "knowledge and attitudes". In addition, we searched for articles and grey literature by browsing the websites of public and private organisations, hand checking relevant publications, and direct contact with experts in the field. Searches were last conducted on December 15th, 2017. The full search strategy is available in the Supplemental File.

2.3. Selection process

A team of nine reviewers worked independently in a three-phase screening process of the records retrieved: by title only, by title & abstract, and by full text. Each record was handed to two different reviewers in each phase. A record was excluded when both reviewers in a given phase deemed it irrelevant (as defined by the inclusion criteria in Box 1). In the third phase, a full text record was eligible when both reviewers deemed it relevant. In cases of disagreement, additional reviewers were consulted and a consensus decision was reached. Three records could not be retrieved and assessed by full text.

2.4. Data collection and quality assessment

First, one or more reviewers worked in data collection and in quality assessment for each eligible study. Studies were assessed using three criteria applicable to both qualitative and quantitative research with the aim of identifying those that can be considered as "fatally flawed" (Box 2) [22,23]. Data and quality assessments for each study were arranged in a spreadsheet. Then, each study was reviewed and discussed by all

Box 1

Inclusion criteria and search strategy.

Inclusion and exclusion criteria

Countries:	Any European country, without language restrictions
Date of publication:	Between January 2008 and December 2017
Methods:	Empirical studies, quantitative and/or qualitative
Sources:	Peer-reviewed journals, grey literature reports
Subjects:	General public (i.e. non-healthcare professionals), including students Knowledge and/or attitudes
Outcomes:	—Consent systems (opt-in, opt-out, mandatory choice)
Issues:	—Ways to express individual preferences (registries, donor cards) —Involvement of the family in the decision-making process
Conditions:	Donation or procurement Solid organs (no tissues, blood, eggs, etc.) Post-mortem (no living donation) Transplantation (no research)

Databases: *Ovid:* MEDLINE; *ProQuest:* PAIS Index, PsycINFO; *Ebsco:* CINHALL Complete; *Scopus;* *Web of Science:* all databases.

Websites: Google, health ministries, patients associations, polling firms.

Other searches: As an ancillary search strategy, we checked eligible studies' references, and we consulted experts in the field for any information on potentially eligible reports.

Example of a search string for Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) <1946 to Present (December 15th 2017):

((public or donor? or famil* or relative? or parent* or next-of-kin) adj4 (decision? or authoriz* or authoris* or accept* or refus* or agree* or disagree* or veto or willing* or override*)).ti,ab,kw.

This is just one step in a 136-step search strategy. The full algorithm is available in a supplementary file.

Box 2

Quality assessment criteria.

Primary criteria applicable to both qualitative and quantitative research

1. Are the aims and objectives of the research clearly stated?
2. Is the research design clearly specified and appropriate for the aims and objectives of the research?
3. Is there a clear account of the process by which their findings were produced?
→ Based on 1 to 3: How would qualify the quality of this study? Sound; Adequate; Unsure; Poor; Fatally flawed.

Additional criteria applicable to qualitative research

1. Methods of data collection used? (Focus groups, interviews, other)
2. Is the data analysis methodology described? What is it?
3. Do the authors report the limitations of their study?
4. Is there enough data to support their results/conclusions?

Additional criteria applicable to quantitative research

1. Is the questionnaire available or the questions asked directly cited?
 2. Is there a response rate given? What is it?
 3. Are power calculations reported?
 4. Do the authors report the limitations of their study?
-

authors during an in-person working group meeting and a consensus was reached regarding their final inclusion in the SR. Three reports were rated as “fatally flawed” and excluded for the synthesis.

2.5. Analysis

We found out that family related data was particularly difficult to interpret due to ambiguity regarding the level of authority given to relatives in organ donation decision-making, as well as discrepancies between laws and actual practices. In order to increase analytical clarity, we conducted separate analyses. We thus created two datasets. One includes all data relative to the policies for individual consent and the procedures to express a preference [18]. The other includes all data relative to the family. This second dataset is the focus of the present article, which builds from previous conceptual and descriptive analyses [1,12,24].

We developed a conceptual framework to clarify and classify the family’s role into four levels of involvement [1]. Then, we clustered the data according to the topics addressed and the varying degrees of precision/vagueness of the information provided. This resulted in a bi-dimensional tree-like structure of questions and answers (Fig. 1). Questions are displayed vertically, from top to bottom, in increasing levels of precision. Answers are displayed horizontally, from left to right, according to the four incremental levels of family involvement.

Using this scheme, a fresh data extraction was undertaken independently by two reviewers, with any differences discussed with a third reviewer and a consensus reached. If the data from a given study could not answer a question with a sufficient degree of precision, the reviewers went for a less specific question. For instance, if a study claimed that a majority of respondents support the idea that “relatives should decide about organ donation”, this information is not specific enough to

respond to the question “Should the family be allowed to overrule the deceased’s wishes (if any)”, but it does answer the less specific question “Should the family preferences matter?”. A few results could not be interpreted unambiguously and were excluded from the dataset.

2.6. Limitations

A statistical metadata analysis was not possible because of the high level of heterogeneity in survey questions and sampling. For this reason, we undertook a descriptive analysis of the quantitative studies following the above scheme (Fig. 1). In addition, we used results from qualitative studies to give quantitative data some perspective.

3. Results

The search yielded 1482 results, 467 of which were assessed in full-text form (Fig. 2). Seventy studies were eventually found eligible. Thirty-seven of these studies did not contain any data related to family decision-making and were therefore not included in this synthesis. The remaining 33 studies are composed of 19 articles (Table 1) and 14 grey-literature reports (Table 2).

3.1. Public knowledge of the role of the family

We found nine studies with some data on people’s knowledge of the role of the family, including four journal articles [38–40,42], four reports from the Welsh government [45,46,48,56], and one private poll [50]. Quantitative results show that, with some exceptions, a minority of the public is aware of the family’s role (Table 3). Qualitative studies in Wales also report people’s ignorance about the family’s capacity to veto a deceased person’s decision to donate [45,56].

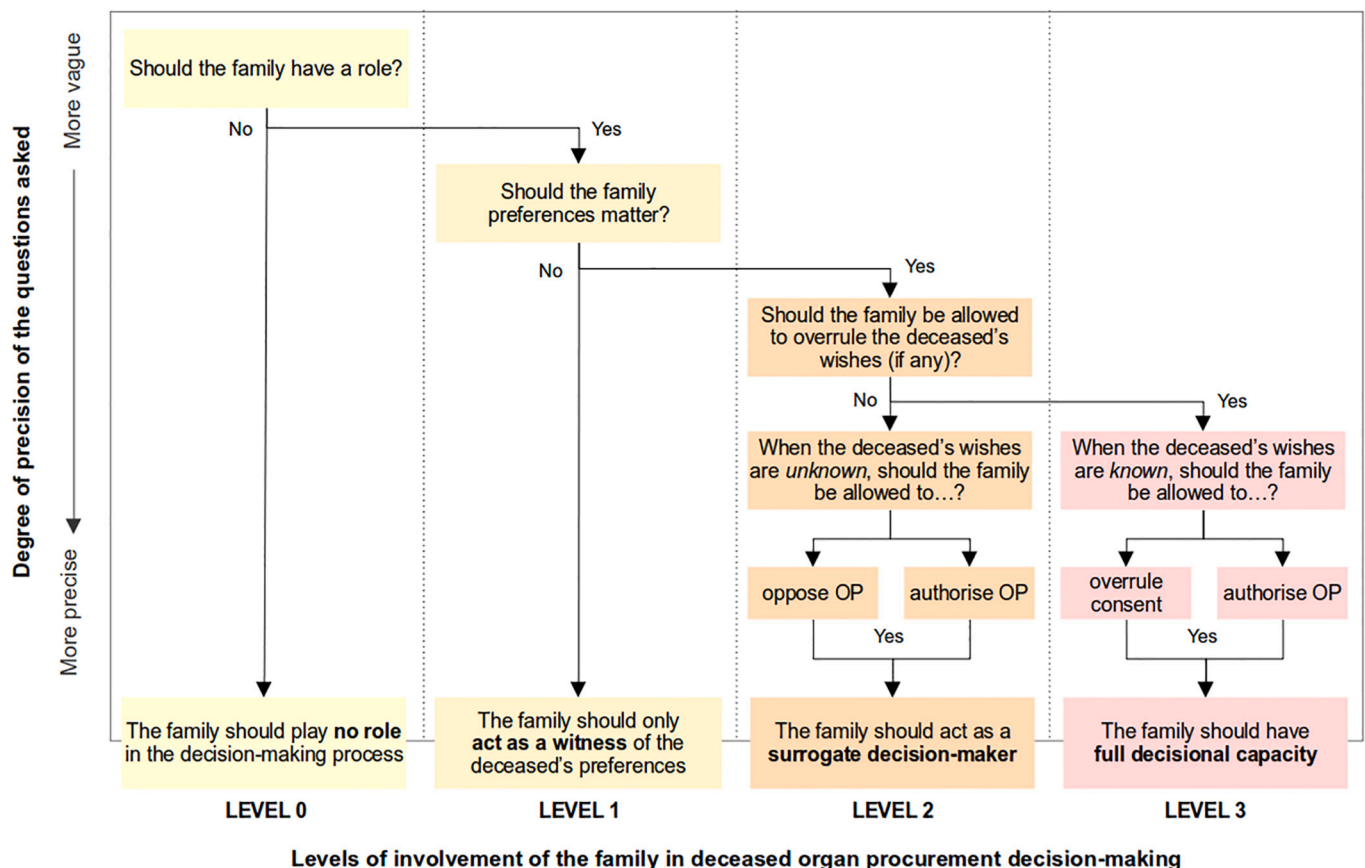


Fig. 1. Tree-like structure of questions and answers according to their degree of precision (vertical) and the level of involvement of the family (horizontal).

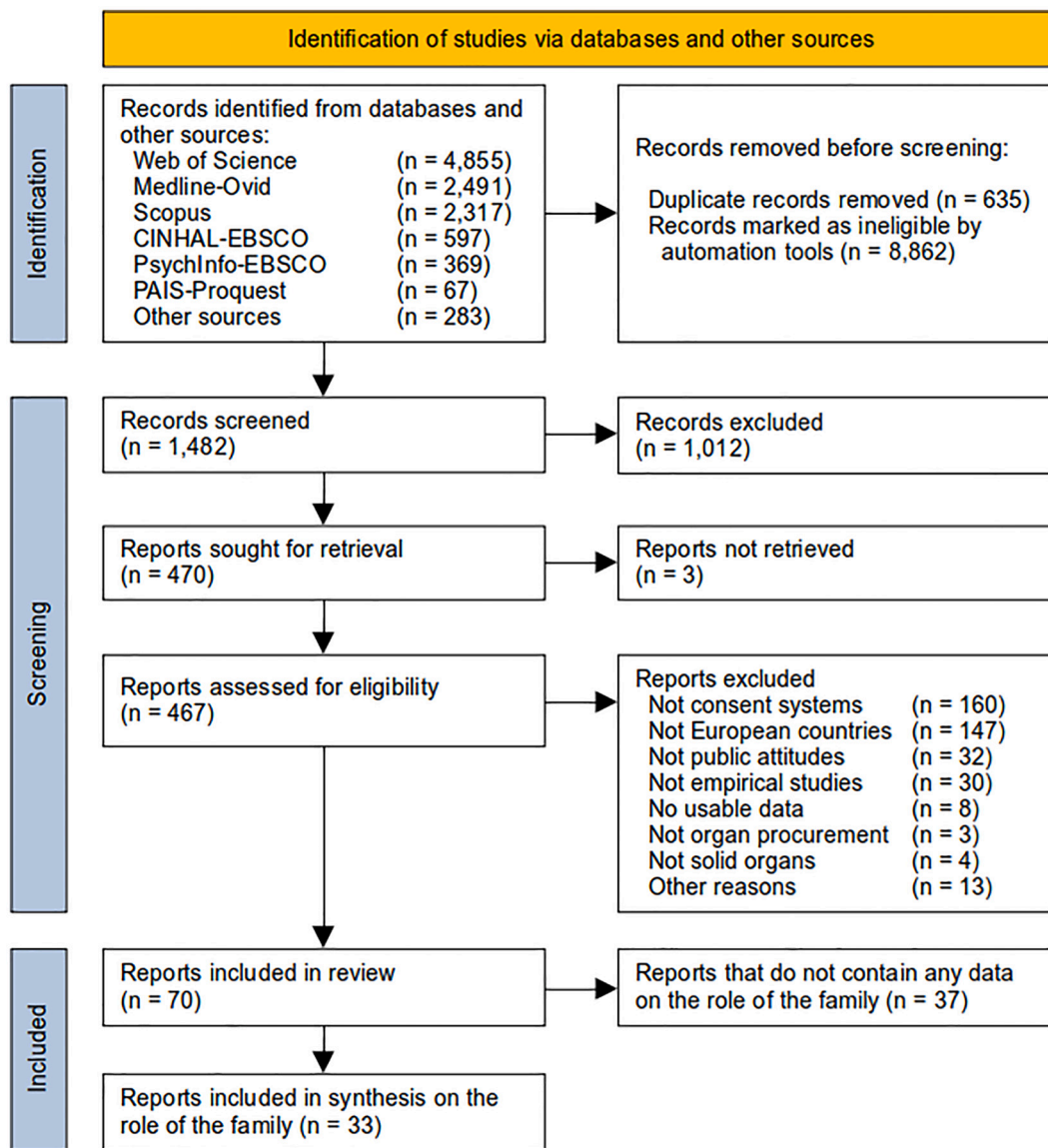


Fig. 2. PRISMA 2020 flow diagram [20]. Records retrieved from databases and non-database sources were mixed before deduplication and screening. Out of the 70 reports included in review, 37 reports did not contain any data related to the role of the family in decision-making and are therefore not included here. These reports have been included as part of a previous synthesis of results regarding policies for individual consent [18]. The remaining 33 studies that do contain relevant data on the role of the family are the focus of the present synthesis.

3.2. Public attitudes towards the role of the family

Results about public attitudes are presented here according to pre-identified four levels of involvement of the family, in decreasing order (from “full authority” to “no role”).

3.2.1. Should the family be able to overrule the deceased’s wishes (full authority)?

This question corresponds to the highest level of involvement of the family in organ procurement decision-making [1] (Fig. 1, Level 3). It means that relatives may either authorise the retrieval of organs despite the deceased’s explicit refusal, or oppose the retrieval of organs against the deceased’s explicit consent (also called “family veto”). This authority can be given to the family for at least two distinct reasons. First, to protect the psychological and moral interests of survivors, especially when their views conflict with those of the deceased—since the deceased can no longer be harmed,— and also to protect the transplant system (that is, potential recipients) from the loss of trust and bad press

that angry families could cause. Second, to ensure that the deceased’s final wishes are being correctly carried out and to reduce risks of errors. In some cases, although the reasons given by a family for objecting to donation are classified as an overrule or veto, they are not genuine overrules at all. For instance, the family can update the medical team by presenting new evidence of refusal when the deceased had registered as an organ donor (or other evidence exists) but changed his or her mind afterwards. However, in such a case, according to our classification, the family is not actually making a decision, but acting as a witness of the deceased’s last wishes [1].

Thirteen studies addressed this question [26,27,29,31,44,45, 47,51,52,54–57]. Five addressed it in general terms, eight addressed the specific question of the family’s capacity to veto the deceased’s consent, and none addressed the specific question of the family’s capacity to authorise organ retrieval despite the deceased’s refusal.

Results show that the answer to this question may depend on its wording and the population it is addressed to. When questions are formulated from the perspective of the next-of-kin—i.e. “Taking into

Table 1
Included peer reviewed articles.

Ref.	Author, date	Country	Data collection	Fieldwork	Sample (response rate %)	Participants	Sampling / recruitment
[25]	Bruce, 2013	Scotland	Questionnaire	2011	200 (~75)	Patients and relatives in emergency department	Convenience
[26]	Coppen, 2010	Netherlands	Questionnaire	2004, 2007	669 (98), 1094 (80)	Dutch Health Care Consumer Panel	Representative
[27]	de Groot, 2015	Netherlands	Interviews	2008–2012	21	Relatives of potential deceased organ donors	Purposive
[28]	Decker, 2008	Germany	Telephone interviews	2005	1000 (n/d)	General public	Representative
[29]	Durczynski, 2011	Poland	Questionnaire	n/d	170 (n/d)	Small town secondary school students	n/d
[30]	Durczynski, 2013	Poland	Questionnaire	n/d	100 (n/d)	Male prisoners	n/d
[31]	Joshi, 2011	United Kingdom	Questionnaire	n/d	439 (84)	University students: South Asian and Whites	Convenience
[32]	Katsari, 2015	Greece	Questionnaire online	2013–2014	1116 (77)	Students of technical schools	Convenience
[33]	Kobus, 2014a	Poland	Questionnaire	n/d	296 (n/d)	Members of Baptist Church	Diagnostic poll
[34]	Kobus, 2014b	Poland	Questionnaire	2012	612 (n/d)	Small and big town residents	Diagnostic poll
[35]	Kobus, 2015	Poland	Questionnaire	2012	395 (n/d)	Rural residents	Diagnostic poll
[36]	Kobus, 2016	Poland	Questionnaire	n/d	405 (n/d)	Medical and non-medical students	n/d
[37]	Lada, 2011	Croatia	Questionnaire	n/d	99 (n/d)	Graduate students	n/d
[38]	Michalska, 2010	Poland	Questionnaire	2008–2009	204 (n/d)	Students of religious seminaries	Requests sent to the deans
[39]	Pawlowicz, 2016	Poland	Questionnaire	n/d	1011 (n/d)	Medical and non-medical university students and high-school students	n/d
[40]	Ryckman, 2009	Netherlands	Questionnaire	n/d	375 (n/d)	High school students	Participants drawn from another study
[41]	Stadlbauer, 2013	Austria	Questionnaire online	2012	2025 (24)	Medical and applied sciences students, ICU nurses	Convenience
[42]	Webb, 2015	United Kingdom	Questionnaire	2013	1549 (n/d)	General public 18+	Commercial survey panel
[43]	Wejda, 2012	Poland	Questionnaire	n/d	296 (n/d)	Nuns, priests and students of theological seminaries	n/d

Table 2
Included grey literature reports.

Ref.	Author, date	Country	Data collection	Fieldwork	Sample (response rate %)	Participants	Sampling / recruitment	Institution
[44]	Beaufort Research, 2012	Wales	Questionnaire	2012	1006 (n/d)	General public 16+	Omnibus survey, representative	Welsh Government
[45]	Beaufort Research, 2012	Wales	Focus groups, interviews		52	Mix of people	Stratified	Welsh Government
[46]	Beaufort Research, 2013	Wales	Questionnaire	2013	1015 (n/d)	General public 16+	Omnibus survey, representative	Welsh Government
[47]	Beaufort Research, 2014	Wales	Focus groups, interviews		80	General public	“free-find” recruitment	Welsh Government
[48]	Beaufort Research, 2014	Wales	Questionnaire	2013	1022 (n/d)	General public 16+	Omnibus survey, representative	Welsh Government
[49]	Beaufort Research, 2016	Wales	Questionnaire	2015 2016	1000 (n/d) 1007 (n/d)	General public 16+	Omnibus survey, representative	Welsh Government
[50]	EenVandaag, 2014	Netherlands	Questionnaire online	2014	18,783 (n/d)	General public	Representative	EenVandaag (television programme)
[51]	Ipsos Mori, 2010	Great Britain	Questionnaire	2010	967 (n/d)	General public 15+	Omnibus survey	Human Tissue Authority
[52]	Ipsos Mori, 2016	Great Britain	Quantitative	2016	1001 (n/d)	Adults		
[53]	PHA, 2013	Northern Ireland	Discussion groups, questionnaire	2013	1012 (n/d)	General public 16+	Representative	Public Health Agency
[54]	Scottish Government, 2017	Scotland	Qualitative, quantitative	2016 2017	824 (n/d)	Individuals and organisations	Online consultation	Scottish Government
[55]	Social Market Research, 2015	Northern Ireland	Questionnaire	2014	1050 (n/d)	General public 16+	Representative	Public Health Agency
[56]	Welsh Government, 2009	Wales	Public meetings, written contributions, telephone interviews	20,082,009	235, 385 (n/d)	People interested	Survey: representative	Welsh Government
[57]	Young, 2017	Wales	Qualitative, quantitative	2017	1993 (n/d)	Adults	Representative	

Table 3
Quantitative results on public knowledge of the role of the family.

Study	Country	Population	Ratio	Issue (what people know about the role of the family)
Can the family override (veto) the deceased's expressed consent?				
[40]	Netherlands	High school students	86%	Relatives cannot stop organ donation when someone is registered as an organ donor.
[42]	United Kingdom	General population	48%	A confirmation of consent by the family is required when the potential donor was registered on the organ donation registry
[46]	Wales	General population	45%	The family cannot override the wishes of the deceased
[48]	Wales	General population	46%	The family cannot override the wishes of the deceased
Can the family act as a surrogate decision maker when the deceased failed to express a preference?				
[42]	United Kingdom	General population	76%	Relatives are approached to make a decision when the potential donor is not registered
[50]	Netherlands	General population	48%	If the potential donor has not registered a choice on organ donation, relatives have to decide.
[38]	Poland	Students	28%	Family consent is not needed for organ procurement
[39]	Poland	Students	10%	Family consent is not needed for organ procurement
[46]	Wales	General population	51%	If the family is in distress over the decision to donate, clinicians will not proceed with organ donation
[48]	Wales	General population	48%	If the family is in distress over the decision to donate, clinicians will not proceed with organ donation

account the cited legal conditions, would you [as next of kin of the deceased] approve a situation in which you are not consulted at all?";—51% to 57% of respondents in the Netherlands answer that they would not approve of not being consulted even if the deceased was registered as a donor [26]. Similarly, 53% of respondents in Poland say they "want to be asked for final permission to collect organs from [their] deceased family member" [29]. A qualitative study of bereaved relatives in the Netherlands found that, although all families greatly value the last will of the deceased, a majority feel that "the family has more right to decide about donation" [27].

By contrast, when questions are formulated from the perspective of the donor or in more neutral terms (e.g. *should the families be able to veto their relatives' expressed consent?*), only 8% to 14% of respondents in the UK support the family's right to veto and 64% to 88% oppose it [52,54–56]. In Wales, 10% to 22% of respondents support the family's capacity to overrule the deceased's wishes [44,49,57]. This result is consistent with qualitative studies in Wales where participants expressed the feeling that organ donation is their decision alone and that their family should not be able to overturn it [45,47,56].

When the question is asked to different ethnic groups in the UK, respondents' support of family veto varies from 9 to 13% among Whites to 22–27% among Indians, and 46–53% among Pakistanis/Bangladeshis [31]. Another study also reports that "black and minority ethnic groups are more equivocal on the question of families overriding a deceased's wishes", with 11% strongly objecting to this—against 32% of whites—, and 37% who neither agree nor disagree—against 19% of whites [51].

Results also seem to vary depending on the relationship between the deceased and the decision-maker: respondents were more inclined (by 4% to 7%) to consider that a married next of kin has the right to overrule their deceased spouses' wishes as compared with parents' given authority to overrule their deceased offspring's wishes, and that difference

in attitudes was displayed by Indians, Pakistanis/Bangladeshis, and Whites [31].

3.2.2. Should the family make a decision when the deceased had not (surrogate role)?

This question corresponds to the second level of involvement of the family [1] (Fig. 1, Level 2). It means that relatives may either authorise or oppose organ retrieval when the deceased had failed to express any preference regarding donation. Six studies addressed this question [26,36,42,51,52,56]. In the Netherlands, 66–68% and 80% of the next of kin consider they should be consulted under an explicit consent (opt-in) and a presumed consent (opt-out) system respectively [26]. In Poland, to a more neutral question (i.e. "Should the doctor ask the family of the deceased person whether they would accept the removal of organs although the deceased person had not expressed their objection before death?"), 76% of respondents answer that the family should be asked to approve the removal of organs [36]. In the UK, 48–50% of respondents think that the family should decide on behalf of the deceased [51,52,56]. Conversely, also in the UK, 30% of respondents answer "I don't have the right to make that decision for someone else" (when the deceased is not registered and they had not discussed wishes) [42].

3.2.3. Should the family be able to make any decision at all?

This question corresponds to the more basic levels of involvement of the family, in which relatives play no role at all or only act as witnesses of the deceased's wishes (Fig. 1, levels 0 and 1). Eleven studies asked if the family should make a decision on organ procurement without any specification of the circumstances of that decision [28,30,32–35,37,41–43,54]. Affirmative answers suggest that, according to respondents, the family should play a role in the decision-making process and that their own preferences should matter. The ratio of affirmative answers is also extremely variable depending on the study and the population asked, ranging from 8% to 81%. Negative answers are more eloquent, as they suggest that, according to respondents, relatives should *not* make any decision and should therefore either play no role at all (Level 0) or act only as witnesses of the deceased's wishes by communicating to health professionals the most updated wishes of the deceased, without expressing their own preferences, for instance when the family knows that the deceased had changed their views on organ donation but had not changed their organ donor register status (Level 1). In a study on prisoners in Poland, 65% "answered that only donors could make a decision regarding donation" [30]. In all other studies reporting negative answers, the proportion of respondents who thought that the family should not make a decision was much lower: around 20% in Poland [34,35] and the UK [42], around 30% in Croatia [37] and Austria among students [41], and 46% in Austria among transplantation patients [41].

3.3. Other results

Some studies explored issues not included in the above synthesis. In particular, one study explored the attitudes of patients and relatives in the emergency department with regard to the acceptability of preservation procedures being carried out to maintain organ viability both before and after discussion with relatives [25]. Other issues include whether or not registration in the organ donor register without having spoken with relatives is sufficient as an expression of the individual's wishes [42], whether participants would register an objection if the soft opt-out system was introduced [53], and whether families are capable of making decisions due to their emotional situation [54].

4. Discussion

Overall, studies show that a majority of the public supports the family's involvement in organ retrieval decision-making and, in particular, their role as a surrogate decision-maker when the deceased

has expressed no preference (a circumstance that may be quite frequent).

We provide two possible interpretations for this result. First, relatives may be perceived (by themselves and by others) as the most reliable authority to protect the posthumous interests of their loved ones. Second, as relatives can be directly affected by the decision, either positively or negatively, some perceive it as legitimate that they have a say.

Although individual consent can be considered the cornerstone of organ donation ethics [58], the notion of relational autonomy may better fit the connection between individual choice and family decisions as guardians of the deceased's beliefs and values [12]. This notion accounts for the fact that people's autonomy, needs, and interests are shaped by their social relations with others [59,60]. Since human beings are socially embedded, their personal decisions also take place in a social context [61–65]. Relational autonomy shifts the attention from the protection of individual choices against others' interference towards the construction of relations which nurture autonomous decisions [66,67].

As mentioned in the introduction, Argentina, Colombia, France, and Uruguay recently changed their opt-out policies to prevent the family's intervention in the decision over organ donation. Some may consider such policy shifts as ethically challenging to the extent that opt-out policies may require “widespread and vigorous public education to ensure understanding, along with clear, easy, non-burdensome, and reliable ways for individuals to register dissent” and, “in view of the difficulty of interpreting silence [...] organ recovery teams also consult the decedent's family” [68]. Importantly, a previous result of our systematic review is that, in opt-out countries, public awareness of the need to express dissent and public knowledge of the procedures to do so are, overall, lower than in opt-in countries and, in any case, suboptimal [18]. By legally preventing the family from objecting, opt-out countries take the risk of not only frustrating bereaved families' wishes, but also removing organs from deceased individuals who did not want to be donors but who failed to register their refusal. This being said, to better assess the governance quality of these countries' policies with regard to the family, improved measures of public awareness and public support of the policy in question are needed [8].

Regarding the capacity of the family to overrule the deceased's explicit wishes, results from this review show a complex picture. This capacity may be granted to safeguard the deceased's last wishes by giving the family the opportunity to correct mistakes, for instance when the deceased had changed their mind. It may also be granted to protect the interests of the deceased's relatives, by respecting their autonomy, and also the interests of potential recipients, by avoiding scandals and bad press. In cases where the deceased and the next-of-kin hold conflicting views, question is: whose preferences should prevail? The way people answer this question seems to depend on whether respondents see themselves as potential donors or as a deceased's next-of-kin. In the first case, a vast majority consider that the deceased's wishes should be respected, regardless of the family. In the second case, respondents are more divided on whether families should have the last say. In addition, answers may vary depending on the nature of the relationship between the potential donors and the decision-maker(s) within the family, as well as depending on the ethnic or cultural background of the deceased and their family. There is some evidence that family-determination plays a greater role in the East Asian principle of autonomy than it does in the West [69]. The relative importance of self-determination and family-determination in organ procurement decisions may also vary between European countries, or depending on age, education, religion, and other psychosocial factors. Although the factors influencing the family decision making in organ donation have been studied extensively [70–73], there is little empirical evidence, to our knowledge, regarding the question of the individual v. family autonomy in the context of organ donation decision-making. This requires further investigation.

With regard to knowledge, in many cases, only a minority of the public seems to be aware of the role families play in the decision-making process of organ donation. Results on this matter are limited to four

countries and fail to cover all aspects of the family's role. Hence, this also requires further investigation.

Anyway, measuring people's awareness of the role of the family in organ procurement proves to be a difficult task because of the opacity over what policy is actually in place in a given country, either *de facto* or *de jure*. A major cause of such opacity is the discrepancy between policy and practice that exists in most jurisdictions, with families usually having a greater role in clinical practice than stated or allowed by the law, as well as the variability of practices from one place to the other [1]. An additional cause of opacity is the ambiguity or the silence of several national regulations about the relatives' rights and duties in this context [11,24].

This ambiguity or silence might partially explain the absence of any survey exploring this topic in most of continental Europe. Indeed, Wales (8) and the rest of the UK (8) account for half of all the results (16/33), while Poland (9) and the Netherlands (4) account for most of the remaining results (13/17). In the case of the UK nations, a move from opt-in to opt-out was considered in 2006 and eventually implemented in Wales in 2015, followed by England and Scotland in 2020. At least 11 of the UK results come from government funded reports related to these legal moves. In the case of the Netherlands, an opt-out law was passed in 2018 and implemented in 2020. We ignore whether or not the four studies identified in the Netherlands are somehow related to the discussions leading to this law. During the 2008–2017 period, results were found in only four additional countries: Austria, Croatia, Germany, and Greece. Before this period, results from a previous SR [15] suggest that only two studies had ever addressed this issue outside of the UK, one in Belgium [74] and one in Spain [75].

4.1. Limitations

A major limitation of this systematic review is the limited number of countries where surveys have been conducted and their uneven regional distribution. This means that the conclusions drawn here cannot be considered representative of all or most European countries. More research is needed and especially comparative research in a broader group of countries.

Another important limitation is the heterogeneity of the sources with regard to the methods employed, as well as the ambiguity and vagueness in studies' questions and reported results. Indeed, we acknowledge that we faced considerable difficulties in interpreting the data because of a lack of clarity on the situations in which relatives could be asked to intervene and the different roles they could play. A common conceptual framework to categorize the role of families and properly standardised questionnaires would help to better address this topic in future studies.

5. Conclusions

The results of this review indicate that a majority of the public supports the family's involvement in organ retrieval decision-making and, in particular, their role as a surrogate decision-maker when the deceased has expressed no preference. However, these conclusions are drawn from a limited number of countries and from heterogeneous sources. A common theoretical framework and validated well-designed questionnaires are needed to address the role of the family in future studies. The findings should be considered in the development of Government policy and guidance regarding the role of families in deceased organ donation.

Funding

This work was supported by the Spanish government, [grant number FJCI-2017-34286] and [grant number MINECO FFI2017–88913-P]. The funding body had no role in the design of the study, data collection, data analysis, data interpretation, nor in drafting the manuscript.

Declaration of competing interest

The authors have no competing interests to declare.

Acknowledgements

We thank Anja Marie Bornø Jensen for her contribution in the process of data extraction. We also thank Fátima Al Mesri Rodríguez for her assistance in several parts of the process.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.trre.2021.100673>.

References

- [1] Delgado J, Molina-Pérez A, Shaw D, Rodríguez-Arias D. The role of the family in deceased organ procurement. A guide for clinicians and policy makers. *Transplantation* 2019;103:e112–8. <https://doi.org/10.1097/TP.0000000000002622>.
- [2] Bilgel F. The impact of presumed consent laws and institutions on deceased organ donation. *Eur J Health Econ* 2012;13:29–38. <https://doi.org/10.1007/s10198-010-0277-8>.
- [3] 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. *Nephrol Dial Transplant* 2012;27:2533–46. <https://doi.org/10.1093/ndt/gfr619>.
- [4] Beier K, Jordan I, Wiesemann C, Schickanz S. Understanding collective agency in bioethics. *Med Health Care Philos* 2016;19:411–22. <https://doi.org/10.1007/s11019-016-9695-4>.
- [5] Molina-Pérez A, Rodríguez-Arias D, Delgado J. Opt-out policies capacity to increase organ donors is limited. PREPRINT. *MedRxiv*. 2021. <https://doi.org/10.1101/2021.08.27.21262033>. submitted for publication to *BMJ Open*: <https://www.medrxiv.org/content/10.1101/2021.08.27.21262033v3>.
- [6] Shaw D, Georgieva D, Haase B, Gardiner D, Lewis P, Jansen N, et al. Family over rules? An ethical analysis of allowing families to overrule donation intentions. *Transplantation* 2017;101:482–7. <https://doi.org/10.1097/TP.0000000000001536>.
- [7] Albertsen A. Against the family veto in organ procurement: why the wishes of the dead should prevail when the living and the deceased disagree on organ donation. *Bioethics* 2020;34:272–80. <https://doi.org/10.1111/bioe.12661>.
- [8] Rodríguez-Arias D, Molina-Pérez A, Hannikainen IR, Delgado J, Söchtig B, Wöhlike S, et al. Governance quality indicators for organ procurement policies. *PLoS One* 2021;16:e0252686. <https://doi.org/10.1371/journal.pone.0252686>.
- [9] 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 Serv Res* 2008;8:48. <https://doi.org/10.1186/1472-6963-8-48>.
- [10] Shepherd L, O'Carroll RE. Awareness of legislation moderates the effect of opt-out consent on organ donation intentions. *Transplantation* 2013;95:1058–63. <https://doi.org/10.1097/TP.0b013e318284c13f>.
- [11] Hilbrich I, Hansen SL. Explorations about the family's role in the German transplantation system: epistemic opacity and discursive exclusion. *Social Epistemol* 2021. <https://doi.org/10.1080/02691728.2021.1913662>.
- [12] Molina-Pérez A, Delgado J, Rodríguez-Arias D. Defining consent: autonomy and the role of the family. In: Hansen SL, Schickanz S, editors. *Ethical challenges of organ transplantation: current debates and international perspectives*. Transcript Verlag; 2021. p. 43–64.
- [13] European Commission. *Special Eurobarometer 333a: Organ donation and transplantation*. Brussels. 2010.
- [14] 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:a3162. <https://doi.org/10.1136/bmj.a3162>.
- [15] Rithalia A, McDaid C, Suekarran S, Norman G, Myers L, Sowden A. A systematic review of presumed consent systems for deceased organ donation. *Health Technol Assess* 2009;13:1–95. <https://doi.org/10.3310/hta13260>. iii, ix–xi.
- [16] Palmer M. *Opt-out systems of organ donation: international evidence review*. Welsh Government Social Research; 2012.
- [17] Palmer M. *The role of families in organ donation: international evidence review*. Welsh Government Social Research; 2012.
- [18] Molina-Pérez A, Rodríguez-Arias D, Delgado-Rodríguez J, Morgan M, Frunza M, Randhawa G, et al. Public knowledge and attitudes towards consent policies for organ donation in Europe. A systematic review. *Transplant Rev* 2019;33:1–8. <https://doi.org/10.1016/j.trre.2018.09.001>.
- [19] Strech D, Synofzik M, Marckmann G. Systematic reviews of empirical bioethics. *J Med Ethics* 2008;34:472–7. <https://doi.org/10.1136/jme.2007.021709>.
- [20] Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;n71. <https://doi.org/10.1136/bmj.n71>.
- [21] Paez A. Grey literature: an important resource in systematic reviews. *J Evid Based Med* 2017. <https://doi.org/10.1111/jebm.12265>.
- [22] Dixon-Woods M, Cavers D, Agarwal S, Annandale E, Arthur A, Harvey J, et al. Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC Med Res Methodol* 2006;6:35. <https://doi.org/10.1186/1471-2288-6-35>.
- [23] Morgan M, Kenten C, Deedat S. On behalf of the DonaTE Programme team. Attitudes to deceased organ donation and registration as a donor among minority ethnic groups in North America and the UK: a synthesis of quantitative and qualitative research. *Ethn Health* 2013;18:367–90. <https://doi.org/10.1080/13557858.2012.752073>.
- [24] Morla-González M, Moya-Guillem C, Delgado J, Molina-Pérez A. European and comparative law study regarding family's legal role in deceased organ procurement. *Revista General de Derecho Público Comparado* 2021;29.
- [25] Bruce CM, Reed MJ, MacDougall M. Are the public ready for organ donation after out of hospital cardiac arrest? *Emerg Med J* 2013;30:226–31. <https://doi.org/10.1136/emermed-2012-201135>.
- [26] Coppen R, Friele RD, Gevers SKM, van der Zee J. Imagining the impact of different consent systems on organ donation: the decisions of next of kin. *Death Stud* 2010;34:835–47. <https://doi.org/10.1080/07481181003765444>.
- [27] de Groot J, van Hoek M, Hoedemaekers C, Hoitsma A, Smeets W, Vernooij-Dassen M, et al. Decision making on organ donation: the dilemmas of relatives of potential brain dead donors. *BMC Med Ethics* 2015;16:64. <https://doi.org/10.1186/s12910-015-0057-1>.
- [28] Decker O, Winter M, Brähler E, Beutel M. Between commodification and altruism: gender imbalance and attitudes towards organ donation. A representative survey of the German community. *J Gender Stud* 2008;17:251–5. <https://doi.org/10.1080/09589230802204290>.
- [29] Durczyński A, Dabrowska A, Strzelczyk J. Organ transplantation remains taboo topic in Polish families - small town youths survey results. *Clin Exp Med Lett* 2011;52:53–5.
- [30] Durczyński A, Pietrzak M, Strzelczyk J. Preliminary report from a prison survey: should prisoners be considered as organ donors? *Ann Transplant* 2013;18:604–8. <https://doi.org/10.12659/AOT.889634>.
- [31] Joshi MS. Whose decision is it? Organ donation attitudes among Young UK south Asians. *Psychol Stud* 2011;56:86–97. <https://doi.org/10.1007/s12646-011-0070-5>.
- [32] Katsari V, Domeyer PJ, Sarafis P, Souliotis K. Giving your last gift: a study of the knowledge, attitude and information of Greek students regarding organ donation. *Ann Transplant* 2015;20:373–80. <https://doi.org/10.12659/AOT.894510>.
- [33] Kobus G, Piotrowska J, Malyszko J, Bachorzewska-Gajewska H, Malyszko J. Attitudes of members of the Baptist Church toward organ transplantation. *Transplant Proc* 2014;46:2487–91. <https://doi.org/10.1016/j.transproceed.2014.09.019>.
- [34] Kobus G, Poplawska W, Zbroch E, Malyszko J, Bachorzewska-Gajewska H, Malyszko J. Opinions of town residents on organ transplantation. *Transplant Proc* 2014;46:2492–5. <https://doi.org/10.1016/j.transproceed.2014.09.020>.
- [35] Kobus G, Poplawska B, Bachorzewska-Gajewska H, Malyszko JS, Malyszko J. Opinions and knowledge about organ donation and transplantation of residents of selected villages in Podlaskie Voivodeship. *Ann Transplant* 2015;20:256–62. <https://doi.org/10.12659/AOT.892659>.
- [36] Kobus G, Reszec P, Malyszko JS, Malyszko J. Opinions and attitudes of university students concerning organ transplantation. *Transplant Proc* 2016;48:1360–4. <https://doi.org/10.1016/j.transproceed.2016.01.045>.
- [37] Lada Z, Zvonimir P, Nikola RL, Vlasta OK. Attitudes towards transplantation and organ donation in high school graduates of math gymnasium in Osijek. *Acta Med Croatica* 2011;65:63–6. PMID: 23120819.
- [38] Michalska E, Kołodziej K, Szymański D, Strzelczyk J. Students of the Polish Catholic theological seminaries and the issue of organ transplantation. *Ann Transplant* 2010;15:56–60. PMID: 21183877.
- [39] Pawłowicz E, Nowicki M. Knowledge about legal regulations regarding organ transplantation among high school and university students in Poland. *Transplant Proc* 2016;48:1350–3. <https://doi.org/10.1016/j.transproceed.2016.01.068>.
- [40] Ryckman RM, Gold JA, Reubsaet A, van den Borne B. Value priorities and intention to register for posthumous organ donation in Dutch adolescents. *J Soc Psychol* 2009;149:213–27. <https://doi.org/10.3200/SOCP.149.2.213-228>.
- [41] Stadlbauer V, Steiner P, Schweiger M, Sereinigg M, Tscheliessnigg K-H, Freidl W, et al. Knowledge and attitude of ICU nurses, students and patients towards the Austrian organ donation law. *BMC Med Ethics* 2013;14:32. <https://doi.org/10.1186/1472-6939-14-32>.
- [42] Webb G, Phillips N, Reddiford S, Neuberger J. Factors affecting the decision to grant consent for organ donation: a survey of adults in England. *Transplantation* 2015;99:1396–402. <https://doi.org/10.1097/TP.0000000000000504>.
- [43] Wejda SCB, Kosieradzki M, Jakubowska-Winecka A, Czerwinski J, Kobryn A, Danielewicz Roman R, et al. Survey on attitudes and knowledge on the organ recovery from deceased donors in Roman Catholic nuns and priests. *Transplant Proc* 2012;44:2173–5. <https://doi.org/10.1016/j.transproceed.2012.07.126>.
- [44] Beaufort Research. *Public attitudes to organ donation: baseline survey*. Welsh Government Social Research; 2012.
- [45] Beaufort Research. *Research to support Wales' organ donation opt-out proposal consultation*. Welsh Government Social Research; 2012.
- [46] Beaufort Research. *Survey of public attitudes to organ donation: wave 2*. Welsh Government Social Research; 2013.
- [47] Beaufort Research. *Evaluation of the human transplantation (Wales) act: qualitative study of public attitudes*. Welsh Government Social Research; 2014.

- [48] Beaufort Research. Survey of public attitudes to organ donation: wave 3. Welsh Government Social Research; 2014.
- [49] Beaufort Research. Survey of public attitudes to organ donation: wave 10, 11 and 12. Welsh Government Social Research; 2016.
- [50] Eenvandaag Opiniepanel. Onderzoek: 'Orgaandonatie.'. 2014.
- [51] Ipsos Mori. HTA general public survey. 2010.
- [52] Ipsos Mori. Ipsos Mori survey for King's College London polling Club. King's College London; 2016.
- [53] PHA. Organ donation: public attitudes and stakeholder engagement in Northern Ireland. Northern Ireland: Public Health Agency; 2013.
- [54] Scottish Government. Organ and tissue donation and transplantation: analysis of responses. Health Soc Care 2017.
- [55] Social Market Research. Evaluation of a public information campaign on organ donation. Northern Ireland: Public Health Agency; 2015.
- [56] Welsh Assembly Government. Options for changes to the organ donation system in Wales: consultation paper. 2009.
- [57] Young V, McHugh S, Glendinning R, Carr-Hill R. Evaluation of the human transplantation (Wales) act: impact evaluation report. Welsh Government Social Research; 2017.
- [58] WHO S-TWHA. WHO guiding principles on human cell, tissue and organ transplantation. Cell Tissue Bank 2010;11:413–9. <https://doi.org/10.1007/s10561-010-9226-0>.
- [59] Dove ES, Kelly SE, Lucivero F, Machirori M, Dheensa S, Prainsack B. Beyond individualism: is there a place for relational autonomy in clinical practice and research? Clin Ethics 2017;12:150–65. <https://doi.org/10.1177/1477750917704156>.
- [60] Delgado J. Re-thinking relational autonomy: challenging the triumph of autonomy through vulnerability. Bioethics Update 2019;5. <https://doi.org/10.1016/j.bioet.2018.12.001>.
- [61] Nedelsky J. Reconciling autonomy: sources, thoughts, and possibilities. Yale J Law Fem 1989;1:7–36.
- [62] Mackenzie C, Stoljar N, editors. Relational autonomy: feminist perspectives on autonomy, agency, and the social self. New York: Oxford University Press; 2000.
- [63] Rogers W, Mackenzie C, Dodds S. Why bioethics needs a concept of vulnerability. LJFAB 2012;5:11–38.
- [64] Mackenzie C, Rogers W, Dodds S, editors. Vulnerability: new essays in ethics and feminist philosophy. New York: Oxford University Press; 2014.
- [65] Straehle C, editor. Vulnerability, autonomy, and applied ethics. London: Routledge; 2017.
- [66] Nedelsky J. Reconciling rights as relationship. Rev Const Stud 1993;1:1.
- [67] Nedelsky J. Law's relations: a relational theory of self, autonomy, and law. OUP USA. 2011.
- [68] Liverman CT, Childress JF. Organ donation: opportunities for action. National Academies Press; 2006.
- [69] Fan R. Self-determination vs. family-determination: two incommensurable principles of autonomy. Bioethics 1997;11:309–22. <https://doi.org/10.1111/1467-8519.00070>.
- [70] Irving MJ, Tong A, Jan S, Cass A, Rose J, Chadban S, et al. Factors that influence the decision to be an organ donor: a systematic review of the qualitative literature. Nephrol Dial Transplant 2012;27:2526–33. <https://doi.org/10.1093/ndt/gfr683>.
- [71] Makmor T, Abdillah N, Ms NurulHuda, Raja Noriza RA, Roza Hazli Z. Family decision-making about organ donation: A systematic review. JUMMEC 2015;18: 1–4. <https://doi.org/10.22452/jummecc.vol18no1.1>.
- [72] Miller C, Breakwell R. 10.1080/17571472.2018.1459226. Lond J Prim Care 2018; 10:103–7. <https://doi.org/10.1080/17571472.2018.1459226>.
- [73] Kentish-Barnes N, Siminoff LA, Walker W, Urbanski M, Charpentier J, Thuong M, et al. A narrative review of family members' experience of organ donation request after brain death in the critical care setting. Intensive Care Med 2019;45:331–42. <https://doi.org/10.1007/s00134-019-05575-4>.
- [74] Roels L, Roelants M, Timmermans T, Hoppenbrouwers K, Pillen E, Bande-Knops J. A survey on attitudes to organ donation among three generations in a country with 10 years of presumed consent legislation. Transplant Proc 1997;29:3224–5. [https://doi.org/10.1016/s0041-1345\(97\)00883-x](https://doi.org/10.1016/s0041-1345(97)00883-x).
- [75] Conesa C, Rfós A, Ramírez P, Rodríguez MM, Rivas P, Canteras M, et al. Psychosocial profile in favor of organ donation. Transplant Proc 2003;35:1276–81. [https://doi.org/10.1016/s0041-1345\(03\)00468-8](https://doi.org/10.1016/s0041-1345(03)00468-8).