


REVIEW



# A narrative review of family members' experience of organ donation request after brain death in the critical care setting

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## Abstract

**Introduction:** Family members of critically ill patients suffer from high levels of anxiety and depression in the ICU, and are at risk of developing post-ICU syndrome following ICU discharge. In the case of brain death, and potential organ donation, the family is at the center of the decision process: within a limited time frame, the family will be informed that the patient is brain-dead and will be approached about potential organ donation.

**Materials and methods:** Family experience with organ donation has been the topic of several research papers allowing one to gain knowledge about family members' experience of organ donation, emphasizing specific needs, adequate support, and pointing out gaps in current delivery of family-centered care. In this narrative review, experts, clinicians, and researchers present the various legal systems regarding family implication in organ donation decisions; describe factors that influence the decision-making process; highlight family perspectives of care and respect for potential donors in the ICU environment; describe the impact of organ donation discussions and decisions on post-ICU syndrome; and suggest communication skills and support to be developed in the future. A research agenda for the next decade is also encouraged.

**Conclusion:** Overall, challenges remain and concern all persons involved in the process, ICU doctors and nurses, the organ procurement organization, family members, and, in some cases, the patients themselves. Looking at the big picture will provide opportunities for further improvements.

**Keywords:** Organ donation, Family experience, Decision-making, Post-ICU syndrome

## Introduction

The experience of family members (FMs) of intensive care unit (ICU) patients has received much attention in the past 30 years. Studies have demonstrated considerable psychological burden as FMs attempt to cope with uncertainty and overwhelming crisis. Throughout this

stressful experience, FMs often have difficulty understanding and processing information provided by the medical team [1] and may also suffer from high levels of anxiety and depression [2]. During the months that follow, FMs are at risk of developing symptoms of post-ICU syndrome, such as anxiety, depression, and post-traumatic stress [3]. Bereaved FMs are at higher risk of developing these symptoms as well as complicated grief [4].

Potential organ donors are admitted to the ICU, either with the initial hope of reversing their condition or with explicit intention to progress towards organ donation and transplantation. In the case of neurological determination of death (NDD), also known as brain death, and

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potential organ donation, the family is at the center of the decision process: within a limited time frame, the family will be told that the patient is brain-dead and will be approached regarding potential organ donation. However, brain death can also occur in older patients with complex comorbidities at the end of a long illness and hospitalization. Clinicians must be mindful that decisions made in the ICU, including end-of-life (EOL) decisions and organ donation decisions, can remain with FMs long after the loss of their loved one.

Caring for FMs is considered one of the ICU healthcare professionals' (HCP) major tasks. However, discussing deceased organ donation can be challenging both for HCPs who initiate and manage the conversations [5] and for the FMs. Many studies have shown that for FMs, communication with ICU HCPs is one of the most highly valued aspects of care [6–8] that impacts on their experience during the patient's stay and after the patient's death [3, 4, 9, 10]. In the context of potential organ donation, quality of communication is vital and influences organ donation decisions. Sometimes ICU teams fail to approach families of potential organ donors as this discussion seems too challenging and/or because they are afraid of adding distress and burden to bereaved family members [11]. Collaboration with the Organ Procurement Organization (OPO) is essential both for FMs and for ICU healthcare professionals (Fig. 1).

In this review, we seek to describe family members' experience of organ donation request after brain death in the critical care setting.

## Take-home message

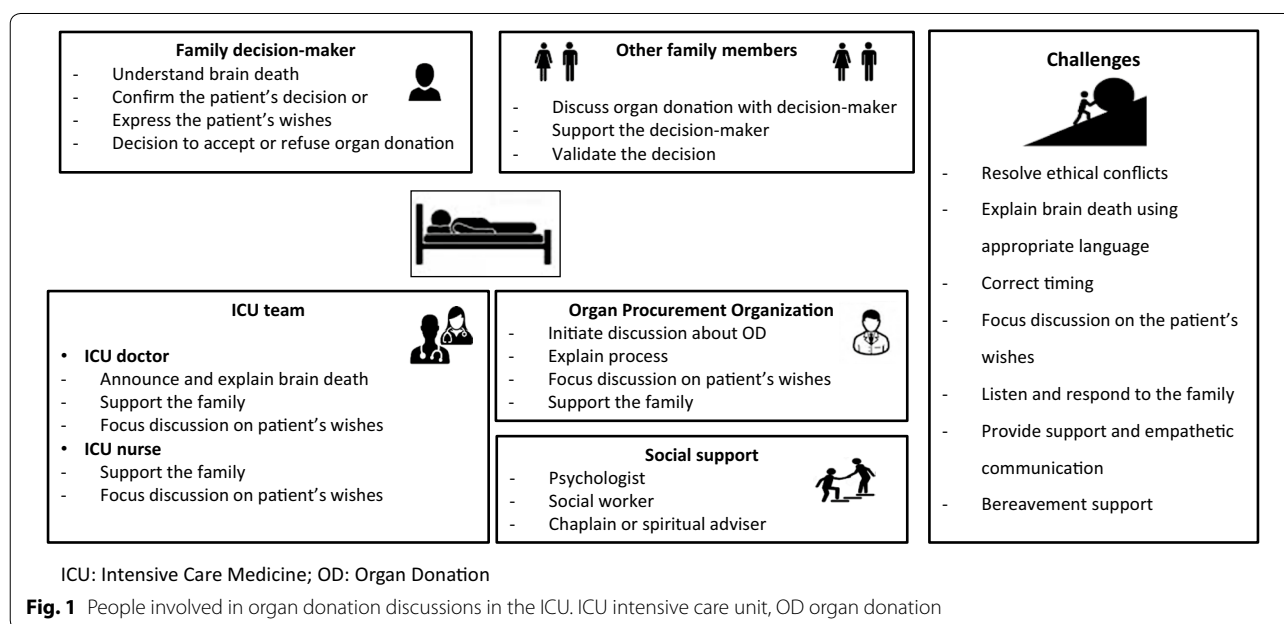
Family experience of organ donation is complex and challenges remain concerning all persons involved in the process.

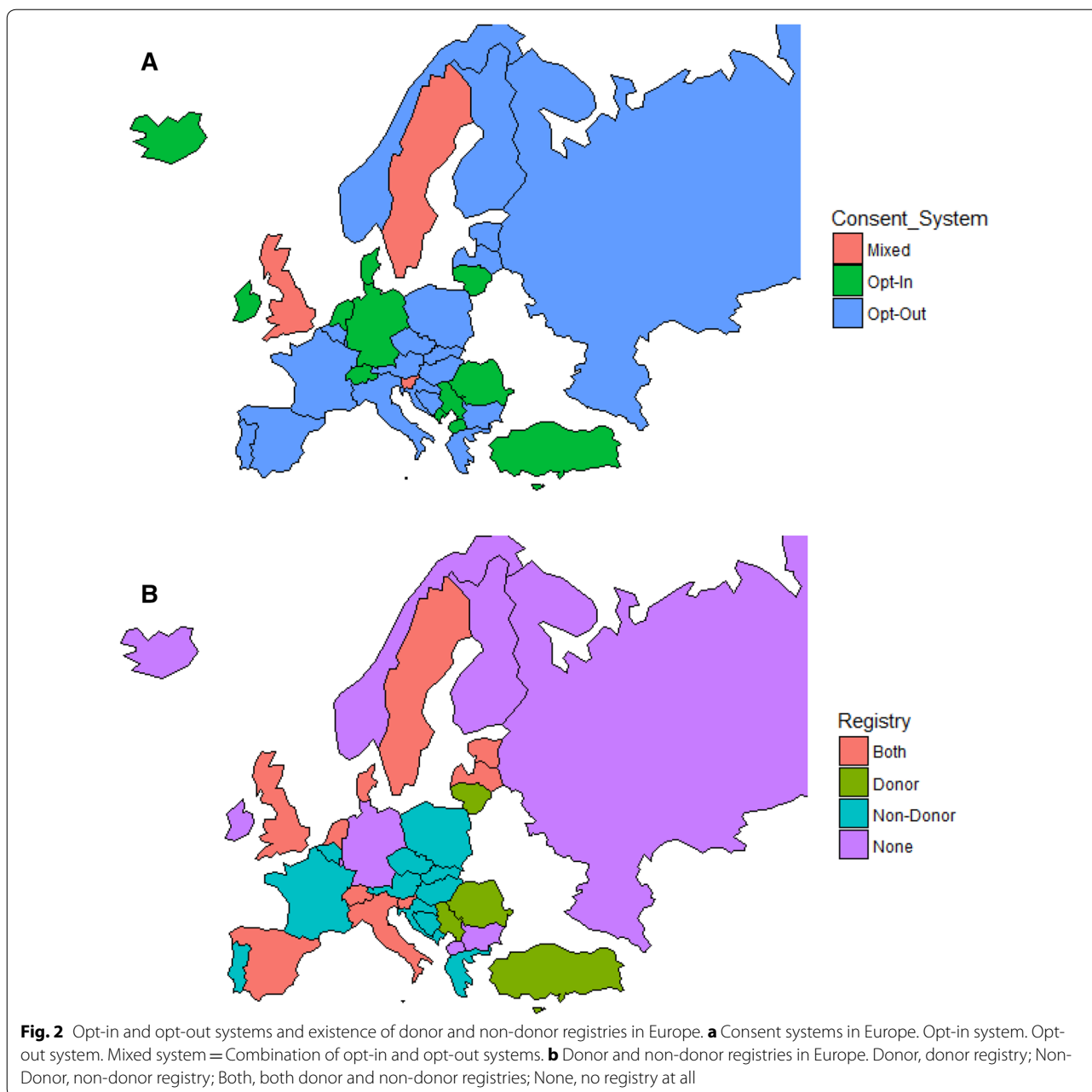
## Methods

Authors of this review are clinicians and researchers who have extensive clinical and/or research experience in the field described. After a preliminary search of the literature using Pubmed and CINAHL databases (1990–2018), the corresponding author qualitatively derived four domains of publication using keywords such as “organ donation” and “family experience” (and equivalent terms such as family decision-making, family stress, family outcomes): (1) legal aspect of organ donation; (2) factors that influence the decision; (3) family perspective of care in the organ donation context; (4) impact of organ donation on families' psychological well-being. We narrowed literature to English-language studies. The four domains were further developed by content experts. Supplemental Table 1 presents 15 major articles used in this paper. After receiving and examining the paragraphs written by the experts, NKB and EA merged and homogenized them, proposed a synthesis of communication skills and support to be developed in the future, and a research agenda that was then discussed and adjusted by all co-authors.

## Opt-in and opt-out systems: different family roles?

The legal authority to procure a deceased person's organs comes from valid consent for donation. This consent





or authorization can be given by the donor him/herself while living or, if the donor has not expressed a written wish, by the family. Depending on the system, the family's theoretical role is different.

#### Different systems

In many countries, consent for donation relies upon a legal framework or at least on national recommendations. Overall, there are two legal consent systems: an opt-in (OI) system and an opt-out (OO) system (Fig. 2 and Table 1). In an OI system, also called explicit consent,

the consent is expressed by the potential donor when he/she is living, as a positive intention to donate organs. This information can be found on a donor registry, a donor card, an official document (driving license, etc.), advance directives, or from a designated person. In an OO system, also called presumed consent or deemed consent, everybody is considered a potential donor unless they express their wish not to donate (negative intention), either on a national registry or by signing a document or, depending on the law, by explicitly expressing this refusal to their family. Application of these rules in both systems

**Table 1 Opt-in and opt-out systems in different countries concerning organ donation from deceased persons**

Country	National consent system	Donor registry	Non-donor registry
Austria	Opt-out	No	Yes
Belgium	Opt-out	No	Yes
Bosnia Herzegovina	Opt-out	No	No
Bulgaria	Opt-out	No	Yes
Croatia	Opt-out	No	Yes
Cyprus	Opt-in	Yes	No
Czech Republic	Opt-out	No	Yes
Denmark	Opt-in	Yes	Yes
Estonia	Opt-out	Yes	Yes
Finland	Opt-out	NA	NA
France	Opt-out	No	Yes
Germany	Opt-in	No	No
Greece	Opt-out	No	Yes
Hungary	Opt-out	No	Yes
Iceland	Opt-in	NA	NA
Ireland	Opt-in	NA	NA
Italy	Opt-out	Yes	Yes
Latvia	Opt-out	Yes	Yes
Lithuania	Opt-in	Yes	No
Luxembourg	Opt-out	NA	NA
Malta	Opt-out	Yes	No
Montenegro	Opt-in	No	Yes
Netherlands	Opt-in	Yes	Yes
Norway	Opt-out	NA	NA
Poland	Opt-out	No	Yes
Portugal	Opt-out	No	Yes
Romania	Opt-in	Yes	No
Russia	Opt-out	No	No
San Marino	Opt-out	NA	NA
Serbia	Opt-in	Yes	No
Slovakia	Opt-out	No	Yes
Slovenia	Mixed system	Yes	Yes
Spain	Opt-out	Yes	Yes
Sweden	Mixed system	Yes	Yes
Switzerland	Opt-in	Yes	Yes
Former Yugoslav Republic of Macedonia	Opt-in	NA	NA
Turkey	Opt-in	Yes	No
UK	Mixed system (opt-put in Wales)	Yes	Yes
Some countries outside Europe			
Australia	Opt-in	Yes	Yes
New Zealand	Opt-in	No	No
Canada	Opt-in	Yes	No
Japan	Opt-in	No	No
USA	Opt-in	Yes	No

**Table 1 (continued)**

NA data not available. Note: some countries do not have registries, but advanced will directives fulfill this requirement. Table adapted from "Legal provisions in European countries for consent to/authorisation of organ donation from deceased persons, P85" in "Guide to the quality and safety of organs for transplantation": <https://www.edqm.eu/en/organs-tissues-and-cells-technical-guides>. Accessed 10 November 2018

varies between countries/regions, mainly concerning the approach of the family, leading to a "hard" (strict application of the system) or "soft" (approach adapted to family's experience) OI/OO system in place.

### Theoretical family roles

In theory, each system should be rigorously applied and FMs should be aware of the law. In addition, the patient should systematically express his/her wish to donate (OI), or not to donate (OO), and the family should accept this expressed wish. Both systems share the same objective: to respect the patient's decision. The difference between them is the "default" treatment of someone who has not expressed a wish [12].

In theory, in an OI system, the FMs know the patient's wish. When approached regarding an organ donation decision, their role is to inform of the patient's wish regarding organ donation and to make sure it is respected. In an OO system, the FMs role is to confirm that the patient had never expressed a refusal for donation. Concurrently and whatever the system, their role is to protect their loved one's body and expressed wishes. In all systems, the role of the OPO and HCPs is to ensure that the FMs understand the situation and the process, and that the patient's wish will be respected. However, in some countries the OPO's role has raised controversy regarding its engagement in favor of organ donation and potential bias during communication with FMs.

### Family's role in practice

In practice the theoretical and simple scenarios presented above are rare. Informing all citizens of the law (OD system) remains a challenge for public health services. In fact, in most countries, the system (OI or OO) is not rigorously applied because HCPs also have the family's well-being at heart. Caring for the bereaved family during this process is a responsibility as FMs are going through a unique and distressing experience. Moreover, the family has to accept and live with the decision once the process is over.

At the center of the process is knowledge of the patient's wish. If the latter is not known, each system will consider the family's role differently but, in fine, the decision will be made by the family. Difficulties can also emerge when there is discordance between the patient's

and the family's wishes. Although explicit individual consent is "binding", HCPs can take a contrary position by respecting the bereaved family's wishes [13], potentially creating a legal and/or ethical tension. The power of veto is not legally recognized in most countries, although in practice it is used everywhere [14].

The situation is complex for the family decision-makers (FDMs) who discuss organ donation with the OPO and HCPs as they must also face other relatives and friends: communicate and explain the situation as well as the next steps of the process. During these discussions, it can be difficult to identify who is the most legitimate relative to give "the consent". In the UK, Germany, and Canada, the law has defined an official family hierarchy; however, family members' acting in the official decision-making role may draw from other family members' opinions as they convey the patient's wishes. This is particularly important in case of internal disagreement about donation. Within a given system, the family's role can also be influenced by social, cultural, or religious considerations.

Overall, although both systems strive to place the patient's wishes at the center of the process, family members play a key role and can decide for the patient or even, in some cases, overrule the patient's wishes. Understanding reasons to refuse donation and family's experience during and after the process may help to both minimize family distress and fulfill the patient's wishes, whether their decision would be to donate or not to donate.

### **Reasons to refuse or accept organ donation: key factors influencing the decision**

Family decision-makers (FDMs) become the gatekeepers to scarce, life-saving organs, particularly when patients have not formally made their wishes known. FDMs must make decisions, often during moments of trauma and acute grief that can have life or death consequences for many people on transplant waiting lists. Thus, the decision-making processes and understanding the reasons to authorize or refuse donation by FDMs has been an important subject of inquiry among organ donation researchers for the past three decades. The literature to date suggests that a variety of factors influence FDMs' authorization decisions.

The strongest and most consistent predictor of donation authorization is knowledge or awareness of the donor-eligible patient's wishes. FDMs' awareness of their loved ones' donation wishes is strongly associated with honoring those wishes [15–24]. A recent study found that 97.6% of FDMs who were aware of their family member's wish to donate did so as compared to 85.6% who did not [23]. Other studies have found similar patterns [15, 16, 20, 24]. However, families are often not knowledgeable about the patient's wishes. One study of more than 1000

FDMs reported that less than two-thirds were aware of their loved one's registration decision [23]. In the USA, computerized state donor registries serve as a repository of patient's wishes, although only slightly more than half the adult US population is on the registry [25].

FDMs have consistently expressed a need for additional knowledge and accurate information about organ donation to aid in their decision-making [26]. In a recent survey of 118 family members of patients in the ICU, only 32% could answer four questions about organ donation correctly [27]. A majority of FDMs reported that receiving more information about donation while their loved one was in the ICU would have helped donation decision-making [27]. This is consistent with other studies that have shown higher authorization rates among FDMs who received more donation-relevant information [15, 28, 29]. Topics of particular importance to FDMs include brain death (specifically, understanding brain death), the condition of the body after donation, costs incurred by the donor's family, and funeral arrangements [16, 22, 24, 30].

The timing of information delivery is less important to FDMs than previously thought. The initial assumption that strictly separating the donation conversation from the brain death conversation or declaration of death—a concept known as decoupling—would increase authorization rates has been shown to be short-sighted. The available data suggest that having the donation conversation before the declaration of death is associated with authorization to donation [19, 31] and that separating discussions about EOL care and donation can decrease consent rates [32]. FDMs are also less likely to authorize donation if they feel "surprised" by the request [15, 33].

Providing complete and accurate information in a timely fashion is important, but equally critical is the manner in which the information is delivered to the FDMs. HCPs are encouraged to employ multimodal communication, to ensure a proper setting for family meetings, and the presence of a support person [26]. The data indicate that the communication skills of OPO requesters can influence authorization decisions among FDMs [17, 19, 21, 28, 34–36], although this can also be overrated as shown in a recent study [32]. Effective communication is a skill that can be taught and learned. Notably, a communication skills training intervention for OPO requesters increased time spent with FDMs discussing donation, number of donation-related topics discussed, and increased authorization rates from 46.3% pre-intervention to 55.5% post-intervention [28]. Further, FDMs noted improved communication, including higher levels of sincerity, honesty, cooperation, and listening, among requesters who completed the communication skills training intervention [34]. FDMs were also less

likely to feel pressured by the OPO requesters who participated in the training intervention [34]; the literature indicates that FDMs who feel harassed or pressured are less likely to authorize donation [15].

Finally, of critical importance is increasing our understanding of the donation decision-making needs and preferences of racial/ethnic minority groups [14]. In the USA, African Americans have significantly lower authorization rates than the general population [14]. However, studies have shown that requesters spend less time with African American families discussing donation and provide less information to them compared to Caucasians [37]. Moreover, African American FDMs are less likely to register as organ donors [38] and also less likely to know the donation wishes of their loved ones [37]. Finally, there are many racial/ethnic groups about whom we know little. The current literature suggests that tailoring donation-related educational interventions to the unique needs of racial/ethnic minority groups may increase authorization rates and help remediate these persistent disparities [39, 40].

### **Family perspectives of care and respect for potential organ donors**

An integral part of EOL care in the ICU is identifying and responding to the needs of FMs who encounter an organ donation decision. A family-centered approach to intensive care recognizes that family members are often at the center of decisions concerning their critically ill or injured relative, and this can impart a significant burden [41]. Exploratory research with bereaved families into the reality of donation decision-making has informed understanding of family-centered issues and specific support needs. Among family-reported experiences of deceased donation is the commonly mentioned need for their relative to be treated with care and respect [42–51].

Respecting a relative's autonomous choice to donate their organs after death and the consolation of knowing that lives may be saved are powerful decision-making motives behind family consent. Evidence suggests that donor families are intent on turning a tragic situation into something positive [48–51] and this can manifest in determination to fulfill a relative's expressed wish to be an organ donor [49, 51]. Health professionals play a key role in helping families to accomplish the hopes and expectations of donation [52] and this can be optimized by the involvement of specialist staff [53, 54]. Researchers have emphasized the importance of organ donor advocacy behavior in the ICU, both to safeguard the will and wishes of the potential donor and his/her family and to protect the dignity of the deceased [55]. Researchers in the UK found that honoring the wishes of the potential donor was important to grieving families, yet this was

not foremost in their thoughts at a time of acute psychological distress. Retrospectively, families positively acknowledged healthcare staff that brought the possibility of organ donation to their attention [51, 52]. As with consent decisions, some families suggest that declining donation is respecting a relative's wish not to donate their organs [46, 49].

The concepts of care and respect also materialize in family narratives about the effects of organ donation on their relative. A need to protect the deceased person's body can lead to decisional conflict; overtly evidenced in one study as a tension between the "gift of life" and "sacrifice of the body" for organ donation to proceed [47]. A more recent study describing the donation-decision making dilemmas of families depicted a similar struggle with utilitarian considerations and protecting the deceased's body [42]. In some cultures, preserving body integrity has a religious or spiritual meaning that families protectively respect [45, 48, 49]. Equally, perceived violation of the body, prolonged suffering, and possible futility of removing organs unsuitable for transplantation can lead to non-donation [47]. Appropriate physiological support before and after brain death is necessary for successful donation [56]. However, for the grieving family, perceptions of keeping their relative "alive" for the purpose of donation after brain death can be a source of emotional turmoil in the context of EOL care [57]. Thus, understanding families' imagery and providing factual explanation of what the process of organ donation involves are important steps in helping to allay notable fears and concerns [58, 59]. Families also need reassurance that their relative will be cared for with reverence both during and after organ retrieval [45, 50, 51].

Family satisfaction with the provision of care for their relative is a significant correlate of the decision to donate [43, 44, 51]. In one study, FMs' expressed that the need for their relative to be treated with dignity and respect was paramount regardless of the final donation decision [43]. An observed respectful deed was caring for and speaking to their relative as though he/she were conscious and alive [43, 51]. Likewise, skilled communication is essential to enabling family acceptance of death and consideration of organ donation [60]. It is well known that families experience internal conflict between the appearance of their relative and the impending or actual loss of life [30], particularly so in the case of brain death [61]. The family experience of brain death and organ donation has been explained in a theory of dissonant loss depicting a sequential process of conflict and resolution [62]. The findings of this seminal research have resonance with and meaning for donor family care policy today. However, an evidence base for contemporary practice is incomplete. Further understanding of what drives family

donation decision-making, including the significance of care and respect, is essential to the provision of quality EOL care, and in supporting families to reach an optimal and enduring decision [59].

### Impact of organ donation on post-ICU family outcomes

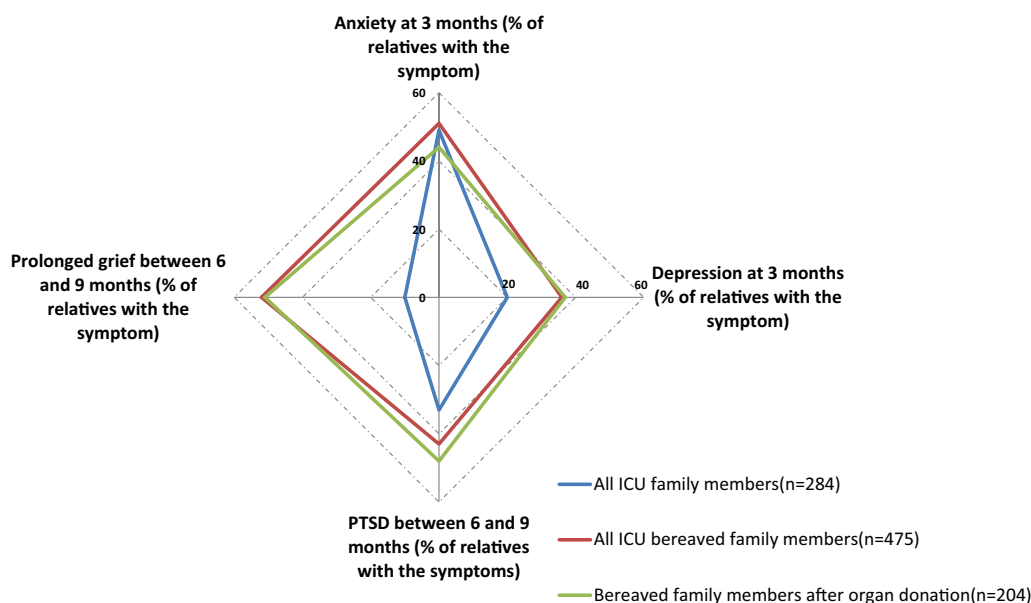
The impact of organ donation processes on FMs' psychological well-being during the months that follow the patient's death has received little attention.

A first group of studies showed the negative impacts of some aspects of the organ donation process on bereaved FMs. Interestingly these negative impacts were due to factors that could be improved in the ICU setting. A study assessing grief symptoms [63] in a large number of relatives of brain-dead patients for whom organ donation was discussed in the ICU showed that 1 month after the patient's death, relatives of non-donors describe a significantly more burdensome experience: they were more dissatisfied with communication, more often shocked by the request and more often found the decision difficult. Interestingly, decisional regret more often occurs when the decision was to decline donation [64] and when organ donation was raised before FMs were informed of the patient's death [65].

Quality of communication is important: understanding the cause of death is necessary for families to give

meaning to the patient's death. Research shows that not understanding brain death is associated with an increased risk of developing complicated grief [63]. A small randomized controlled trial showed that family presence during brain death evaluation improved understanding of brain death with no apparent adverse impact on psychological well-being [66]. Lack of understanding may hinder the grieving process. In the months and even years that follow the patient's death, FMs describe the questions they felt they should have asked at the time, but were too distressed to do so [67]. A qualitative study [68] has shown that relatives' ambivalent decision-making style and perception of HCPs' behavior as "organ focused" appear to be risk factors for traumatic memories. In another qualitative study [69], clinicians' quality of communication (quality information and ability to listen to the relatives) affected donation decision-making and appeared to impact on the relatives' grieving process. Moreover, dissatisfaction with hospital care was associated with depressive and grief symptoms [70, 71].

Nonetheless, information and support do not stop at the patient's death. Families who want but lack information about the transplantation outcomes experience more stress throughout their grief as well as uncertainty about their decision to donate [30]. This suggests that a proactive follow-up by the OPO (telephone call, card, or letter) may help promote family well-being [62, 67]. The absence of adequate bereavement support means that



**Fig. 3** Post-ICU syndrome in three groups of ICU family members. This figure displays post-ICU syndrome-family (PICS-F) in three groups of patients, namely, overall ICU relatives (blue line), relatives of patients who died in the ICU (red line), and relatives of organ donor patients (green line). Relatives of overall ICU patients present less symptoms of depression or PTSD than other groups of relatives. Bereaved relatives report similar rates of post-ICU syndrome, regardless if death was associated organ donation or not

families have to live with unanswered questions [26, 30]. Follow-up needs are of course variable and responses require flexibility: further research is needed to better understand FMs' needs in this field.

A second group of studies show that the decision itself (donation/refusal) neither hinders nor furthers the grief process [3, 4, 63, 70, 72]. As shown in Fig. 3, if bereaved FMs are more at risk than non-bereaved FMs of developing post-ICU syndrome, implication in an organ donation process does not alter the risk of developing such symptoms. If families of non-donor patients experience the process as significantly more burdensome, it is interesting to note that the decision itself (donation vs refusal) is not associated with grief symptoms over the 9 months that follow the patient's death [63]. As shown in another follow-up study of FMs, levels of depression and problems with detachment from the deceased are similar among bereaved families of donor and non-donor patients as well as families who were not approached for post-mortem organ donation [70]. In a qualitative study in the pediatric context, consent or refusal of organ donation per se did not seem to affect the overall grieving process. It is the meaning attributed to the act of donation that affects how parents perceive the child's death and subsequently facilitates or hinders their adjustment to loss [73].

Most qualitative studies have focused on families of donor patients and show that the act of donation may assist families in their grief [74, 75] and have a beneficial effect on the bereavement process [71, 75]. Those who felt most comforted reported fewer symptoms of depression [71]. For some families the decision to donate is beneficial in the bereavement process, for various and sometimes very different reasons such as the knowledge

that donation had benefitted people, the belief that the deceased person "lives on", or the feeling that the death was not in vain [52]. Qualitative studies focusing on families of non-donor patients are lacking and should be developed in the future (Table 2).

These data show that more than the decision itself, it is the quality of the process that impacts on family outcomes in the months that follow the patient's death: quality information that permits one to understand and accept the death as well as adapted support. This leaves room for strategies to improve communication in this specific setting.

## Perspectives for the future

### What family support can we provide?

In the ICU, brain death remains an EOL situation that requires similar communication and support strategies as other EOL situations, such as available HCPs to help FMs understand the situation and to show respect to the patient. As shown in Table 3, communication skills must be developed both by ICU doctors and nurses, and by the OPO specialists.

Organ donation cannot remain the OPO's preoccupation only. All ICU clinicians are concerned as research shows that the more the FMs have the opportunity to discuss the subject with HCPs, including those who actually care for the patient, the more likely they are to accept donation [15] and to feel comfortable with the process [63]. Cooperation between ICU HCPs and members of the OPO is paramount to optimize organ procurement [76] and supports the embedding of teamwork principles in the design and delivery of organ donation training programs. The ICU culture plays an

**Table 2 Research agenda**

Family-orientated research	Clinician-orientated research
Understand the donation decision-making needs and preferences of racial/ethnic minority groups	Examine impact of clinicians' specialized training on family outcomes [5]
Understand the minutiae of the dynamic interaction at the time of the approach and discussion about organ donation: a prospective ethnographic observation study [51]	Examine impact of clinicians' specialized training and awareness on clinicians' experience and on clinicians' perception of family experience
Causal research to test for an association between a positive family care experience and consent to donation [51]	Examine the effectiveness of "teamwork training" on team behavior, performance, and organ donation outcomes in ICU
Understand refusal and decisional regret: in-depth qualitative research Enhance understanding of family veto	Examine the effectiveness of training using simulation on clinicians' experience and on family outcomes
Understand family outcomes in other donation settings (donation after the circulatory determination of death)	Examine the effectiveness of interventions to improve clinicians' skills to communication about brain death
Explore the impact of system-level variables on family member outcomes, including impact of opt-in and opt-out legislation	Unit staff level: examine the impact of communicating about transplantation outcomes for brain-dead donor patients who were hospitalized in the ICU on clinicians' motivation and satisfaction
Test specific support programs during decision-making period Test tailored bereavement support programs	Examine the effectiveness of a standardized organ donation procedure on family outcomes



**Table 3 Suggestions to improve communication skills**

Upstream	
	Better inform citizens about their organ donation system (opt-in/opt-out) and donor or non-donor registries
	Physician and nurse education about organ donation and brain death in order to improve knowledge and communication skills
In the ICU	
Clinician orientated	Develop organ donation culture in the ICU: explicit communication about organ donation with physicians and nurses Unit staff level: communicate about transplantation outcomes for brain-dead donor patients who were hospitalized in the ICU
Family orientated	Provide optimal communication, similar to other EOL situations (family conference, VALUE mnemonic: Value the family, Acknowledge emotions, Listen, Understand family emotions, Elicit family questions)  Timing Timing the conversation about organ donation: prepare the conversation about organ donation. However, brain death and organ donation conversations do not have to be separate Adequate time spent with family members (do not rush) Explain brain death in a clear and understandable manner Give meaning to the patient's death  Focus on the patient The patient's wishes (and decision) The patient's dignity The respect of the patient's body Help families honor the wishes of the potential donor  Adequate support during emotional turmoil Understand families' imagery associated with organ donation Provide factual explanations Provide reassurance  Communication adapted to cultural context and ethnic origin Listen to and answer family members' questions Be attentive to verbal and non-verbal communication Show empathy
After the ICU	
	Adapted support at the morgue (when the family discovers the patient's "cold body") Available clinicians to answer questions about the process Adapted bereavement support and screening for prolonged grief and other symptoms of post-ICU burden

important role [11] and one must favor an approach that includes all HCPs, ICU doctors and nurses, as well as the OPO. Encouraging a positive attitude to FMs of potential organ donors cannot be separated from clinicians' experience of EOL in the ICU. A more holistic and collaborative approach (ICU team/OPO) [77] may help overcome certain barriers or apprehensions and improve attitudes and support offered to FMs.

#### **What research should be developed? (Table 2)**

Improving FMs' experience of organ donation process as well as long-term family outcomes remains an important challenge. Qualitative research will permit better insight into cultural/ethnic-specific experiences, as deeper knowledge of cultural aspects of organ donation is needed. It will also help understand who initiates organ donation discussions and whether this has an impact on consent rates. This approach will also allow better insight into the positive effects of organ donation, such as involvement in community work, participation in support programs for other FMs, or promoting

organ donation education. Interventional studies should also be designed to examine the impact of specific support programs during decision-making [32], as well as bereavement support programs, on family outcomes. Moreover, research should focus on FMs and clinicians simultaneously to best understand the dynamic that underpins decision-making. Other precise questions still remain unanswered such as the impact of matching the requesters to FMs' culture on consent rates and family well-being. Research is also needed to enhance the understanding of family veto in organ donation.

Future research should approach the potential conflict between a documented living will and organ donation as tension can develop in situations where patients have expressed "anti-treatment" wishes as well as the wish to be an organ donor. Better insight into families' and clinicians' experience and practical answers to these situations are needed.

Another important research topic concerns the patients themselves, as in certain situations they may be conscious and competent to consent in the ICU, such

as patients with end-stage neuromuscular diseases on invasive or non-invasive ventilation, or, in certain countries, patients requiring medical assistance in dying (or euthanasia). In this context, patients', FMs', and HCPs' experiences should be studied as well as discussions and organization of EOL care and organ donation process.

Last, it is crucial to develop research projects in the field of organ donation after the circulatory determination of death (DCD) that accounts for a growing percentage of deceased organ donations. FMs' experience in this context can be complex as not only are they involved in the decisional process to withdraw life-sustaining therapies but they are then involved in the organ donation decisional process. Better understanding of their involvement in this specific situation is pressing, including their perception of the dying process and their experience of decision-making.

### Limitations

First, we opted for a narrative review as we believe it is the most suitable review method for this topic in that it provides for a comprehensive appraisal of the state of current knowledge and critically considers a wide range of issues that will feed debates to come. Second, much of the data is observational and stems from the USA, Canada, or Australia, and raises the question of generalizability to the European or other international contexts. However, research is being developed in Europe and results are not incoherent with those of previous published studies. Last, many references include only small sample size and the strength of evidence is very weak. However these studies provide interesting data that will help design future larger studies.

### Conclusion

Research has permitted one to gain considerable knowledge concerning FMs' experience of organ donation in the case of brain death and has enabled HCPs to better understand their needs and expectations. However, challenges remain and concern all persons involved in the process, ICU doctors and nurses, the OPO, FMs, and, in some cases, the patients themselves. Looking at the big picture, rather than only at some elements will provide opportunities for further improvements. Moreover, time has come to expand research to FMs and organ donation after circulatory determination of death—a field underexplored to date.

#### Electronic supplementary material

The online version of this article (<https://doi.org/10.1007/s00134-019-05575-4>) contains supplementary material, which is available to authorized users.

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#### Compliance with ethical standards

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Authors have no conflict of interest in relation to the paper.

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