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Emotional landscape of organ donation: a qualitative study of families' experiences in Spain

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Abstract

Objectives To explore families' experiences of deceased organ donation and examine the perceived influence of participation in the donation process on grief and bereavement in Spain.

Design Qualitative study with a phenomenological orientation, conducted as the qualitative component of a broader mixed-method prospective cohort study, using semi-structured interviews and thematic analysis informed by an abductive approach.

Setting The study was conducted in Spain with relatives of patients declared dead by neurological or circulatory criteria following potential deceased organ donation processes.

Participants 47 relatives were interviewed approximately 1 month after the death of their family member. Interviews explored experiences of end-of-life care, communication with healthcare professionals, the organ donation request process and grief.

Results Participants described organ donation as a meaningful experience that, in many cases, contributed to consolation, emotional well-being and a more adaptive grieving process. Trust in healthcare professionals, clear and compassionate communication, understanding of death determination and knowledge of the deceased person's wishes emerged as important facilitating factors. However, some participants also reported ambivalence, uncertainty, guilt or regret, particularly when disagreement within the family or doubts regarding the diagnosis persisted. Beyond its practical implications, organ donation was frequently associated with symbolic meanings such as continuity of life, solidarity and the preservation of the deceased person's legacy.

Conclusions Families' experiences of organ donation are complex and emotionally nuanced. When relatives feel supported, informed and confident in the decision-making process, organ donation may help provide meaning and comfort during bereavement. These findings highlight the importance of sensitive, family-centred communication and relational care practices in deceased organ donation processes.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ We conducted a large-scale qualitative study using semi-structured interviews with bereaved family members involved in organ donation processes in Spain.
⇒ Participants were recruited prospectively through local transplant coordination teams following the donation interview.
⇒ Particular attention was given to participants' vulnerability during bereavement, and additional protection measures were implemented to safeguard their well-being throughout the research process.
⇒ Multiple coders independently analysed transcripts, and disagreements were resolved through consensus to enhance credibility.
⇒ Methodological limitations include recruitment challenges among non-donor families and potential selection bias due to reliance on clinical gatekeepers.

INTRODUCTION

Families hold decisive power in deceased organ donation: regardless of opt-in or opt-out systems, their authorisation—or refusal—ultimately determines whether organs are procured.[1–5] This makes their experience at the end of life a pivotal moment, not only for transplant outcomes but also for the families' own grieving trajectory.

Previous research has shown that relatives' perceptions of healthcare professionals (HCPs), including the quality of information, the treatment of the patient, the farewell and respect for the body, strongly influence how they cope with loss.[6–8] Communication around deceased organ donation can affect relatives' mental health in the short term and shape the grieving process in the long term.[7 9–12] Some families report comfort and even growth when convinced that donation was the 'right' decision,[8 13] while others experience regret, post-traumatic stress or

emotional turmoil, particularly when the deceased's wishes were unknown or professionals insisted inappropriately.[12 14] The donation request is therefore not a neutral act—it can ease or complicate bereavement, depending on how it is conducted.

Findings in the literature, however, remain inconsistent, likely reflecting differences across health systems, cultures and religious contexts.[15] Moreover, the follow-up of donor families has been scarce,[16 17] and their normative role in decision-making is often overlooked.[18] Yet understanding how donation affects relatives is crucial, as families are not merely 'gatekeepers' to organ procurement: they are individuals in acute grief, whose participation has ethical, psychological and policy implications.

Spain offers a unique case to explore these dynamics. With the highest donation rates worldwide,[19–21] its system is widely regarded as a model. But less is known about what this success means for families themselves: How do they experience the request for deceased organ donation? Which factors help—or hinder—their grieving process? And how might their testimonies inform better care and communication?

This study addresses these questions by exploring the lived experiences of relatives of potential donors in Spain. We focus on how they narrate end-of-life care, the deceased organ donation request and the meanings they attribute to donation, with the dual aim of identifying predictors of grief and pinpointing areas for improvement in family care. To our knowledge, this is one of the largest qualitative studies of donor families conducted in Spain, and it provides empirical evidence to inform both national and international policies on organ donation.

METHODS

Study design and participants

This manuscript reports the qualitative findings from a broader mixed-method prospective cohort study, exploring the impact of the organ donation request and the subsequent decision on the grieving process of potential donors' relatives.[22] Participants were adult family members of patients declared dead by neurological or circulatory criteria in Andalusia, Spain, belonging to one of three groups: families authorising donation (G1), families refusing donation (G2) and families who were not offered the option (G3). Participants were recruited from five public hospitals within the Andalusian Public Health System, all with established intensive care units and active deceased organ donation and transplantation programmes coordinated under the Spanish National Transplant Organisation (ONT). During the hospital process, donor transplant coordinators asked families for permission to share their contact details with the research team for a possible future invitation to participate. Approximately 1 month after the patient's death, families who had agreed to be contacted were approached by the researcher and provided informed consent prior to participation in the study. Semi-structured interviews, based on a previous study,[6] were conducted face-to-face at the University of Granada, by telephone or online according to participants' preferences, audio-recorded and transcribed. All interviews were conducted by the first author, a female nurse and doctoral researcher in Philosophy, trained in qualitative methods, who had no prior relationship with participants; information about both the researcher and the study was provided in the written consent and reiterated verbally before each interview. Interviews were conducted between November 2021 and February 2024. Interview quotations were translated from Spanish into English by the first author and reviewed by a professional translator and the research team to ensure conceptual consistency and fidelity to participants' meanings.

Data analysis

Once the interviews had been transcribed and anonymised, they were thematically analysed using an abductive approach, combining a priori categories related to the study aims (eg, factors facilitating or hindering the grieving process) with inductive coding to capture additional themes emerging from participants' narratives.[23] All interviews were coded in full by the first author using ATLAS.ti V.7 (Scientific Software Development GmbH, Berlin, Germany). To enhance rigour, three additional researchers reviewed transcripts; discrepancies were discussed until consensus was reached. Intercoder reliability statistics were not applicable. The analysis concluded when thematic saturation was reached, and the coding tree was iteratively refined. Member checking with participants was not performed. The themes, supported by verbatim quotations, are detailed in the Results section and in online supplemental file 1.

Patient and public involvement

Patients and members of the public were not formally involved in the design, conduct, reporting or dissemination plans of this study. However, the interview topics and overall study focus were informed by previous research and clinical experience concerning families' experiences in deceased organ donation processes.

Reporting and reflexivity

To ensure transparent reporting, the study was written in line with the COREQ (Consolidated criteria for Reporting Qualitative research),[24] covering research team characteristics, study design, analysis and findings, with the completed version available in online supplemental file 2. Given the sensitivity of the topic, specific precautions were also taken to protect both participants and researchers, including allowing pauses or discontinuation of interviews and incorporating researcher self-care practices.[25] English translations were carefully revised to preserve the original meaning. Extended verbatim extracts and the interview guide are available in the institutional repository of the University of Granada.[26]

Table 1 Sociodemographic and clinical characteristics of participants and potential donors

Characteristic	Participants (n=47)	Potential donors (n=32)
Sex, n (%)	Women: 31 (66) Men: 16 (34)	Women: 18 (56) Men: 14 (44)
Age, years (range)	18–73	31–82
Group*, n	G1: 40/G2: 5/G3: 2	Not applicable
Relationship to deceased	Parents, spouses, children, siblings, other relatives	Not applicable
Nationality	All Spanish	All Spanish
Religion, n	Christian: 37, Muslim: 1, non-religious: 7, not available: 2	Christian: 23, Muslim: 1, non-religious: 6, not available: 2
Causes of death	Not applicable	Cerebrovascular, cardiovascular, neurodegenerative, infectious, traumatic and other causes
Interview mode	Face-to-face, telephone, online	Not applicable
Hospital location of end-of-life care/donation process, n	Seville: 25, Granada: 8, Cádiz: 8, Málaga: 4, Córdoba: 2	

Some participant-level demographic information was unavailable for a small number of cases due to participants' emotional distress or incomplete data collection during interviews. To preserve confidentiality and avoid potential identifiability, some contextual details have been anonymised.
*G1: relatives who authorised donation; G2: relatives who refused donation; G3: relatives who were not offered the option of donation.

RESULTS

A total of 47 relatives (31 women and 16 men) of 32 potential donors from five hospitals in Andalusia were interviewed. In addition, 11 relatives declined participation once contacted or could not be reached by telephone. Table 1 summarises the main sociodemographic and clinical characteristics of participants and potential donors. Additional contextual characteristics of participants represented in verbatim quotations are provided in online supplemental file 3. Thematic analysis of the interviews identified five overarching themes: (1) Experience of end-of-life care, (2) Understanding death, (3) The family interview and decision-making, (4) The meaning of donation and (5) The experience after death. Although all themes were interrelated, they are presented here following the chronological sequence of the families' experience. In this way, the findings trace the emotional journey of families through the final days of illness, death and donation, showing how their experiences influenced the early stages of bereavement. No consistent centre-specific differences were identified across the participating hospitals; similar themes emerged regardless of study site.

Theme 1: experience of end-of-life care

This theme captures families' experiences surrounding end-of-life care and the final days of life of their loved one. Participants described how these experiences were shaped by the sudden disruption of everyday life, the perceived quality of healthcare, opportunities for accompaniment and farewell, communication with HCPs and the interaction between end-of-life care and donation-related procedures. Compassionate care, symptom control, trust in professionals and the possibility of saying goodbye emerged as particularly meaningful aspects of these experiences.

Families described the first moments after the event with anguish, shock and unreality, especially when death was sudden, in contrast to prolonged illness.

> No, it's that one day she was fine and the next day she was dead, bang! … every Sunday I am constantly reliving that phrase 'your mother has already been declared clinically dead'. (G1 364, daughter) (Quotations have been lightly edited for readability (see Methods)

Access to care influenced experiences: delays in rural emergency services were viewed negatively, while hospital care was generally valued for respect, comfort and pain management, especially when suffering was minimised.

> I don't know if she felt pain … and since I don't know that, it's killing me a bit. (G1 364, daughter)

The opportunity to be present and to say goodbye was deeply significant. Despite intensive care unit restrictions, many families highlighted the support they received to share meaningful moments, which eased the farewell and helped construct a sense of peace. In contrast, the absence of conscious interaction could generate feelings of incompleteness and regret.

> For those five days, although I didn't know it, I said goodbye to him … I held his hand, I hugged him and I didn't say anything. (G1 031, wife)
>
> I said goodbye to her body, but not to her. (G1 364, daughter)

Empathetic communication from HCPs was another key factor. Calm and repeated explanations facilitated trust, while poorly timed or insensitive messages contributed to confusion or mistrust in moments of high vulnerability.

> They often have to repeat things many times before you realize or find out what is going on. (G2 121, daughter)

Families across all study groups emphasised the importance of clear, honest and compassionate communication from HCPs during the final stages of life.

> The doctors explained everything very well… they reassured us that she would not suffer and that they would make sure of that. (G3 171, daughter)

Finally, families reflected on the tension between end-of-life care and donor-oriented procedures. For some, these interventions represented 'extra time' to assimilate the death; for others, invasive procedures or interruptions during the farewell diminished the quality of accompaniment.

> We are saying goodbye and a nurse starts coming, 'Now I'm going to prick him…' … don't take away this moment! That's why [now] I would reconsider donating. (G1 111, daughter)

Theme 2: understanding death

This theme explores how families understood, interpreted and emotionally processed the death of their loved one, particularly in contexts involving neurological determination of death. Participants reflected on the communication and comprehension of prognosis and death, the meaning of consciousness and bodily functioning, and the ambiguity surrounding the precise moment at which death was perceived to occur.

Families generally understood brain death as the irreversible loss of consciousness, with bodily functions maintained by intensive care. Experiences of ambiguity or difficulty accepting death were especially present in cases involving neurological determination of death. Some participants struggled to fully accept or grasp the diagnosis, particularly when the heart was still beating or when communication felt ambiguous. Despite these doubts, confusion about brain death did not usually translate into moral opposition to donation.

> They told us it was brain death, but her body was functioning, except for her brain […] so when they took my daughter for the transplant, was her whole body still alive? I was left with that doubt. (G1 102, father)

For many families in cases involving neurological determination of death, 'being connected to a machine' was not perceived as being alive, but as a body artificially maintained. Yet relatives expressed uncertainty about the precise moment of death, locating it anywhere between the diagnosis of brain death and the withdrawal of life support.

> For me, she was no longer there. They were keeping her, but she wasn't there anymore. (G1 363, stepdaughter)
>
> My father died in the operating room, when they disconnected his respirator and disconnected the machines. (G1 152, son)

Theme 3: family interview for organ donation and decision-making

This theme explores families' experiences of the organ donation conversation and the factors shaping decision-making regarding donation authorisation. Participants reflected on how donation was introduced, the role of HCPs and family members in the process, the importance of autonomy and family consensus and the emotional, ethical, relational and cultural factors that facilitated or hindered donation decisions.

Families described different ways in which the donation conversation was initiated: sometimes by HCPs, and in other cases by relatives themselves, who already knew the patient's wishes. When the approach came from professionals, participants generally perceived it as appropriate and necessary, provided it was not imposed and they felt free to decide. Some even described the request as 'comforting'. Above all, families emphasised the importance of being asked and involved in the decision-making process.

> When I was told of the situation I raised two things: I wanted a chaplain to visit her, and if there was nothing else to do, to please prepare the protocol for organ donation. (G1 051, wife)
>
> Making the donation without having the family's authorization… I think it's our word that has to count. (G1 101, mother)

The time available to decide was usually considered sufficient, particularly when families already knew their loved one's wishes. By contrast, when the wishes of the deceased were unknown, some families described greater uncertainty and emotional burden while trying to infer what their relative would have wanted based on their values, personality or previous attitudes toward helping others. In these situations, family consensus and trust in HCPs became particularly important in facilitating decision-making. Most participants expressed satisfaction with the support of the transplant coordination team, valuing the clarity of explanations, the sensitivity in communication and the availability of a reference person.

She is not a psychologist, but you could see in her eyes the empathy she had. There couldn't be a better professional than her. (G1 341, brother)

Although themes frequently overlapped across groups, some experiences were particularly prominent among families who declined donation. The main reasons for refusing donation were respecting the deceased's prior refusal, concerns about body integrity (sometimes linked to religion) and disagreements within the family. In such cases, relatives highlighted the importance of honouring the will of the deceased, even if professionals asked more than once.

The doctor insisted a lot, but we said it was her decision… if something was clear we had to do it and that was it. (G2 142, son)

I'm not a big supporter [of donation]… Call it religion or call it what you like. What if I need it? Maybe it's selfish, but it's hard for me to think about it. (G2 141, daughter)

Families whose relatives were not eligible for organ donation also expressed favourable attitudes towards donation. In some cases, relatives themselves raised the possibility of donation, although it could not proceed because of medical contraindications.

I suggested organ donation to the doctors, but they told me it was impossible because she had recently received a bone marrow transplant. (G3 173, sister)

Factors facilitating donation included knowledge or belief about the deceased's wishes, family consensus, solidarity experiences, trust in professionals and the meaning donation could bring to grief. For some, donation was seen as an ethical duty and a way of avoiding regret.

I would not have been able to bear the burden of conscience of not having donated the organs… we had to respect her wish. (G1 091, husband)

It was not difficult because I knew my husband very well, and I knew he would have liked it. (G1 133, wife)

Theme 4: the meaning of donation

This theme explores the meanings families attributed to organ donation and the symbolic, moral, emotional and relational significance it acquired within their grieving process. Participants described donation not only as a way of helping or saving others, but also as an expression of solidarity, reciprocity, continuity and hope. Donation was frequently associated with comfort, pride and a sense that the death of their loved one had acquired meaning beyond the loss itself.

Donation was often described as a profoundly positive act, giving families comfort in the belief that their loved one's death could help others. Relatives highlighted that 'if it is no longer useful, it is better that it serves others', emphasising donation as a way of saving lives and ensuring that the death was not in vain.

It's something that doesn't make sense [not to donate]. You lose one life, but you can save many. (G1 051, wife)

Donation was also framed in moral and social terms, linked to values such as solidarity, civic duty, reciprocity and Christian beliefs. For many, authorising donation felt like the right thing to do, imagining themselves in the position of waiting for an organ for a loved one.

I imagined the daughter of someone like me, waiting for some organ to help her father… at least the misfortune had served for something else. (G1 181, daughter)

Today for you and tomorrow for me… it is better that my body gives life. (G1 221, brother)

Beyond altruism, donation carried symbolic meaning. Some participants felt that the donor continued to live on through recipients, while others saw donation as separating the soul from the body, with organs merely providing life without identity. Relatives also distinguished between organs that could 'give life' (eg, heart, kidneys) and those that merely 'improved life' (eg, corneas, bones).

My mother is not gone: my mother is still alive in bodies I don't know. She is still alive not in one person, but in several. (G1 071, daughter)

My sister passed away and that's it. The thing is, yes, she has helped other people if something could be used in the end. (G1 221, brother)

Families frequently described donation in terms of a duality between death and life: the simultaneous pain of their own loss and the relief they imagined in recipient families. This contrast intensified the symbolic value of the donation and made it easier to cope with grief.

They are two very big moments in life, one which is death and one which is life. On one side, you are crying in pain and, on the other, another family is crying with relief. Those tears can be turned into life with the donation. (G1 051, wife)

The emotions associated with donation ranged from pride and satisfaction to peace and comfort. Families described it as 'something positive within the negative', providing continuity and hope amidst grief. Some even saw it as 'good news' after tragedy, or as a way of preserving honour.

When they told us that he could donate his corneas, I was very proud of him… two people could see thanks to his eyes. Even if I am broken with grief, it gave us joy. (G1 191, wife)

If it has helped a parent to see that their child is saved… at least he has left this world with honor, helping others. That comforts us and helps us to cope better. (G1 251, son)

Theme 5: experience after death

This theme explores families' experiences after the death of their loved one, including the emotional impact of the loss, ongoing doubts and regrets, the memories that

remained particularly significant after the process and the needs and improvements identified regarding end-of-life and donation-related care. Participants reflected on how the experience affected their daily lives, relationships, coping processes and perspectives on life, death and healthcare.

After the loss, families reported emotions ranging from anger and disbelief to eventual acceptance, and some described personal growth and renewed responsibility toward relatives.

> I have two other [children] and I have to keep going for them. They can't see me go down, because they need me. (G1 101, mother)

Others described personal growth and a renewed appreciation of life inspired by the resilience of their loved one.

> I don't think it will make my life more difficult… on the contrary, seeing how she fought gives me strength and makes me want to enjoy life the way she did. (G3 173, sister)

Lingering doubts often centred on whether different choices or circumstances might have prevented death, and refusal of donation sometimes caused later regret.

> The doubt that will always stay with me is that maybe she would have woken up. I'm still taking Valium to get some sleep at night. (G1 072, sister)

Memories associated with the final moments were particularly vivid and often painful, such as the last time the relative was seen alive or the identification of the body in the morgue.

> The three of us brothers went to the mortuary for the identification, which was the worst thing I ever did. And that image is burned into my mind. (G1 364, daughter)

In some cases, particularly when family conflict prevented donation despite participants being favourable toward it, relatives described persistent feelings of regret after the death.

> It's the only part [not donating] that I regret. At the time we did it to avoid conflict, but I regret it a lot… To this day, it's the only thing I regret, not having done it. (G2 122, daughter)

Finally, participants proposed several improvements for care: greater diagnostic accuracy, clearer communication, more flexible visitation policies, stronger psychological support, better management of family disagreements and hospital infrastructure improvements.

> I feel a deep sorrow because I think that if three or four months before, when he was due to have the CT scan, they had done it, it [the tumor] would have been smaller and he could have had better results. (G1 191, wife)

Figure 1 presents a conceptual synthesis of the relational, contextual and emotional factors identified across themes and their potential influence on bereavement experiences.

DISCUSSION

This study provides an in-depth understanding of how families experience the end of life, the request for organ donation and the subsequent grieving process. While prior research has focused mainly on family consent rates or on identifying predictors of authorisation, our findings highlight the benefits and challenges that participation in the donation process itself can bring to bereaved relatives.

One of the most consistent results was the importance of HCPs in shaping the experience. Families greatly valued respectful care, clarity of information and the presence of a sensitive reference professional, especially donor transplant coordinators. Satisfaction was linked not only to technical competence but also to warmth and empathy, which fostered trust and eased decision-making. This aligns with previous literature showing that respect for preferences, dignity and meaningful participation are central to satisfaction.[14 27] Likewise, poorly timed communication, or the perception of invasive procedures during the farewell, generated mistrust and regret, highlighting the need to carefully balance end-of-life care with donation-related protocols.

Another key contribution of this study is the ambivalence observed in how families conceptualise death. Brain death was often described as an 'ambiguous state', where the body remained alive but consciousness was irreversibly lost. This uncertainty mirrors findings from other qualitative studies,[7 15 28] and was described particularly in cases involving neurological determination of death, where bodily functions were maintained artificially despite the diagnosis of death. By contrast, relatives of patients who died following circulatory criteria generally expressed less ambiguity regarding the moment of death itself. However, our results nuance the picture: while ambiguity sometimes generated doubt or even remorse, in other cases it offered time for progressive acceptance, closure and emotional adjustment, as also described in the literature.[29 30] Importantly, mistrust toward the diagnosis rarely translated into moral opposition to donation—families often relied on trust in HCPs to resolve doubts.

The decision about deceased organ donation itself was usually grounded in pre-existing attitudes.[31] Many relatives arrived at the interview with coordinators already predisposed to donate, often because they knew the deceased's wishes or because donation was widely normalised in Spanish society. Similar findings have been reported in international research, including a recent Australian study by Potter *et al*,[32] which highlighted the importance of prior wishes and the possibility of finding solace or meaning in donation decisions. However, while several themes identified in our study are consistent with previous international research, our findings also

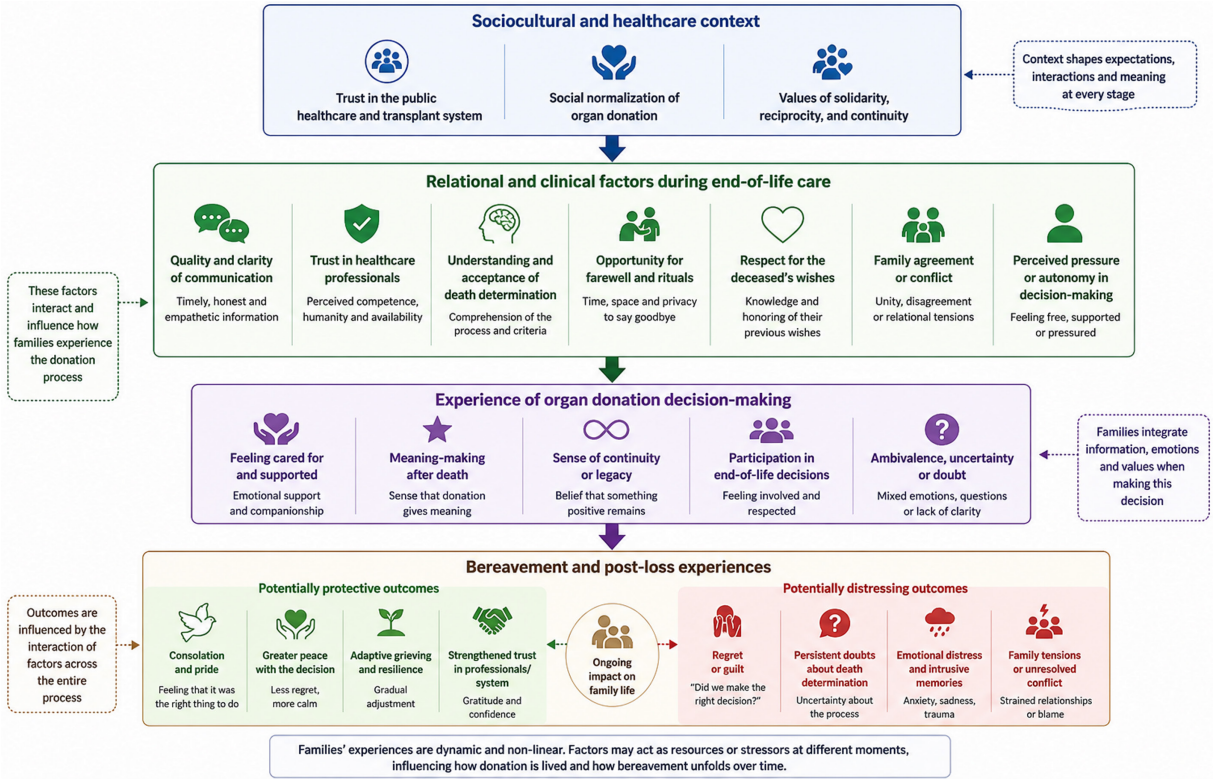

Figure 1 Conceptual framework of families' experiences during deceased organ donation and bereavement. Conceptual framework developed from the study findings, illustrating the factors that shape families' experiences throughout the deceased organ donation process and subsequent bereavement. The framework shows the influence of sociocultural and healthcare context, relational and clinical factors during end-of-life care and experiences associated with donation decision-making. It also depicts how these interconnected factors may contribute to both protective and distressing bereavement outcomes, with ongoing impacts on family life over time.

highlight the potential influence of the Spanish sociocultural and healthcare context. In particular, participants frequently described trust in HCPs and in the public healthcare system as central to both decision-making and emotional adjustment after donation. Rather than framing donation primarily as an altruistic act, many participants understood it through notions of reciprocity, collective solidarity and confidence in a public healthcare system perceived as fair and universally accessible. Given the high social normalisation of organ donation in Spain, our findings suggest the existence of a potential 'feedback loop', whereby positive experiences and public confidence in the transplant system may reinforce willingness to donate, which in turn contributes to the continued legitimacy and sustainability of the system itself. This study therefore contributes to the international literature by exploring how organ donation is experienced within a healthcare system characterised by high levels of institutional trust and social normalisation of donation. Despite this, in situations where families expressed reluctance or refusal regarding donation, repeated requests from professionals could be perceived negatively, underscoring the importance of respecting autonomy and avoiding perceived pressure during the donation conversation.[33 34]

Donation was consistently framed as an act of continuity and meaning. Families described it as 'something positive within the negative', a way of transforming loss into life. This meaning operated at multiple levels: moral duty, solidarity, reciprocity or even transcendence, echoing the classical anthropological view of the gift as a practice of reciprocity and social continuity.[35] Some saw donation as a moral obligation to alleviate suffering, in line with notions of altruism born of suffering,[36] while others understood it as a continuation of the deceased's existence—through organs, recipients or legacy. This resonates with the concept of 'legacy giving',[37] whereby relatives construct meaning in grief by ensuring that their loved one continues to have an impact. Notably, these accounts suggest that donation is not defined by altruism alone: the comfort families described stemmed both from moral values and from deeply personal dimensions—such as the reassurance that the deceased 'lived on', the sense that their death had served a purpose or the awareness that anyone might 1 day depend on donation themselves. In this way, donation combined solidarity, reciprocity and personal meaning-making, offering multiple avenues for resignifying death.

Finally, the experience after death revealed both vulnerabilities and growth. Families often needed time to reorganise roles, expressed doubts about whether the right decisions had been made and retained vivid

painful memories of the last moments. Yet many also described resilience and personal growth, particularly when donation provided a sense of pride, continuity or legacy. Families also pointed to concrete areas for improvement in clinical management, communication, visitation policies, and hospital infrastructure.

These findings suggest that maintaining public trust in organ donation systems requires not only successful transplantation outcomes, but also sustained attention to how families experience care before, during and after the donation process. This relational understanding of trust is consistent with previous conceptual work highlighting trust as a multidimensional construct involving HCPs, institutions and the donation system itself.[38] Although the Spanish transplant system has well-established coordination structures and specialised communication training, participants' accounts point to areas where further improvement is still needed: clearer and more consistent information between professionals, support for family agreement and conflict management, protection of farewell rituals from donation-related interruptions, psychological follow-up after death and greater attention to the care of the body and family accompaniment after procurement. Systematically incorporating families' experiences into quality improvement strategies could help strengthen family-centred care, support professionals in ethically complex situations and sustain public trust in the donation system.

This study should be interpreted in light of several methodological limitations. Although the study included relatives from different donation-related groups, recruitment was more challenging among families who refused donation or experienced particularly distressing situations, which may have contributed to an under-representation of more negative experiences. In addition, initial contact with potential participants was facilitated through transplant coordination teams, as families first had to authorise being contacted by the research team, which may have introduced a degree of selection bias. As this was a qualitative study conducted within the Spanish healthcare context—where organ donation is highly institutionalised and socially normalised—the transferability of findings to other sociocultural settings may be limited. Our findings highlight the need to place families at the centre of the donation process, not only as decision-makers but also as recipients of care. Supporting families through clear communication, respect for their values and attention to their emotional needs may improve both the grieving process and public trust in the donation system. Future research should further explore how gender roles, family dynamics and different contexts of death determination (eg, neurological vs circulatory death) shape participation in organ donation decisions, emotional responses, understanding of death and subsequent bereavement experiences. In our study, women were more frequently represented among participants, which may reflect both gendered caregiving dynamics and differences in willingness to participate in qualitative research on emotionally sensitive experiences. Although gender differences were not formally analysed, the findings suggest the importance of examining how caregiving roles, family responsibilities and decision-making dynamics may influence experiences of organ donation and bereavement across different sociocultural contexts. In addition, further studies are warranted to explore strategies to optimise family care in diverse healthcare contexts and to assess the appropriate scope of family authority in donation decisions and its implications for policy.

CONCLUSIONS

Our study shows that relatives' well-being and grief processing are strongly influenced by the possibility of donating organs, the opportunity to say goodbye and the quality of communication and support received from HCPs. Knowing and respecting the wishes of the deceased facilitated decision-making and was perceived as an ethical duty that alleviated doubts and reinforced family cohesion. Organ donation was often understood not only as a way of helping others, but also as a source of comfort, continuity and meaning-making during bereavement.

These findings highlight that family involvement in the donation decision does not undermine the process but instead supports coping, fosters trust in professionals and contributes to the construction of new and positive narratives around death. Caring for families means providing evidence-based medical care to the patient, ensuring dignity after death and creating an environment where families can participate meaningfully in the decision to donate.

By documenting families' experiences in Spain, a country internationally recognised for its leadership in transplantation, this research contributes evidence on how donation can simultaneously sustain the transplant system and support the grieving process of families. These insights can inform healthcare practice, training, and communication strategies aimed at maintaining public trust and improving family care in organ donation contexts.

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